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Disability, Citizenship And Uncivilized Society: The Smooth And Nomadic Qualities Of Self-advocacy

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Abstract

People with the label of "intellectual disabilities"[1] are often objectified and devalued by master narratives of deviance, tragedy and lack. In this paper, we draw on poststructuralist and feminist resources (e.g. Deleuze & Guattari 1987 and Braidotti 1994, 2002, 2006a) to argue that a disabling society is uncivilized in ways that block the becomings of citizenship. We draw upon our work with self-advocacy groups in England and Belgium where self-advocates open up different life worlds. We shed light on their politics of resistance and resilience, and map how they, as politicized citizen subjects, move in a web of oppressive disability discourses. However, we suggest, as nomads, they set foot on the landmarks of their lives in a never-ending search for smooth spaces in which something different might happen.

Introduction

Disability studies originally took shape between areas of social and political life. Over the last decades, however, developments in theory, practice and policy making, share exclusionary tendencies towards people with the label of 'intellectual disabilities' who are turned into interested spectators rather then proactive participants in disability studies (Chappell, 1998; Chappell, Goodley & Lawthom, 2001; Gilbert, 2004, and see British Journal of Learning Disabilities *special issue*, 2004). Our worries are that currently models and orthodoxies tend to prevent debate and experimentation and block possibilities for re/territorializing different theoretical, practitioner and activist terrains (Allan, 2004). In the British context, [2] impairment, and "intellectual disabilities" in particular, remains as an unspoken—and consequently not fundamentally social —issue in contemporary culture (Goodley & Roets, 2008).

Critical disability studies is an emerging interdisciplinary academic field that examines social, cultural, political, historical, psychological and relational theories of disability and impairment related to the dynamic interplays between impaired bodies and minds and various aspects of contemporary

culture, politics, and society (see Corker & Shakespeare, 2002; Snyder, Brueggemann & Garland-Thomson, 2002; Garland-Thomson, 2005; Tremain, 2005; Shildrick & Price, 2005/2006; Snyder & Mitchell, 2006; Goodley, 2007a, forthcoming). In this growing tradition, translations of disability that relegate impairment to negative and pre-social ontology and inertia are increasingly critiqued (Price, 2007). Ontological and epistemological notions of impairment are challenged as conjuring up the dark era of biological determinism and essentialism (Hughes, 2002, 2007a).

Our desire for praxis-oriented theorizing in the field of critical disability studies springs from our participation in the growing social and political movement of people with the label of 'intellectual disabilities' (Williams & Shoultz, 1982; Dybwad, 1996; Dybwad & Bersani, 1996; Taylor, 1996, 2000; Goodley, 2000). Disability activisms and actors of new social movements are crucial participants in this debate; they invite the field to radically unsettle 'social categories' like race, class, age, gender, and queer sexuality (see for examples of early impulses Corker, 2001; Davis, 2002; Traustadóttir, 2006; Meekosha, 2006), and challenge social barriers to identity experimentation (Goodley & Roets, 2008). In that vein, self-advocates around the world are stressing the transformative character of the self-advocacy movement, like Daniel in Belgium:

> We want to make something of our life. (…) We are out in the world. Our human lives all together are a thrilling chapter in our society. (…) And so they do not watch at us any more as if we were kids within our great rotten society. We cross swords worldwide for our rights and equal opportunities.

In the UK too, self-advocates challenge the ways they get positioned and marked as inferior. Let's listen to self-advocate Dai:

> People think that I'm not right. That I'm scary. I say, "screw them!" What do they know? What do they know?

His comrade Jon complements:

> Its not nice being called those things. It can make you depressed. Sad. No more of that. No more depressed. Move on.

In this paper, we want to tackle the mundane incivilities and ontological violations that are part of disabled people's everyday lives (Hughes & Watson, 2007). In that light, we need sensitivity to the creation of new discourse bridges, hybrid structures of knowledge and arenas of political struggle and action in spaces where activists and critical theorists make a common cause for social transformations (see Hughes et al., 2005a). Our aim in this paper is to ground and contextualize our motivation for a critical and philosophical engagement in the field of disability studies as a task that requires a reconfiguring of conceptions of disability research in terms of theory, method, analysis and activism[3]. Following the feminist Braidotti, the theoretical challenge might be to create transversal links to support activists in the re-invention of new subjectivities:

> The fundamental political desire is for an individual and collective re-appropriation of the production of subjectivity, along the lines of 'ontological heterogenesis', chaosmic desegregation of the different categories. We need actively to desire to reinvent subjectivity as a set of mutant values and draw our pleasure from that. (2006a, 123)

In this paper, we continue our engagement with these perspectives through an exploration of the ideas of striated/smooth space of Deleuze and Guattari (1980/1987) and the concept of nomadic subjectivity of Braidotti (1994, 2002, 2006a) to analyze some of the elements of 'uncivilized society' and the re-making of civil society.

People First: Label Jars Not People

In the self-advocacy movement, people so-labelled challenge pathological discourses associated with their personhood and a modernist, unitary vision of the human subject (Goodley, 2001). As self-advocate Monroe smartly states:

> We have a lot of troubles with labels. Labels are for jars, not people… (Monroe, 1994, quoted in Smith, 1999, 130)

People First exists as a counter-hegemonic movement to the human services industry, which augments the disciplinary powers of professionals and their institutions. Self-advocacy can be understood then as contributing to a civil society (Della Porta, 2007) and the disability movement (Goodley, 2000). In the UK, for example, the last 30 years has seen a huge proliferation of People First groups (see *British Journal of Learning Disabilities* special issue, 2006). In Belgium, the movement is younger but has a strong political impulse (see for example Schoeters, De Winne & Roets, 2007). Over the last ten years, we have researched disablement while also supporting disability activist groups such as Huddersfield People First in the UK and Our New Future in Flanders, the Dutch speaking part of Belgium. In this paper, we draw upon emerging life stories, narratives of travel, accounts, ethnographic field notes, moments and events (Doloughan, 2006) that we have collected in our personal and political engagement with self-advocates and our research involvement with self-advocacy (see also Goodley *et al*, 2004). In both formal and informal ways, self-advocates have fundamentally informed our learning and revitalised the possibility of occupying a more dynamic academic life (Roets & Goedgeluck, 2007).

As researchers, we hope to create a space for reclaiming and establishing new subjectivities in collaboration with self-advocates and to embrace the production of particular cultural meanings (Peters, 2000, 585), as a form of activist academic work with a sharp political edge and a strong commitment to create cultural re-symbolization (Garland-Thomson, 2003). Our shared epistemological conversations with people first allow us to denaturalize and shift the way we imagine phenomena (Haraway, 1991), such as here `intellectual disabilities'. We will look at insights from a current action research project (see Reason & Torbert, 2001 for method), The Travellers, that was set up by and with self-advocates or Our New Future, and shared with Huddersfield People First later. **4** In collaboration with self-advocates, we used life story research**5** as their stories offer us an in-depth understanding of their disqualified knowledge and creative life worlds (Angrosino, 1998; Booth & Booth, 1996; Ferguson & Ferguson, 1995; Gillman et al., 1997). As researchers, we describe our positionality as being self-advocates' *compagnon de route*, following their footsteps, trying to look at their thickly peopled worlds through their eyes, and getting to know their community of interest and relationships (Goodley, 1999; Roets & Goedgeluck, 2007). Their words and actions are provided here with their consent.

Master Narrative: Striated Self-advocacy Culture

All-encompassing, foundational theories central to modernism (Lyotard, 1979) characterize popular and professional thinking on 'disability' as an ideological and constructed category (Danforth, 1997; Perry & Whiteside, 2000; Hughes, 2002). In a modernist frame of reference (Hughes, 1999), people with the label of 'intellectual disabilities' are objectified, classified and devalued as 'other' in terms of a grand narrative of deviance, tragedy and lack (Goodley & Rapley, 2001). Over the past century, people with the label of 'intellectual disabilities' were judged to be 'abnormal' and deviant from the abstract standard of 'normal man' (May & Simpson, 2003; McClimens, 2003). This supposed intellectual inferiority of 'savages' was an important drive for moral treatment in institutions (van Drenth, in press). They were hidden from the

public sphere by being removed to disability ghettos (Smith, 1999), and their culture was defined for them as a professional construct rooted in the eugenics movement, used to justify institutionalization, sterilization, and other repressive policies (Taylor, 1996).

But let's turn a critical eye upon contemporary ideas about 'intellectual disabilities' as well. The cult of professional expertise still compels people to believe the voices of its authority unquestioningly as a totally coherent system of necessary knowledge within a precise territory. The master narrative of modernism yet remains as a dominating story with profound socio-political implications in the lives of self-advocates (Danforth, 1997, 2001, 2004; Roets, Goodley, & Van Hove, 2007). Epistemological grounds of 'intellectual disabilities' are drawn on modernist cultural territory and social maps of expert professionals (Skrtic, 1995): people described as having 'intellectual disabilities' inhabit landscapes that are pathologized and marginalized, surrounded by impermeable label borders (Smith, 1999). Listen to self-advocate Monroe:

> …we do not want that label anymore. Certainly, you people have the control. You are the experts in your field, but I am an expert too, in my own field. I lived in the institution, and I lived in a group home. (self-advocate Monroe, 1994, 9 quoted in Smith, 1999, 117)

The cast-iron formation of expert power and practice may further be witnessed in orthodoxies in the here and now, which masquerade and operate as hidden, taken-for-granted and toxic truths (Peter, 2000). The poststructuralist philosophers Deleuze and Guattari open up possibilities to destabilize master regimes of modernist truth and knowledge in order to alter our grasp on the geography and cartography of knowledge production (Deleuze & Guattari, 1980/1989, 422). In *The Smooth and The Striated*, in *A Thousand Plateaus Capitalism and Schizophrenia* (1980/1987), they say that one of the fundamental tasks of discourse is to striate the space of which it reigns: "The function of the sedentary road is *to parcel out a closed space to people*, assigning each person a share and regulating the communication between shares. (…) What is both limited and limiting is striated space" (1980/1987, 420).

In the existence of these striated spaces, the circulation and metamorphosis of discourse (knowledge) is regulated. Striated discourse associates itself with "a process of capture of flows of all kinds, which restricts speed, regulates circulation, relativizes movement, and measures in detail the relative movements of subjects and objects" (Deleuze & Guattari, 1980/1987, 425). In the context of disability discourse, striation refers to the blocking of possibilities and movements of subjects and objects in the social nexus of power and knowledge, the occupation of terrains of knowledge and the setting of territories by powerful others. So too we see the marking and colonization of `deviant` bodies and minds. These are then captured in institutional and discursive cul de sacs. Striated bodies and minds reside—such as the 'intellectually disabled' ones—and are socially created in striated environments and territories—such as care homes, sheltered workshops and institutions—where the environment is marked, doors locked and opportunities limited. But all Bodies, families, homes, schools, communities may be striated. So too are selves, subjects and objects:

> There is the smooth space of bodies, and the striated space of bodies. The latter is the space of 'body systems'—of the 'organism', the 'human', the 'subject' and the 'agent' … these are the marked bodies, that bear the signs—contortions, wounds, scars—of their 'societalization'—today they are the locatable bodies, studied bodies, probed bodies, simulated bodies, designer bodies. (Bogard, 2000, 84)

In that vein, the label of 'intellectual disabilities' serves to offer particular truths and ways of being: a deficient and lacking subject and a striated

subjectivity. The vital concern of oppressive, striated disability discourse is to striate all the flows of being, becoming and acting of disabled people. Listen to self-advocate Eva:

> I will never be able to forget it all. You know I am damaged. They did great damage to me. Deep down in my heart. You simply cannot see it all the time. You can't trace it in my outside being. It's becoming, inside me. My soul. Everyone has one, a soul, eh? You know it. Well, mine is damaged. And it's never really acted out. Never will be. (a quote from Arduin documentary, 2007)

Fortunately, striated cultural space actually exists but *only* in mixture with smooth cultural space: variability is an essential feature of cultural spaces and discourse. We will theorize on and illustrate striated spaces, bodies and discourses in disabling, uncivilized society that threaten to block the smooth becomings of citizenship of people with 'intellectual disabilities.'

Mixture: Striated/smooth Space

Deleuze and Guattari define cultural spaces in terms of striated and/or smooth:

> Smooth space and striated space (…) no sooner do we note a simple opposition between the two kinds of space than we must indicate a much more complex difference (…) we must remind ourselves that the two spaces in fact exist only in mixture: smooth space is constantly being translated, transversed into a striated space, striated space is constantly being reversed, returned to a smooth space. (1980/1989, 523)

Where there is striation there is also smoothing. Smooth disability culture does not just go from the smooth to the striated; "it reconstitutes smooth space, it re-imparts smooth in the wake of the striated" (Deleuze & Guattari, 1980/1989, 523). Striation simultaneously enables smoothing and vice versa. **6** What is, for us, common with disability culture, is the variability of disability discourse that makes us hopeful in our attempts to re-author experiences that have historically been excluded in master discourses. Following Giroux (1991a, 1991b), the postmodernist view of culture holds that master narratives are "rejected in favour of narratives of difference" (Giroux, 1991a, 229), and that boundaries for producing meaning, difference and subjectivity are subject to flexible reconstruction. In a sense, we see pathways to multiply and disclose new and powerful potentialities to shift modernist terrains of knowledge and disability discourse, and to highlight the importance of flows of knowledge exchange in shifting societal networks. As a lens, disability culture allows us to rearticulate fresh and diasporic modes of subjectivity (Mutua & Swadener, 2004). In postmodern views, identity is regarded as multiple, fragmented, contingent, liquid and uncertain: identity has been transformed from the singular to the plural; it has become a project, an event, rather than a fixed attribute heavily influenced—if not determined—by one's social and political circumstances (Hughes, Russell & Paterson, 2005b, 5).

We agree with Hughes et al that this should make interesting reading for sociologists interested in disability studies, however we disagree when they observe that disabled people cannot travel through the regimes of value that mark contemporary culture, cannot gain entry to significant symbolic territory and mainly face forms of immobilization. According to Bogard (2000, p289), at the limits of the striation of the body and sustainability, in order to smooth its insertion in the social, we can re-encounter the smooth body as a place for flights of resistance, be it in the family, art, a crowd or collective improvisations (see also Gibson, 2006). And as one of us has argued elsewhere (Goodley, 2007a), to smooth is to find hiding places, regions for shelter, plateaus for sustenance, high flat expanses to wander. After all, even the most striated spaces have hidden cracks of resistance. No matter how

striated the uncivilized, there are always opportunities for smoothing civil society.

> The sea, then the air and the stratosphere, become smooth spaces again, but, in the strangest of reversals, it is for the purpose of controlling striated space more completely. The smooth always possesses a greater power of deterritorialization than the striated. (Deleuze & Guattari, 1980/1987, 530)

Smooth bodies, selves, subjects, relationships and landscapes—which we will demonstrate can be found in self-advocacy—emerge and *are made from* striation. In any striated body or territory there are opportunities for mapping new territories; processes referred to by Deleuze and Guattari as re- and deterritorialization. As Bogard argues: "…if society is like striated space—bearing, grids, systems—it is also like the sea, a space of continuous becoming" (2000, 284).

In what follows, we suggest and illustrate that people with `intellectual disabilities` involved with self-advocacy border and travel smoothly upon uncertain sands of becoming, and their stops follow from their trajectory. As we shall see, processes of de- and re-territorialization in self-advocates` everyday lives provide possibilities for exciting forms of being, becoming and acting through nomadic travels in a political sense (Braidotti, 2006b). As with the words of Deleuze and Guattari, in the smooth: "the points are subordinated to the trajectory. This was already the case among the nomads (…) the dwelling is subordinated to the journey" (1980/1987, 528).

Smooth space is associated with the making of a number of productive possibilities including nomadic bodies, minds and journeys through which occur the dynamic process of unfolding subjectivity outside the classical frame of the humanistic subject (Braidotti, 2005/2006). At the heart of social practices, lives and epistemologies, we need to replace the version of a fixed biological ontology of being with a social process and an ontology of becoming (Grosz, 1994, 2005; Hughes, 2007b). Braidotti continues:

> Becomings are the sustainable shifts or changes undergone by nomadic subjects in their active resistance against being subsumed in the commodification of their own diversity. Becomings are un-programmed as mutations, disruptions, and points of resistance. Their time frame is always the future anterior, that is to say a linkage across present and past in the act of constructing and actualising possible futures. (2005/2006, point 29)

In disabled people`s lives, the birth of smooth space involves a 'spatial nomadic reworking' of bodies and minds, and a promising reconfiguration of disability concepts, disability worlds, sub/cultures and landscapes (Colebrook, 1999). Here the aim of our paper is theorising these spaces of resistance as a self-advocacy culture, a smooth and social space with/in and across the self-advocacy movement.

Praxis: Flavourings Of Political Practice As Intensifiers Of Thought

> It is a place we create when—in hosting others—we change, hybridize our discourses and identities, and let others teach us, from the beginning, how we are different and multiple within ourselves (Gregoriou, 2001,146; quoted in Allan, 2004, 426)

Let's not swerve away from our purpose as critical researchers: disability studies is an academic as well as an emancipatory paradigm (Oliver, 1990), focused upon praxis (Lather, 1991) and in our case tied to the development of the politicized self-advocacy movement. According to Grosz (2005),

Deleuze is above all interested in what theory enables us to do, to make, more than, or beyond, what it says; discourses are modes of action, practices we perform to facilitate or enable other practices, ways of attempting to deal with and transform the real. Unlike social constructivist philosophies in which we remain prisoners of what Foucault called the 'episteme of man' and openness is achieved by making the world depend on human interpretation, Deleuze's approach achieves it through making the world a creative, complexifying, problematizing cauldron of becoming (De Landa, 1999). Deleuze (1986/2004) observes that Foucault writes about the political impetus for his project with Guattari in that they use political practice as an intensifier of thought, and analysis as a multiplier of the forms and domains for the intervention of political action. Theory does not express, translate, or serve to apply practice; "[theory] *is* practice" (Deleuze, 1986/2004). To get a grip on these elusive and diffuse centers of power and resistance, Foucault argues that we need those who cease being submissive in an electric way:

> I'm very careful to get a grip on the actual mechanisms of the exercise of power. I do this because those who are enmeshed, involved, in these power relations can, in their actions, their resistance, their rebellion, escape them, transform them, in a word, cease being submissive. (St.Pierre, 2004, 293)

Hardt and Negri (2000, 216), Shildrick and Price (2005/2006) emphasize the submissive body as one that is completely incapable of submitting to command, a body that is incapable of adapting to family life, to factory discipline, to the regulations of a traditional sex life, and so forth (if you find your body refusing these 'normal' modes of life, do not despair—realize your gift!). The exhaustions of modernity create an affective space, a smooth becoming space, where we feel that we cannot continue as we are—the subject of a politicized postmodernism (Lather, 1991), where we can think and act with one another in ways that both mark and loosen limits, in order to multiply the levels of knowing upon which resistance can act. For Deleuze and Guattari, praxis, as philosophical move and travel, as an instrument that multiplies potentialities, is: "…the art of forming, inventing and fabricating concepts (…) that need conceptual personae (*personnages conceptuels*) that play a part in their definition" (1991/1994, 2).

Transformative praxis can be situated as a particularly fertile site for researchers given its investment in political concerns (Gregoriou, 2004; St. Pierre, 2004). Shaped by the interplay of power, language and meaning, these micro-politics of knowing and being known, in line with the current disability studies paradigm where scholars are doing disability research *with* rather than *on* or *for* disabled people (Clough & Barton, 1998), take on urgency in social praxis (Lather, 1991). We hope to open up new and smooth spaces for shared action and thought with/in the politicized social movement of self-advocacy on a more creative plane:

> Smooth space is filled by events, (…) it is a space of affects (…) that is why smooth space is occupied by intensities, wind and noise, forces, and sonorous and tactile qualities, as in the desert, steppe, or ice. The cracking of ice and the song of the sands. (Deleuze and Guattari, 1980/1987, 528-529)

Our research (text) is growing out of intersecting lives, journeys, relationships, and our desire to smooth and shift the terrains of disability discourse as allied others. In the next section, we will illuminate the smooth, striated and nomadic qualities and intensities of self-advocacy.

Travellers: A Smooth And Social Self-advocacy Culture

> Not all nomads are world travellers; some of the greatest trips can take place without physically moving from one's habitat. (Braidotti, 1994, 5)

We find ourselves located within shifting networks of self-advocates with their (academic) allies connected to Our New Future, the first self-advocacy group in the Dutch speaking part of Belgium (see Van Hove, 2000; ONT, 2002). We will illustrate here that people with `learning disabilities`, and their self-advocacy, are striated by what is defined as uncivilized society. Simultaneously, self-advocates find nomadic ways of creating smooth forms of civil society, activism, resistance and resilience. The idea of the project originates from Ludo Schoeters, currently the president of Our New Future:

> I am a world journey traveller. In a sense, I am a traveller every day. Every day in the week. And in the weekend too. When I do what I truly wish to do. Then I travel off to Gent. I am the President you know. I've gone so far the world—I am the President. I am always discovering new worlds and new folks. I really want to unravel them. It's a true voyage of discovery. Discover people's dreams to make them true in a joint adventure. That's my gift you know. I unravel with other people what their talents are. I want to wake up every one. I strengthen people to hold on in their world. That is my mission as a president and more, I am an advisor too. I am the leader of my movement. I see this as my mission in life. (Schoeters with support of De Winne & Roets, 2007)

At a later stage in the project, we made connection with the English self-advocacy group Huddersfield People First to include voices of veteran self-advocates and to display the international character of the self-advocacy movement. Listen to **Jeremy** Hoy, the present president of Huddersfield People First:

> I am involved with the group for a very long time now. I do not know exactly how long any more, sure twenty years actually. I am 46 years old now. We just like meeting up and talking about different things, like changing the label of people with intellectual disabilities. We speak up for ourselves, and want to change the label. (…) I want to have my own freedom. Do some travelling on buses. Cos its free on the bus, I am allowed to go where I like. I like to go to the meetings, we talk and meet people. What we are trying to do now is looking for new members. We want as many people as possible to join us. I like meeting people and especially new ones. People with intellectual disabilities need to find out what we do. (Jeremy Hoy at http://www.ont.be/travellers)

The voices of professionals and the voices of self-advocates and their allies tell conflicting stories about what it means to have been labelled with intellectual disabilities in modern society. Following Smith (1999), Ludo and Jeremy offer different tales of travel to those associated with uncivil society; which maps out a road leading to pathology and passivity. Along the way voices are excluded. In that light, poststructuralist feminism is experienced as one of the most powerful analytic resources for displaying the way culture constructs categories and subject positions that we then assume to be pre-given, universal and unchanging (Parker, 2003). Poststructuralist feminist theorists have been very influential in opening up unexplored territories of subjectivity (see Davis, 1997), like Rosi Braidotti (1991,1994, 2002, 2006a, 2006b) who introduces a new figuration of layered, embodied subjectivity which she calls nomadic existence. Nomadic subjectivity is a political project in which a new subjectivity is created, in which the self is expressed as incomplete, fragile, plural, multiple and yet rooted in her bodily reality (Braidotti, 1994). Braidotti borrows insights from Deleuze (1968/2004) and Deleuze and Guattari (1980/1989) who perceive the raw materials of existence as a nomadic distribution of meaning, being(s) constantly in flux, multiplicities:

> The nomadic trajectory distributes people (or animals) in an open space (…) one without division into shares, in a space without borders or enclosure. (…) The nomad distributes himself in a

smooth space, he occupies, inhabits, holds that space; that is his territorial principle (…) the nomad clings to the smooth space (…) [and] invents nomadism as a response to this challenge (Deleuze & Guattari, 1980/1987, p420)

Perhaps our reference to nomadic subcultures in self-advocates lives and stories may seem strange and alien to disability studies. The nomadism in question here refers to the kind of critical consciousness of self-advocates and their allies that resists settling into socially coded modes of thought and behaviour. In a sense, notions and flavourings of nomadic epistemologies allow us to travel through the life worlds of self-advocates involved in order to see the tensions, resonances, transformations, resistances and complexities in their lives (Haraway, 1991, 195). Nomadic sub/cultures designate a conflicting and dynamic set of experiences, rooted in and marked by self-advocates' flows of being, becoming and acting in their daily lives. In what follows we illustrate with some illuminative examples from The Travellers project and take experiences into account that perhaps previously have been ignored, forgotten, ridiculed and devalued all too soon.

Let's listen to a leading self-advocate in Belgium, Daniel. Apparently the testimony of being part of an outlaw culture penetrates him with a trauma that is felt in every fiber of his being:

> Folks walking down the streets sneer at us like we are worthless. They only see impairment. But they have to look beyond their own limitations. We are more than cast-off good-for-nothings in our damn great fucking society. We demand respect as equal citizens of the world. Sometimes I get out on the streets like a lost soul; then I feel like a dog in the gutter. Some bastards dare to peep at us and fuss about us round the clock. Anyway I think they have only loose talk to say. They can listen to us. Then they at least have serious tobacco to chew.

The value and the emphasis of the self-advocacy movement lies in how it enables people with "intellectual disabilities" to critically navigate, negotiate and challenge the power of the dominant and striated disability discourse. Most of the time, the members of Our New Future meet on the first Saturday of the month in the local pub near the railway station in Ghent. Obviously it makes sense for self-advocates to invest in a shared collective future, in the pleasures of the warmth of solidarity; teasing out with others why and when alternatives have stopped being alternatives.

On his first self-advocacy meeting, Philippe, a new member, looks stupefied and puzzled, and reacts loudly shocked "*You really dare to drink alcohol? Wow! Alarm! Would cause me trouble!*" when veteran member Pat signals the waiter and orders his 3rd dark Belgian Trappist. Pat asks why and the freshman tells about the pub culture of his day care center and explains how the structured, striated routine of the business goes in there.

> There's a pub in my day care centre. Every day at precisely 3pm we can buy a drink there. In 'The Pub'. Us service users have a card with ten turns; to buy one drink each week. Caregivers sell this. They decided to sell no more coke. Just diet coke and juice. Definitely no alcohol. Alcohol is dangerous. Drink needs to get finished at 15.15pm. If not it's taken away! The buses are waiting! To fling us down home. Four busses waiting: the yellow one for the mentally retarded, the green one for the physically impaired one, the white one for the mixed impairment group, and the red one for the lunatics. Every group in the centre has a special bus. And yes we all need to hurry! To catch our special bus.

Self-advocate Marie bears witness of the implications of this kind of striated discourses and practices that govern how people act and are acted upon within a myriad of private and public spaces, within disabling disability

cultures. Marie looks serious, when talking about what happened before when professionals imposed a sterilization on her as an ineluctable necessity.

> Yes, and all I got was reprimands all the time. From Tina [psychologist] and Myriam [her personal caregiver]. But I didn't want the sterilization. I had to go to the big boss. "If a shady bloke rapes you, then you have to find out yourself", Tina [psychologist] said. She snapped my head off, that I'm just stupid and that I couldn't go out any more. Luckily, my mother and my friend were backing me up. Besides, you know, I like little ones very much. But have them myself? Hey, that's not my cup of tea!

Through sharing life stories, self-advocates are able to recognize their oppressed status in the dominant discourses and institutions in which they find their selves positioned. Pease (2002) already stresses that it is crucial for marginalized people to come into contact with new discourses that produce new knowledge(s) and promise alternative and free ways of living. Marie continues to tell the self-advocacy group about her constant attempts to push against the grain, and as such she is reviving the group's dynamics. She gained a respected position in the group, as she defines herself as *straatluuper* (daisy on the road):

> If they command that I must stay in my house here all the time, it's getting my prison! Have to get out. I mouse away. I'm gone with the wind. Free like a bird to fly out. I can go everywhere I want. Like a daisy on the road. When I am fed up with their control, they can wait till I am back to iron the problems out!

She challenged, for example, stereotypes of disabilities that are often based on asexuality. Just as children are assumed to have no sexuality, disabled people are subject to infantilization, perceived as "eternal children" and "not quite women" (Phillips, 2005). Their sexual expressions—just living together sharing a place that feels like being at home, just having a private (sex) life of your own, just having and raising your own children—often remain very controversial issues and taboos (Brantlinger, 1995; Lesseliers & Van Hove, 2001). Take this account of Charlotte, a member of a self-advocacy group in the UK, who finally gets her own Council house.

> No more living away from each other. Of protective sisters. Of disapproving keyworkers. At last, home, *our* home. With the homehelp in the morning and evening, sorting out our food. And 7.30pm is soap opera time. Together. On the sofa. Hands held. Secret glances. Smiles. (Dan Goodley's diary, January 2005)

And Marie's mother Laura compliments her story:

> I have to keep those professionals well in my eye. My daughter needs her freedom. My Marie wouldn't hurt a fly. They tried to ruin her reputation, telling me that my own flesh and blood is man-crazy and needed a sterilization. They suggested she wanted to have sex head over heels, with some sort of a perfect stranger! They imposed upon me that this gynaecologist had to cut through her oviducts. That's sabotage of a woman's dignity, I told them! And I know better: I know my daughter, and she knows who she can trust. If those caregivers would be as bright as you are, that would make it better, what do you think love?

In the meanwhile, Marie got acknowledged in Our New Future for her gift: knowing how to resist official orders which people do not explain to her. Daniel calls Marie "our little elf"; she's short, but he has great respect for her.

> Our tease Daniel brightens up, discovering Marie who enters the pub: "Ha! There we have our cool little elf again!" She tumbles in panting with the heat and the weight of her two backpacks,

handbag, body warmer on top of her sweater and a cool cap
topping it off. This time, the lady in question can't get her magic
smile to pass over his bit of teasing. She flops into a chair,
grumbling at the waiter: "bring me a beer please", bad-tempered if
you ask me. (Griet Roets' diary, in Roets, 2008)

People with "intellectual disabilities" may perceive a status as self-advocate
that emphasizes "otherness" and gives the impression that they only exhibit
self-advocacy in their self-advocacy group, but their nomadic subcultures
show that self-advocacy may exist prior to and as the consequence of joining
groups. Their self-advocacy, resistance and resilience is contextualized,
looming in a variety of socio-political and inter-relational contexts (Goodley,
2000, 201).

Sumatra, one of her colleagues at work, insisted that Marie
couldn't leave work before 4 o'clock. (…) "Well, I told her where to
get off! I am a volunteer, do not get paid and they do! Sumatra
said she was only teasing me, "Hey, with all respect, you are a
retard, you can't get paid". She can boil her head; a joke isn't
harassment, you know! I can't have that, I replied. Ho, don't you
meddle in my life! It's *life*, what do you think?". Joking apart,
Daniel's bitter silence speaks volumes. Now, again, he offers
Marie a shoulder to lean on. He encourages his comrade. Daniel
is apparently in a strop with the guys at work again. Marie calms
down, listening to how he tackles work troubles. (Griet Roets'
diary, in Roets, 2008)

Self-advocates around challenge orthodoxies all the time. And perhaps,
these contradictions and clashes give self-advocacy culture its rich and social
nature, and self-advocates involve their creative capacity to become nomads.
Relationality in particular declares where self-advocates find the strength to
act, upon their self and with others, to cease being and to become (Galvin,
2003). In that light, Daniel emphasizes the importance of international
networks and being connected with other self-advocates. In the summer of
2006, self-advocate Marie turns up in the UK all the way from Belgium to the
party of Huddersfield People First, to share with European comrades 20
years of People First.

People say that we do not need to get alcoholic drinks in for the
People First party; anyway: the members won't drink. Well now,
tell those people this … the BBQ is stoked up in the garden and
the party starts. Party goers meet the neighbours. Dai falls up the
steps to the house because of his 7th beer. Jon pops in to see the
neighbours' CD collection. And everyone is still up at 12 midnight
and still going strong. And now those people try to tell us that
people with "intellectual disabilities" have no culture, no friends,
can't relate, can't socially interact, can't become something else
other than the "intellectually disabled." Well, now, try and tell us
… (Dan Goodley's diary, August 2006)

Self-advocates clearly divide their loyalty between different forms of power,
and join hands to struggle against multiple sites of oppressive discourse.
Inclusive relationships with others, such as comrade self-advocates, family,
friends and/or professionals can be very encouraging and empowering.
These mutual sets of interdependence and interconnections, these sets of
encounters and interaction with others, coincide with a play of complexity that
encompasses all levels of one's multi-layered subjectivity (Braidotti, 2006a,
156). Becoming nomad means to desire the self as a process of
transformation, to desire change, flows and shifts and to reinvent a
multiplicity of selves for your own (Braidotti, 2003, 53). Daniel says:

From me—it is my story. I've told my precious things. I've commit
my story to paper. I've declared my true colours.

His friend Pierre lives in a house with three other adults. From time to time, he isolates himself in his attic room. Asking Pierre why, he says:

> That's my place to make culture. My culture: go to events, listen concerts, music and accessible presentations, walk out on the streets, ride my bicycle, feel freedom and friendship, write my poems. How do I deal? Culture makes me dream what I want to reach, who I want to be. I want to construe my impairment in my poems. My culture is a story. I need to be approachable, my language. Poems tend to be complicated, but they need to be rhymed as well. Am I a rainbow chaser? Ideas do not die. Sometimes I all do not grasp it any more neither. But I am in rhyme.

Let's try to rhyme Pierre's poem *peterkind*, his *neological* word "godfatherchild," that he wrote when he became a godfather of his brother's little baby boy:

Godfatherchild

all of a sudden

dream appears to me

full of stars from heaven

dream dreams

about my godchild

wonderful

as cauliflower floret

have a look

floret child

dazzling lucky

my godchild

my four-leaf clover

four new dreams

new wishes

true

impaired nobel prize wnnner

Pierre P.

The nomadic subject is embodied, embedded, anchored, multiple, and hence affective, interrelational and fundamentally social (Braidotti, 2006a). The multiplicity of Pierre's forces, energies, desires, affects and thoughts have to do with the creation of new possibilities of empowerment. Remarkably, we would like to note the differing dimensions of time, place and relationality involved with these nomadic processes of being, becoming and acting: the subject occupies a variety of possible positions at different times and places, across a multiplicity of constructions of the self in relationality with others. In the UK, self-advocate Gerry has a varied week.

A day with mates in the day centre—but only to say 'Hi', not to be

there. The service user, indeed! Tuesdays and the weekend, in
the market. At the stall. Selling shoes and getting the coffees for
the traders. And Friday night to church with my sister.

Nomadic subjects often seem to lead an invisible, stubborn life at the margins
for their own survival. However, for the outside world, self-advocates' lifestyle
and sense of taking control remain often invisible; they clearly become
accustomed to avoiding the voyeuristic eye of intrusive professionals. The
clincher of Daniel's story is a photograph taken at the museum of
contemporary art in Ghent. With a poker face—and with a sense of black
humour and a wink—he is posing before a pamphlet stating:

Nobody is watching. I know exactly what I am doing and why I am
doing it. And if they do not like it, I do not give a shit. Being honest
is the most important thing.

These life stories and illustrations show that self-advocates, perhaps nomads
par excellence, are faced with the need to creatively re-configure and
re-invent themselves to resist (professional) control, voyeurism, bio-power,
existential challenges and oppressions they have to face in their everyday
lives (Goodley & Roets, in press). Self-advocates appear to be/come and act
critically positioned in a gendered and smooth social space/self-advocacy
culture.

Uncertainty: Becoming Territorial Border-crossers

Voyaging smoothly is a becoming, and a difficult, uncertain
becoming at that. (Deleuze & Guattari, 1980/1987, 532)

Our journey through the lives and stories of self-advocates allowed us to map
social life worlds of survivors occupying nomad lands. Self-advocates have
become territorial border-crossers. Peters (2000) embraces the notion of
disability culture as hybrid, and characterizes disabled people with such a
hybrid consciousness as border crossers whose essential qualities are in flux.
Sexed and impaired bodies-and-minds can get recast as social and political
sites of process ontology, power, discourse and action (Goodley & Roets, in
press). A radical re-mapping of border experiences required us to see
ourselves involved in social and political change processes with
self-advocates in developing new routes, dismantling borders. After all,
Deleuze inspires, we are all involved in a complicated and uncertain being,
becoming and acting: "…all things are in absolute proximity, and *whether
they are* large or small, *inferior or superior, none of them participates more or
less in being*" (1968/2004, 47).

With self-advocate Eva's words, we all have a soul deep down in our heart.
This stresses our belief in the creation of a social and political nomad space,
a smooth self-advocacy culture in which flows of knowledge exchange in
shifting societal networks take place. These new territories of knowledge
need to be explored and inhabited by us all.

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Endnotes

1. We adopt this term, for this paper, to comply with the terminology normally (and normatively) employed in North America. In our own contexts we would often employ the term "learning difficulties" because this is the preferred term of the self-advocacy movement. Both terms, as we aim to demonstrate in part through this and a recent paper (Goodley and Roets, 2008), illuminate the cultural politics that underpin the labelling, separating, segregating and dehumanising impacts of the psychologization of people's lives through diagnosis, exclusionary schooling and community marginalization. We therefore also understand the term "intellectual disabilities" as a cultural artifact of North American responses to the treatment of diversity, disruption and difference (see Goodley, forthcoming). We also need to acknowledge that people whom we work with in our own local context would have serious reservations about the use of yet another label in their lives.
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2. In the British context for example, the social model historically reflects the close relationship between academics and the disabled people's movement (UPIAS, 1976; Barton, 1998, 2000; Shakespeare, 1998, 2006; Barnes & Mercer, 2003).
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3. Recently we have suggested that these debates would benefit from a more grounded engagement with concepts of the poststructuralists Deleuze and Guattari (see Goodley, 2007a, 2007b; Mclaughlin & Goodley, in press), the poststructuralist feminist Braidotti (see Roets, Reinaart & Van Hove, 2008; Roets, Reinaart, Adams & Van Hove, 2008) and an exploration of the actions of self-advocacy groups (see Roets, Goodley & Van Hove, 2007; Goodley & Roets, 2008).
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4. See http://www.ont.be/travellers
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5. Relevant to study social and cultural change, we used complementary research methods and visual anthropology methods (Collier & Collier, 1986; Booth & Booth, 2003) making photographs which are meaningful to (re)present ourselves to the world as a medium to relate to self-advocates' lives and selves (see Roets & Goedgeluck, 2007 for first reflections on this method). In this article, we cannot include the photographs which were chosen, sometimes made, and used as a medium to dialogue and facilitate the story-telling process.
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6. A point developed in Goodley (forthcoming) is the notion that disability

studies itself might be seen as a mixture of smoothing (opening up possibilities for reconfiguring the politics and theories of disability) and striation (recreating the victimhood of disabled people through emphasizing their oppressed and marginalized status); articulating with difficulty when, at times, further making difficulties (see Clough and Barton, 1995, 1998).
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