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Putting Emotions to Work: The Role of Affective Disablism and Ableism in the Constitution of the Dis/abled Subject¹

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By conceptually framing disability under the lens of the Foucauldian apparatus, this work applies dis/ability studies to examine the constitution of the disabled subject by exploring how ableism and other axes of oppression (such as ageism and heterosexism) intersect in everyday situations of affective disablism. The article illustrates these processes using four narrative productions with men and women who are disability rights activists or community rehabilitation services users. A two-pronged analysis that combines structural and subjectification process analysis suggests that: (i) participants who deviate from the able-bodied norm are constituted as ‘impaired’, ‘immoral’, ‘supercrip’, ‘unproductive’, ‘(un)reproductive’ subjects or as ‘objects of care’ within disablist situations; (ii) ableism intertwines with different axes of oppression; and (iii) becoming an activist contributes to one’s constitution as the ‘subject of rights’, although such process is fraught with tensions.

Keywords: disability; psycho-emotional disablism; ableism; intersectionality; apparatus.

Points of Interest

- This article looks into how society labels people as ‘disabled’ when they display unusual abilities and looks.
- The results suggest that discrimination against disabled people happens when society takes their rights away. Discrimination also takes place when non-

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disabled people do not treat disabled people as equals in everyday conversations.

- Also, health professionals may discriminate against disabled people when they do not listen to what disabled service users have to say about mental distress or physical pain.
- Age and gender may influence how people experience disability. For example, working-age disabled women are worried about not finding a partner because they are living on welfare benefits.
- The results suggest that disability activism can break down prejudices against disabled people. For instance, activism can help people see that not only disabled people need help, but we all do. However, some disabled activists may find it hard to let their weaknesses show.

Dis/ability Studies: A Hybrid Approach

Dis/ability studies (Goodley 2014, 2017) consider ability and disability as mutually constituted and reproduced simultaneously by disablism and ableism¹. The social-relational model of disability defines disablism as the oppression imposed on people with biological impairments. This includes 'structural disablism' (Reeve 2012a, 79) or barriers that operate 'on the outside' (whether they be physical, communicational, or attitudinal; Thomas 2004, para. 18) and 'psycho-emotional disablism' (Reeve 2012a, 79) or barriers that operate 'on the inside' (Thomas 2004, para. 18), which is the undermining of the psycho-social well-being of people with impairments. Ability studies define ableism as the network of hegemonic social practices that project 'the corporeal standard' as the 'species-typical and therefore essential and fully human' so that disability 'is cast as a diminished state of being human' (Campbell 2009, 5). Ableism is therefore 'the hidden referent of disablism' (Goodley 2014, 26) and other systems of oppression such as heterosexism or ageism (Goodley 2014; Wolbring 2008), since being cast as 'less-than-human' legitimises being discriminated against.

The work of Liddiard (2011) and Slater (2013) has shown the usefulness of employing the notions of psycho-emotional disablism and ableism while also exploring the intersection between heterosexism and dis/ablism (Liddiard 2011), and between these and ageism (Slater 2013). In the following sections, we argue how this approach has contributed to the problem formulation of the current investigation.

From Psycho-Emotional Disablism to Affective Disablism

Dis/ability studies examine how ability and disability are co-constituted at the inter-subjective level (Goodley 2014) and the emotions involved in this process (Goodley, Liddiard, and Runswick-Cole 2017). For this reason, researchers within this framework have used the notion of psycho-emotional disablism. Donna Reeve considers that psycho-emotional disablism has two sources (Reeve 2004, 2012a). On the one hand, indirect psycho-emotional disablism derives from structural disablism, which keeps those who cannot overcome 'external' barriers 'out of place' (Reeve 2004, 85), potentially undermining their subjective well-being (Goodley 2014; Watermeyer and Swartz 2016). On the other hand, direct psycho-emotional disablism is the functional and aesthetic invalidation (Hughes 1999, 2000) of disabled people within their relationships with the non-disabled, with themselves or with other disabled people (Reeve 2012a). Also, Thomas (2004, para. 32) advances the notion of 'impairment effects' to refer to impairments' 'direct and restricting impacts on people's social lives— "restricting" as judged against socially defined age-norms'. In this respect, Ferrie and Watson (2015, 61) conclude that, especially when it comes to people with progressive diseases, 'the psycho-emotional effect of the impairment and a focus on limitations in private spaces' must be considered.

The social-relational model has proven useful in identifying everyday situations in which disabled people are harmed, their emotional effects, and the role of gender in such situations (Thomas 2006). However, this approach is based on several modern dualisms, namely, nature/society (in impairment effects/disablism); inner/outer (in barriers that operate on the outside/inside); and cognition/emotion (in the very notion of psycho-emotional disablism).

The notion of 'affective disablism' (Goodley 2014, 64), based on affect theories, overcomes the cognition/emotion and inner/outer dualisms since it places discrimination in the relationships between humans and between humans and non-humans (Goodley, Liddiard, and Runswick-Cole 2017). Thus, affective disablism is a form of relational, cultural, and political discrimination that depends on 'the binary distinction between the same and his many Others' (Goodley 2014, 65), which is the basis of ableism.

Affective Disablism as an Element of the ‘Disability Apparatus’

Some works that explore psycho-emotional disablism have used poststructuralist notions (Neller 2016; Reeve 2002, 2009, 2012b). For example, Reeve (2009) uses the notion of ‘state of exception’ (Agamben 1998, 12) to refer to the suspension of the disabled subject’s citizenship rights. Also, she considers the suspension of the norms that regulate daily interactions as an act of direct psycho-emotional disablism that locates the disabled subject in a ‘psychic state of exception’ (Reeve 2009, 203).

Some authors within disability studies have been highly critical of poststructuralism and, particularly, of Foucault’s alleged idealism (Hughes 2015). Feely (2016) contends that such criticism omits that the concept of ‘apparatus’ gives equal importance to discursive and non-discursive practices. For Foucault, life—and by extension the ‘impaired subject’—is a historically specific ‘dynamic ensemble of matter and meaning’ (Lemke 2015, 14).

The kind of subject (neo)liberalism requires in order to function (i.e., a self-contained, self-regulated, rational, independent, and productive individual) can be understood as the ‘strategic imperative’ (Foucault 1991, 129) of the ‘disability apparatus’ (Contino 2013; Tremain 2017)². Tremain (2017) defines the disability apparatus as a network of historically specific power relations that connects several material-semiotic elements that reinforce each other. In addition, the disability apparatus is also intertwined with other apparatuses, such as gender and sexuality (Tremain 2017). Tremain (2017) argues that the disability apparatus performatively produces impairment as a pre-discursive reality that causes disability. The disability apparatus produces ‘able-bodied’ and ‘disabled’ as distinct subject positions that can be potentially occupied by everyone, depending on affects (Goodley, Liddiard, and Runswick-Cole 2017), the physical environment (Goodley 2014), and the institutional environment.

Regarding affects, emotions such as fear, pity or disgust govern the able-bodied subject’s conduct toward the disabled, and are internalised as shame by the latter (Hughes 2012). Particularly, ‘disgust’ has been described as ‘the emotional fuel of ableism’ (24); a neoliberal ‘governing technology’ (Soldatic and Meekosha 2012, 145) that reproduces ‘othering’ and individualises disability (Soldatic and Pini 2009, 82). Also, the notion of ‘emotional work’ (Hochschild 1983, 7) describes how the disabled subject manages both their feelings and those of the ‘demanding public’ to match the ‘expectations of non-disabled culture’ (Goodley 2017, 110). Although every social interaction requires

affective management, the emotional work the disabled subject employs ‘reflects an inherent inequality’ (Hochschild 1983, 19). Such inequality stems from a ‘conspiracy of silence’ (Olkin 1999, 96) imposed by the demanding public on dis/ablism and impairment. This ‘conspiracy’ prevents the able-bodied subject from being distressed by these realities (Hughes 2012, Watermeyer and Swartz 2008). In our view, *both* the performances that confirm the ableist claim that the disabled subject is ‘less than human’ *and* the ones that aim at *subverting* such claim require emotional work. Indeed, countering ableism entails managing the ‘existential insecurity’ (Reeve 2012, 80) derived from the awareness that one’s humanness is not taken for granted³.

Regarding the physical and institutional environments—which are the materialisation of certain normative discourses (Imrie 1996)—we argue that indirect affective disablism produces disabled subjects by keeping certain bodies ‘out of place’ (Kitchin 1998, 345; Reeve 2004), as opposed to the ‘legitimate’ able-bodied subject. Thus, able-bodiedness is also a performative subject position that requires constant actualisation (McRuer 2006) through an adequate performance in an allegedly neutral environment.

In this light, ableism can be understood as a set of semiotic-material practices that constitute the regime of light and enunciation (Deleuze 1992) of the disability apparatus. Ableism, which is underpinned by the medical model of disability (Palacios and Romañach 2006), renders unthinkable the social conditions of disablement (Contino 2013) and, in fact, anything beyond the personal tragedy theory of disability (Oliver 1990).

Building on the empirical works conducted in Spain addressing discrimination against disabled people from a critical perspective (García-Santesmases 2017; Gutiérrez 2011), this investigation illustrates how the notions provided by dis/ability studies can enrich that line of work. Specifically, this study examines the constitution of the disabled subject by exploring how ableism and other axes of oppression (such as ageism and heterosexism) intersect in everyday situations of affective disablism.

Methodology

People produce narratives in order to make sense of their experiences (Moen 2006). Narrative research assumes that narrating an experience for a certain audience performatively produces the narrator’s subjectivity (Schongut-Grollmus 2015; Martínez-

Guzmán and Montenegro 2014). Narrative productions (NP) is a research technique (Balasch and Montenegro 2003) that has been used in several critical social psychology studies conducted in Spain (see Sadurní, Montenegro, and Pujol 2019). NP draws on the notion of ‘situated knowledges’ (Haraway 1991, 186), which claims that the articulation of the partial subject positions embodied by narratives produces a better understanding of phenomena (Balasch, Montenegro, and Pujol 2003). The validation of narratives by users and the use of memos that account for the decisions regarding participants’ selection, interviews, and analysis (Birks, Chapman, and Francis 2008) improve the rigour and auditability of research (El Hussein, Jakubec, and Osuji 2015). These decisions are closely related to the subject positions occupied by both the researcher and the participant. In this study, the following axes of sameness/difference become particularly important:

- (1) Dis/ability. Even when both the participant and researcher are legally classified as ‘disabled’, at a relational level, they both occupy relative positions that must be negotiated in each particular context. Thus, their belonging to a homogenous category cannot be taken for granted (Scott 2013).
- (2) Gender. The experience of disablism depends on one’s position in the heteropatriarchy (García-Santesmases 2017).
- (3) Belonging to a disability rights organisation. People who participate in such organisations tend to detect discriminatory situations to a greater extent than those who do not. Also, they are less prone to emulate ableist norms (Loja et al. 2013; Munger 2011; Reeve 2012a).

Participants

This paper outlines preliminary results of a wider investigation on dis/ablism that began in 2016 and included 11 participants. Here, we present the analysis of the narratives constructed with four physically disabled participants. The study uses theoretical sampling (Mejía-Navarrete 2000) considering the aforementioned axes of differentiation (dis/ability, gender, and belonging to an organisation for disabled people’s rights). The selection of participants considered different corporealities from that of the researcher, because dis/ablism takes on various forms depending on how the body transgresses the ableist norm (O’Toole 2013; Reeve 2012a). Specifically, while the researcher has an early-onset, stable, and visible condition that allows for independent ambulation, the

study includes people diagnosed with progressive conditions with varying degrees of visibility, three of which started in adulthood and one in childhood. Gender and participation in an organisation for disabled people's rights have also been taken into account.

Participants were recruited via two different information documents. One of them was addressed to the users of a local community rehabilitation centre. The other one was addressed to the members of the *Foro de Vida Independiente y Diversidad (FVID)*⁴. A brief description of each participant is provided in the following list⁵:

- J. C., * a 57-year-old man, is an activist from the FVID who has participated in an independent living program from the Centre for Independent Living in Barcelona since its inception. He defines himself as a person with the same features as any other while, at the same time, he is unique. After struggling for many years in an environment that metaphorically only offered a one-size-fits-all suit to fit in, he managed to weave a tailored suit made up of networks that allowed him to have independence and autonomy.
- Montserrat Garcia, a 33-year-old woman, defines herself as a person, rather than a patient, and a practical utopian that is involved in social activism around human rights and designs for diversity, collaborating with the ECOM Federation, the Catalan Rheumatology League, the Independent Living Movement, the Council of Organisations in Barcelona, and other citizen platforms such as Streets for Everyone.
- Abril, * a 42-year-old woman, holds a degree in Geography. She is currently a member of a community rehabilitation centre called Associació Vallès Amics de la Neurologia. She defines herself as a better, more open, positive person since the onset of a disease that has changed the way she walks. Currently, she devotes much of her time to reading and taking on new challenges.
- Arnau Renom, a 47-year-old man, is passionate about sports and literature. Two years ago, he joined a community rehabilitation centre called Associació Vallès Amics de la Neurologia, where he attends physiotherapy. Almost a decade ago, he was diagnosed with a disease that hinders his mobility and speech. Since then, he has been struggling to rebuild normalcy.

Organising Stories

Building the narratives involved five steps:

- (1) Definition of the form of communication and the meeting place. All participants chose oral interviews and selected different meeting places: home, workplace, or civic centres.
- (2) Main semi-structured interview. The interviews were conducted by the first author. Each interview took about 45 to 90 minutes, and interviews with activists were the longest. The audio was recorded with the permission of each participant to guarantee reliability (Izcara-Palacios 2014). Participants were encouraged to express any doubts regarding the informed consent and the research process. The interview outline explored the following topics: (a) internalised ableism and its intersection with other differentiation axes; (b) indirect affective disablism (in the educational, labour, and physical environments); (c) interactions with the able-bodied subject; and (d) suggestions for a better future. Finally, a space was opened for participants to raise additional questions (Martínez-Guzmán and Montenegro 2014).
- (3) Textualisation. Drawing on the recordings and field notes taken after the first interview, the researchers selected relevant topics and organised the interview to build a story. A title and several headings were added to enhance readability (Schongut-Grollmus and Pujol 2015).
- (4) Modifications, clarifications, and consecutive encounters. Each participant received the text for revision, and subsequent meetings were organised (García-Fernández and Montenegro 2014). These were 90 to 120 minutes long and took place under similar conditions to the previous ones. Each meeting involved: (a) reflecting on the contents and form of the narrative (style, degree of formality, and organisation); (b) discussing and making those changes suggested by each participant; (c) extending those issues that had not been addressed in the previous session; and (d) asking for participant's self-description, deciding on whether to appear with his/her the real name or a pseudonym (two participants chose a pseudonym), and considering if real place names should appear (they were all preserved). The procedure continued until all participants expressed their agreement with the narrative (Pujol,

Montenegro, and Balasch 2003), normally after one or two additional encounters. The recognition of the narrative by the participant enhanced the credibility of the study (Noreña et al. 2012; Rodríguez-Sabiote, Quiles, and Torres 2005). Each participant received the final narrative.

- (5) A final interview explored the transformation of participants' subject positions and how participants felt about the research process. The field notes included this final interview. In total, 12 interviews were carried out for this study.

Narrative Analysis

Narrative analysis consisted of the following steps:

- (1) Textualisation-revision cycles until reaching the final narratives. During textualisation, the researcher took some analytical field notes on the narrative's content as well as on the narrative-production process (Hammersley and Atkinson 1995). Although NPs can be considered finished products in themselves, two additional steps have been followed to prevent a hostile interpretation of narratives (i.e., in light of the personal tragedy paradigm) (Goodley et al. 2004).

- (2) Intra-narrative analysis. First, this involved familiarisation with narratives and field notes. Subsequently, two parallel phases took place. On the one hand, a *structural analysis* allowed us to identify the elements that constitute the horizontal dimension of each narrative (Frank 2012). The horizontal dimension may include a summary (which announces that a story will be told and its genre); an orientation (which sets the time and place, and introduces the characters); a complicating action (which demands a response from the characters); an evaluation of what happened (the meaning of the story and the emotions involved in it); and a resolution. On the other hand, *subjectification process analysis* was comprised of identifying the practices (Youngblood-Jackson 2013) that contribute to producing and subverting the disabled subject. Specifically, this involved identifying text extracts that illustrated explicit ableism, indirect and direct affective disablism, and the emotions that arose by these. The authors reflected on how each dis/ablist situation performatively constituted the disabled subject, how each participant actively negotiated or subverted such subjectification process,

and the intersections between the dis/abled subject position and other subject positions.

(3) Inter-narrative analysis. This involved establishing the commonalities and differences between narratives and identifying subjectification processes through an inductive-deductive dialectic approach (Gomes-Campos and Ribeiro-Turato 2009).

Findings and Discussion

This section includes the results of the inter-narrative structural and subjectification process analyses. Regarding the latter, each section shows the subject positions that, in our view, constitute the process of conformation of the disabled subject.

Structural Analysis

The commonalities between narratives point to an overarching narrative (which includes several sub-accounts): ‘having a medical condition in an inaccessible world’. Figures 1 through 4 outline the horizontal dimension of individual NPs. What follows is the description of commonalities and relevant differences between narratives. As can be seen, none of the NPs have all the elements suggested by Frank (2012), while all of them have a complicating action and resolution.

[Figures 1-4 near here]

First, the complicating action consists of the onset of a set of physical symptoms or conditions that call for a resolution. The complicating action poses a conflict that requires emotional work (Hochschild 1983) to be performed by participants concerning impairment effects (Thomas 2004) such as pain or the gradual loss of abilities; discomfort in the face of failure to perform able-bodiedness in several subject positions occupied by the participant (e.g., worker, student, older brother, man, woman); and the fact that the physical and social environment performatively positions participants as ‘impaired’, ‘immoral’, or ‘supercrip’ subjects or as ‘objects of care’ (Clare 2001) in multiple situations of direct and indirect affective disablism (Reeve 2012a).

Second, several characters, including the participant, move the story towards a resolution. Participants perform emotional work when problematising ‘truths’ they had taken for granted before the complicating action, such as the meaning of ‘normalcy’ and ‘illness’ or heterosexist ideals. Participants’ relatives and partners materially contribute to

the development of their academic or independent living projects (Figures 1 and 2) or by raising the participant's symbolic status (Figure 3). Healthcare and social service professionals enhance participants' management of impairment effects (Figure 2) as well as affect regulation and promote a shift in their conception of normalcy (Figure 3). Also, they encourage participants to meet other disabled subjects (Figure 1) or promote their physical independence (Figure 3). Being in touch with other disabled people provides participants with a 'safe space' to build relationships and take on an active role. For activists, other disabled people also contribute to their subjectification as 'subjects of rights'.

Third, the narratives' resolutions are 'in the making', since they demand constant emotional work regarding impairment effects, ableist and heterosexist standards, and/or multiple situations of affective disablism that constitute participants as 'impaired', 'immoral', 'supercrip', 'unproductive', or '(un)reproductive' objects of care. All narratives end by envisioning a better future. They all agree in pointing out the need to eliminate 'intangible' barriers, such as values that lead to the invalidation of disabled people's voices or to displaying a differential treatment towards them. Remarkably, activists' narratives articulate more specific proposals that point to the need to work with other marginalised groups.

As for the differences between narratives, whereas non-activist ones (Figures 3 and 4) include a single resolution that comprises emotional work and a tension between the reproduction of ableist standards and their subversion, activist narratives include a three-stage resolution. The first phase of both activist narratives involves problematising the ableist ideal of physical independence by embracing assistive technologies. The second phase of the narrative represented in Figure 1 is partly consistent with the first phase of the narrative depicted in Figure 2, as it involves meeting people with a similar diagnosis in a biomedical organisation. Such a context triggers the desire for independence from the family, which constitutes the complicating action that will resolve when the participant abandons the biomedical organisation. The third phase in the narrative represented in Figure 1 matches the second phase of the narrative in Figure 2 and involves discovering activism for disabled people's rights. Becoming an activist allows participants to reject ableist standards more decisively. The narrative represented in Figure 2 presents a third phase that involves the will to resume a life project that is not limited to mere survival.

Lastly, regarding the evaluation of what happened, in three of the narratives, participants evaluate the advent of their condition as a turning point that involved

problematizing ableist and heterosexist ideals (Figure 2), or the notions of ‘illness’ and ‘normalcy’ (Figures 3 and 4), although these changes do not always destabilise the regime of intelligibility of the disability apparatus. For activists, embracing human and non-human assistive technologies, engaging in independent living projects, and taking on job opportunities (Figures 1 and 2) also appear as turning points. Finally, when evaluating what happened, three of the four participants appear to psychologise their discomforts.

The Disabled Subject as Unproductive and (Un)reproductive: Negotiating (Re)productive Paces

Once, I applied for an official examination. It was around the end of the [Francoist] dictatorship and the beginning of democracy. They had just passed a law that dictated that a certain percentage of workers had to be disabled. . . . I do not know if I did well in the exam or not, but I know the public examinations were called off because the unions would not see it happening. I understand positive discrimination was not widely accepted back then: giving the job to a disabled person was not very understandable when everyone needed to work. . . . If we ask for complicity and understanding from others (let alone sympathy), we must make an effort to understand the human being in general: immigrants and other circumstances. (J. C.)

Preventing access to a job despite the proposed legal measures—as the excerpt above shows—can be understood as an act of indirect affective disablism (Reeve 2012a) that entails carrying out emotional work (Hochschild 1983) in order to ‘excuse’ the structural barrier imposed by the able-bodied subject.

Medical authority performatively divides subjects between ‘productive’ and ‘unproductive’. Being cast as ‘unproductive’ at the normative working age constitutes an act of direct affective disablism (Reeve 2012a), as Abril’s narrative suggests: ‘The day the medical court granted me “Absolute Disability” I was devastated. I asked my brother: “Who is going to love me like this: a 35-year-old pensioner?”’. The notion of ‘unlovability’ suggests internalised disgust at the immoral ‘workless status’ of the welfare subject (Soldatic and Meekosha 2012, 142).

The labelling of the disabled subject as ‘unproductive’ also occurs regarding the normative paces of daily activities (Kafer 2013) and in conversations with acquaintances. This can be considered an act of direct affective disablism (Reeve 2012a) that, when

internalised as shame, leads to emulating the ableist norm (Campbell 2009). ‘Passing’ (Goffman 1963) can be interpreted as a strategy to manage internalised shame and prevent others from having to deal with one’s ‘difference’ (Hughes 2012, Watermeyer and Swartz 2008). Moreover, ‘passing’ generates frustration and isolation that require further emotional work. The following excerpt illustrates this:

[When I was younger] and went out, I did not want to live my life as it was, but to live life like everyone else. Identical. And I could not: I arrived exhausted at home. And when I was exhausted, I stayed at home so nobody would see me that way. I never showed that reality, that truth: I used to throw a heavy veil over it. (J. C.)

The constitution of the disabled subject as ‘unproductive’ is subverted by different means, such as the claim for a structural change in production rationales:

How does functional diversity contribute to work environments? It provides them with more humanity, among many other things, such as questioning production rationales and highlighting the importance of care for sustaining lives. (Montserrat Garcia)

The positioning of the disabled subject as an ‘object of care’ (Liddiard 2014) by close relatives or health professionals can lead to infantilisation, making access to the position of ‘reproductive subject’—associated with adulthood—more difficult:

Ultimately, I am a burden to my partner because of my lack of balance and my speech; she would like me to be well and there is no cure. . . . Sometimes, I feel upset. For example, at the moment, I would like to be with my five-month-old daughter, but she is with her mother. Leaving her alone with me would be dangerous and it makes me feel sad, but I understand. (Arnau Renom)

The previous extract illustrates an act of direct affective disablism (Reeve 2012a): first, because feelings of guilt emerge due to being positioned as an ‘object of care’; and second, because the participant’s efforts to perform able-bodiedness in caregiving tasks are cast as excessively ‘risky’ by others (Rush, Kjørven, and Hole 2016, 495). Being positioned as a ‘risky parent’ requires emotional work to manage the ‘impairment effects’

that impede performing normative (independent) parenthood. Thus, impairment effects and ableist independent parenting go hand in hand. Deeming one's position as a 'risky parent' to be *understandable* can also be read as the result of emotional work, performed both on the participant himself (to rationalise pain) and on others (to avoid the conflict involved in problematising the current organisation of parenting).

Performing 'able-bodiedness' in reproductive tasks and resignifying 'caregiving' are resistance strategies to one's constitution as an 'object of care'. However, they require demonstrating to others one's ability to do care work. This imperative demonstration inherently entails emotional work, since it involves acting while knowing that one's ability is not a taken-for-granted:

When I started a relationship, it was a major shock for my family that my partner had a spinal cord injury. They said 'No! Why?' My family was expecting me to find someone to take care of me. . . . We had to problematise what it meant to have someone take care of you. For example, he is the only person I let accompany me to the doctor. . . . In this sense, taking care may be more about supporting and accompanying than about getting someone out of bed. (Montserrat Garcia)

One of the narratives tells how the pressure exerted by relatives and acquaintances to have offspring goes as far as to omit how having children would impact the participant's body. In turn, health professionals sometimes pressure in the opposite direction, omitting information about possibilities regarding reproduction. Both situations constitute acts of direct affective disablism (Reeve 2012a). The intersection between gender and disability appears in the following excerpt, where relatives express their will to give the participant support for motherhood but not to undertake a labour project:

In short, they have expressed that they would support me to be a mother, but not to leave the comfort zone at work and continue with my professional career. Would they have reacted like this if I were a man? This has hurt me a lot. (Montserrat Garcia)

The Disabled Subject as an Impaired Body in a State of Exception: Physical Autonomy as a Moral Imperative

Some participants internalise their position as ‘impaired subjects’ who must discipline their bodies through physiotherapy in order to match the ableist standard of physical autonomy (Yoshida and Shanouda 2015):

[In physiotherapy], I am taught that I can do by myself things never would I have imagined: climbing stairs without grabbing the handrail, getting up from the floor. . . . Physiotherapists supervise each of my moves, teaching me how to lean in order to shift the weight of the body at every moment, and how to do it automatically. (Abril)

Physical exercise appears as a moral imperative, as opposed to ‘getting carried away by one’s illness’ and succumbing to the ‘comforts’ of assistance. This disciplining process constitutes the ‘impaired subject’ as ‘immoral’ and, ultimately, a ‘supercrip’ (Clare 2001):

Some people are quite idle, but I am not like that. For example, I know someone who, although he can bathe himself, is more comfortable when someone else bathes him. . . . For me, it would also be easier, but I know that I have to make an effort and do it myself. Otherwise, one day I will not be able to do it and I will need help. (Abril)

This excerpt illustrates how disgust at *both* ‘bodily unruliness’ *and* ‘unworthiness’ operates as a ‘governing technology’ (Soldatic and Meekosha 2012, 145) of the disabled subject’s own conduct. Notably, some physiotherapists consider such bodily unruliness as ‘cheating’ or ‘deception’. Also, the normative functioning is conceived as a matter of overcoming, inciting the disabled subject to embody the ‘supercrip’. Regulating this distressing incitement in order to perform the ‘proper patient’ requires emotional work:

[The physiotherapist] has an idea of how the body is to be controlled and wants me to continue to control those body parts I do not use anymore. During the session, she insists that I do not cheat when exercising. I listen to her, but I stop doing it when the session is over. Were it for her, I would be exercising 24 hours a day. I just ignore the comments she sometimes makes. I am not saying she treats me like a child, but she does try to force me make an effort

and overcome. That's OK for me, but I am not sure that will be useful in my daily life. (J. C.)

Participants actively subvert their positioning as 'impaired subjects' by claiming their status as 'whole persons'. However, this claim is precarious, since such status is claimed 'in spite of' illness (Campbell 2009), and the feeling of completeness depends on a morally imperative performance according to the ableist norm:

I think that a whole person is one who, like me, does everything they can in their daily life. However, in some contexts, I feel incomplete. . . . The fact that I need help to move, that people have to be very attentive to understand me, and that I cannot teach . . . makes me feel incomplete. (Arnau Renom)

Omitting legal resources and available assistive technologies that could mitigate physical barriers or impairment effects (Thomas 2004) is a source of indirect affective disablism (Reeve 2012a). The following excerpt reflects the obligation to perform according to the ableist standard of independence despite the undesirable consequences that result in daily life:

The primary goal of the doctor (and that of the entire system) is to stop the disease, to make you normal. Since we cannot be fixed, what happens in the meantime with your life goes into the background. That's why nobody told me that wearing splints at night would reduce the pain a lot and would help me rest at night. . . . What if I do not heal? I will not have lived because I was waiting for the so-called cure? (Montserrat Garcia)

Such omission places the 'impaired subject' in a 'state of exception' (Agamben 1998) where citizenship rights—as well as the right to comfort—are suspended until the ableist standard is eventually met (Campbell 2009). This omission promotes the internalisation of the ableist ideal of physical autonomy and ensuing disgust at dependence. In turn, this results in 'passing' and 'covering' (Goffman 1963, 124) by rejecting assistive technologies or organising them in a hierarchy according to the degree to which these technologies distance the body from the ableist ideal (Gibson and Teachman 2012). Such internalisation may prevent the individual from engaging in activities that used to be part of an allegedly 'truncated by the disease' life project:

I wanted to continue studying. . . . Both my illness and my laziness have prevented me from doing so. . . . However, I am not doing it because of what the trip to the university involves. Recently, I told my brother I would like to study Law. . . . However, once on the faculty, I am not sure if I could move around there if the terrain is not even. . . . I might need an assistant or a walking frame. However, I would be embarrassed to go in a wheelchair around the faculty, because I think that, at this moment, I do not need it. (Abril)

This extract also points to the individualisation of disability and the resulting *immoralisation* of the disabled subject: although Abril attributes quitting her studies to both structural barriers and internalised disgust and shame at dependence, this is initially ascribed to *laziness* (an individual moral defect).

However, this ‘state of exception’ is not passively accepted by participants but resisted through emotional work involving claiming one’s rights in a context where the very entitlement to them is explicitly questioned:

I went to the social worker at the onset of the illness to see how I could benefit from the [Spanish Disability Act]. She told me that I was ill and that the hospital was the right place for me. Later on, I went back to her with the law in hand, with the appropriate article underlined. (Montserrat Garcia)

The Disabled Subject as Impaired, Immoral, and an Object of Care in a Psychic State of Exception

The following excerpt illustrates how the able-bodied subject places participants in a ‘psychic state of exception’ (Reeve 2009) in which the hypervisible body that departs from ableist standards becomes the object of multiple situations of direct affective disablism. In such situations, the subject is constituted as a ‘space invader’ (Puwar 2004, 144) who is ‘out of place’ (Kitchin 1998; Reeve 2004):

The other day I went to the supermarket. The workers and the people in the line would hit me. Some told me: ‘Come on, girl! Hurry up!’ Then, someone told the cashier: ‘I have to go and pick my son up at school’, and she told me afterwards. (Abril)

The internalisation of the 'space invader' subject position makes the participant feel she is altering the ordinary course of events and restricting the 'legitimate bodies' freedom. Also, embodying the 'space invader' position calls for emotional work consisting of affect regulation to erase any external sign of resentment (Olkin 2002):

I move slowly and delay the queue, but if they had helped me, I would have left faster, setting them free. People expected me to go faster and get out of the way, but I could not. I felt very powerless. . . . I left and went into another shop. I was almost crying. However, once there I plucked up courage and asked myself: 'Why do I have to feel bad? They do not have to help me, but they should not have pushed me'. (Abril)

Continuing with the focus on hypervisibility, the subject that does not fit the 'disabled body' stereotype (because of their age or an invisible condition) is discursively constituted as 'immoral' when using accommodations (Reeve 2004). This requires constant pedagogical, emotional work that generates frustration and leads to avoiding some environments: 'I have also received comments such as: "What a lazy person you are, why do not you use the stairs?" or "You are too young to have arthritis"'. (Montserrat Garcia).

Paternalistic attitudes can also be considered as a form of direct affective disablism that place the subject in a 'psychic state of exception'. This is especially true when they involve unnecessarily constituting the disabled subject as an 'object of care' who is epistemologically invalid (Tremain 2000) to define their own needs and how they should be met:

Once, I had an accident with the engine of my wheelchair and my foot got stuck. One person started trying to get me out of the wheelchair. I tried to warn him that he only had to move my foot, but people do not understand me, and they hurt me. (Arnau Renom)

On the one hand, this requires emotional work insofar as the participant feels forced to be compliant, and this generates anger (Olkin 2002). In addition, this is psychologised as a personal lack, to the extent that the participant conceives his 'passive' response as a defence against expressing anger and as a means to preserve social relationships (Williams 2003). On the other hand, the fact that he speaks out against this power dynamic

can be considered a productive response in light of such emotional work which, in turn, destabilises his positioning as an ‘object of care’:

Sometimes, I feel ‘out of place’ because since I got ill, I have many limitations. Also, in the face of obstacles—such as curbs and steps—everyone tries to help you when you do not need it. I have the feeling that, if I did not accept the help, I would still feel more ‘out of place’. If I knew how to say “No, thanks, I do not need it”, it would be OK. Maybe they would be very surprised, and then they would leave. However, I must be too impulsive, and I cannot say it kindly. I would sound aggressive. . . . I would like strangers to take me into account when they help me and not to try to position themselves as superior beings. (Arnau Renom)

Psychologising the Disabled Subject: Making Dis/Ablism Unthinkable

In accordance with the disability apparatus’ regime of light and enunciation (Contino 2013), participants’ discomfort is frequently psychologised (Goodley 2017). On the one hand, the psychologisation of physical discomfort by the medical gaze can be interpreted as a gendered act of direct affective disablism (Reeve 2012a), since it rests on the attribution of irrationality to the gendered body:

The diagnosis process was very long because, in the beginning, when they saw that I was in severe pain, they filled me up with diazepam instead of referring me to a rheumatologist or doing some tests. They thought it was a psychosomatic issue. That’s not the way things should work. I could see my fingers were very swollen, but since they were thin, the doctor did not see it that way. She told me that maybe I was very nervous about the university, so they might be swelling up because I would clench my hands during sleep. When my feet started to swell, no one dared to suggest that I was ‘clenching’ them, and they began to listen to me. (Montserrat Garcia)

‘Psy complex’ professionals (Rose 1996) also promote the psychologisation of direct and indirect affective disablism (Reeve 2000, 2012a). In the following excerpt, we appreciate that the regime of intelligibility of the disability apparatus renders unthinkable both

problematizing structural barriers and breaking the ableist standard of physical autonomy as a legitimate solution in the face of these:

I know someone who has been given psychiatric treatment because he could not leave his house, and the problem was that he actually did not have the appropriate supports to do so: he only needed a scooter and an accessible home! (Montserrat Garcia)

In addition, the regime of intelligibility of the disability apparatus promotes emotional work consisting of affect regulation (Olkin 2002) in situations of direct affective disablism. Interestingly, as Abril reported, this happens even when she places the cause for discrimination beyond herself:

Over time, when [others] have noticed that I did not care about these [discriminatory] situations, they have stopped doing it. I think that people know if you care or not and act according to this. Now, I am sure of one thing: *it's their problem and not mine. . . . Psychologists have helped me see that no one should tell me that I am less than them and, if they do—it could happen—I have to decide whether it affects me or not.* It used to affect me a lot. Now, not so much, and I will get to the point when it does not affect me at all. (Abril, original emphasis)

It is worth noting that the psychologisation of affective disablism can also occur for those participants to whom activism has provided the opportunity to contest personal tragedy theory (Oliver 1990) and subjectify themselves as 'subjects of rights': 'I am a quite conformist guy, and I was not enough of a fighter to rise against the world or my family' (J. C.).

The Disabled Subject as a (Supercrip) Subject of Rights: Ableism and Sexism Within and Outside Activism

Lastly, activists' narratives show that there is an inherent tension between subversion and reproduction of the subjectification processes mentioned above. Activism promotes partial de-subjectification from the disability apparatus (which encourages the subject to adjust to the circumstances) and leads to being subjectified as a 'subject of rights' that seeks to transform something beyond the individual's body:

When I say I am a conformist, I mean I always try to adjust to the circumstances. . . and when you do so, you are not struggling to change them. I think this is due to my family's culture; to an education based on Christian values, such as resignation. . . . On the other hand, in the Forum [of Independent Living] . . . they demonstrated to me that not being compliant was the key to moving the project forward. (J. C.)

However, subjectification as a 'subject of rights' is precarious insofar as the required emotional work to position oneself as such is either questioned by the able-bodied subject or perceived as too costly by the disabled subject. Such a hostile atmosphere may be considered a form of direct affective disablism (Reeve 2012a). In the face of such emotional work, the disabled subject may 'corpse' (Williams 2003, 535) as an activist by renouncing to use a transformative discourse and validating the 'inferior' subject position in which they are relegated:

If I talk to my mother about functional diversity, I will probably spend two hours without getting anywhere; she will better understand the term 'disabled' or 'handicapped', and that does not mean she is being offensive. . . . When I speak of being independent and autonomous, they [my relatives] argue that I cannot do everything on my own. They do not understand that this is not my goal. . . . Having to make an effort so that those close to me understand it is exhausting, and makes me feel bad. (J. C.)

Subjectification as a 'subject of rights' is also precarious within activism. Participants claim that ableist and heterosexist rationales remain among disabled activists. These are embodied by a masculinised and invulnerable 'supercrip subject of rights'. On the one hand, this subject reproduces ableism by accepting productivity as a valid criterion for establishing personal worth (Jammaers, Zanoni, and Hardonk 2016) and casting high work performance as a means for 'respectability' (Soldatic and Meekosha 2012, 152). The following excerpt illustrates this:

In the [functionally diverse] community, it is often argued that 'people with disabilities never take sick leave' in order to fit in the productive system. . . . Nobody can fully reach the productive standard, the 'machine-like' person

who never breaks down. Some people in the [functionally diverse community] have ended up worn out by trying to reach it. (Montserrat Garcia)

On the other hand, the unthinkability of bodily frailty and interdependence as the basis for a political claim results in othering ‘people with illnesses’ within the disability community. This drives participants to engage in emotional work to ‘pass’ as invulnerable:

For instance, I now feel super comfortable when I’m with the ladies of the community centre. However, I may feel uncomfortable if my fellow activists are there because I know their language is different from that of the ladies. It seems that we cannot give the impression of being ‘sick’ or ‘helpless’ and my mates may think I go along with the way these ladies talk [about disability]. It seems we cannot show our frailty. (J. C.)

Conclusions

This work argues for the usefulness of dis/ability studies (Goodley 2014, 2017) to understand the performative production of the disabled subject. Also, although it has been suggested that Foucault’s approach precludes the subject’s agency (Hughes 2015), this study illustrates how subjects deploy their agency to subvert that subjectification process. First, the research suggests that the most conflictual aspect in the onset of physical symptoms is not ‘impairment effects’ (Thomas 2004) in themselves, but the failure to perform the able-bodiedness as expected for each activity and each stage of the life cycle (Kafer 2013). Therefore, the impairment effects/disablism dualism loses its meaning. Failing to perform the ableist norm results in a set of acts of direct and indirect affective disablism (Reeve 2012a) that constitute the subject as ‘unproductive’ and as ‘(un)reproductive’. These temporalities and normative abilities, as well as their adverse effects on psychosocial well-being, differ depending on the position occupied in gender and age axes. Thus, ableism cannot be considered without attention to heterosexism (García-Santesmases 2017; Liddiard 2011, 2014) and ageism (Slater 2013). Legislation aimed at removing discrimination against disabled people should, therefore, contemplate the normative expectations regarding the duration and timing of any particular activity as potentially discriminatory aspects and address ableism as the source of such discrimination (Campbell 2015) from an intersectional stance (Platero 2012).

Second, those people whose bodies depart from ‘species-typical’ are subjectified as ‘impaired’, ‘immoral’, ‘supercrips’, and ‘objects of care’ in multiple situations of direct and indirect affective disablism (Reeve 2012a). This study suggests that the medical model underpinning ableism seems to have absorbed other individualistic models that used to frame past conceptualisations of disabled people. Thus, the moral model (Clare 2001) has aligned itself with the medical model, since the ‘impaired’ individual’s refusal to ‘mitigate impairment’ (Campbell 2009, 37) is considered ‘immoral’. The ultimate expression of the moral imperative to overcome both impairment and those barriers imposed on the ‘impaired subject’ is the supercrip model (Clare 2001; Kafer 2013), which encourages a hyper-abled performance in order to be valuable. In line with previous works (Soldatic and Meekosha 2012, Soldatic and Pini 2009), this study shows that disgust at dependence is deeply intertwined with the models that rest upon morality. In turn, the charity model (Clare 2001) also considers that impairments should be mitigated (albeit through help) and has not hesitated to align with medical knowledge, as can be seen in the telethons collecting funds for biomedical research (Oliver 1993).

Occupying the subject positions mentioned above requires strong and distressing emotional work (Hochschild 1983) that takes different forms. Regarding the ‘use value’ of emotional work (Hochschild 1983, 7), this study suggests the disabled subject may use it to maintain (Williams 2003, Goodley 2017) or challenge current relationships in order to socially survive (Watermeyer and Swartz 2008). While Reeve (2012a, 81) states that emotional work may be used to avoid being ‘excluded and “Other”’, we suggest it comes precisely at the *cost* of reinforcing ‘othering’. Besides being a form of affective disablism (Liddiard 2014) that generates ongoing frustration, emotional work is an exercise of power that not only fits the demands of ‘non-disabled culture’ (Goodley 2017, 110), but reproduces it by generating two asymmetrical subject positions: the disabled subject (bound to carry out emotional work) and the able-bodied subject (positioned to keep the Other in an ‘psychic state of exception’; Reeve [2009]). Not only are these subjectification processes promoted in interpersonal relationships but also in the interactions with healthcare and social services professionals. These latter agents generate states of exception in which citizenship rights are suspended (Agamben 1998) until full compliance with the ableist ideal of physical autonomy occurs (Campbell 2009; Gibson and Teachman 2012). In this regard, accessibility legislation will remain insufficient until those professionals who work with disabled people problematise how ableism pervades their practices.

Third, the results suggest that ‘psy complex’ professionals (Rose 1996) can contribute to the psychologisation of physical discomforts as well as direct and indirect affective disablism (Reeve 2000). Therefore, training programs for professionals who work with disabled people should include a critical disability perspective, which is currently scarce in higher education psychology programs taught in Spain.

Finally, structural analysis suggests that being in touch with other disabled people contributes to the problematisation of ableism. In a context in which professional ableist biases favour the dispersal of disabled subjects (Campbell 2009), knowledge on discourses and practices that destabilise the regime of intelligibility of the disability apparatus should be promoted (Contino 2013). In turn, narratives suggest that activism is not exempt from heterosexist and ableist dynamics in which human vulnerability is rendered invisible. As Ferrie and Watson (2015) suggest, it is urgent to change these dynamics, not only because they prevent those who do not fit the stereotype of ‘a person with a spinal cord injury’ from participating in political struggle, but also because they hinder activism’s potential to problematise the very root of discrimination: ableism.

Notes

1. Accordingly, we use the terms ‘dis/ability’ and ‘dis/ablism’ when referring to both categories or systems, respectively. Conversely, we use ‘ability’, ‘disability’, ‘ableism’, and ‘disablism’ to refer to a specific side of these dualisms.
2. Regarding capitalism as the disability apparatus' strategic imperative, Preciado (2013) argues that the process by which the impaired and disabled body was produced in the late 19th and early 20th centuries has to do with industrialisation, for the ‘disabled body’ is precisely disabled because of its inability to enter the Taylorist production chain. In the same vein, Goodley (2014, 28) advances the notion of ‘neoliberal ableism’ to refer to the fact that ‘The functioning neoliberal self is an able-bodied and minded one’.
3. Wong (2000) and Liddiard (2014) have given different uses to the notion of ‘emotional work’. Wong (2000) argues that ‘work’ includes both the barriers that the subject experiences and the actions undertaken to manage them, and distinguishes ‘emotion work’ from, inter alia, ‘identity management’. We suggest that ‘emotional work’ *also* includes dealing with the emotions associated with both normative and subversive identity management strategies. In turn, Liddiard (2014) states that emotional work encompasses ‘private’ phenomena (i.e. that happen within the

family or home). However, in line with feminist problematisations of the private/public divide (Pateman 1989), we contend that emotional work happens both within and beyond domestic settings.

4. The Forum for Independent Living and ‘Diversity’ [neologism which results from combining ‘diversity’ and ‘liberty’] is a virtual activist space founded in Madrid in 2001. Since its inception, it has been the main disseminator of the independent living philosophy in Spain. One of their most notorious contributions is advancing the notion of ‘functionally diverse people’ to refer to those people who are discriminated against because they carry out daily activities in a nonstandard way.

5. An asterisk after the participant’s name indicates that they chose to use a pseudonym, and no asterisk indicates that the participant chose to use their real name.

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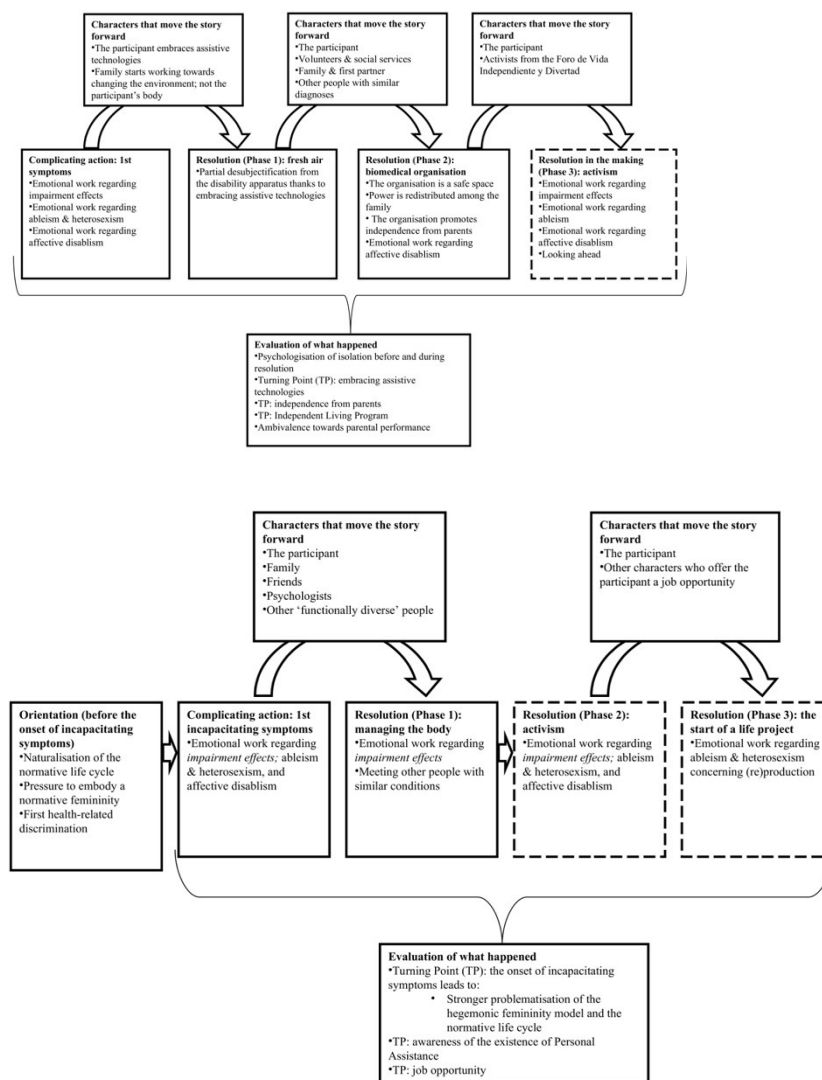
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Figures



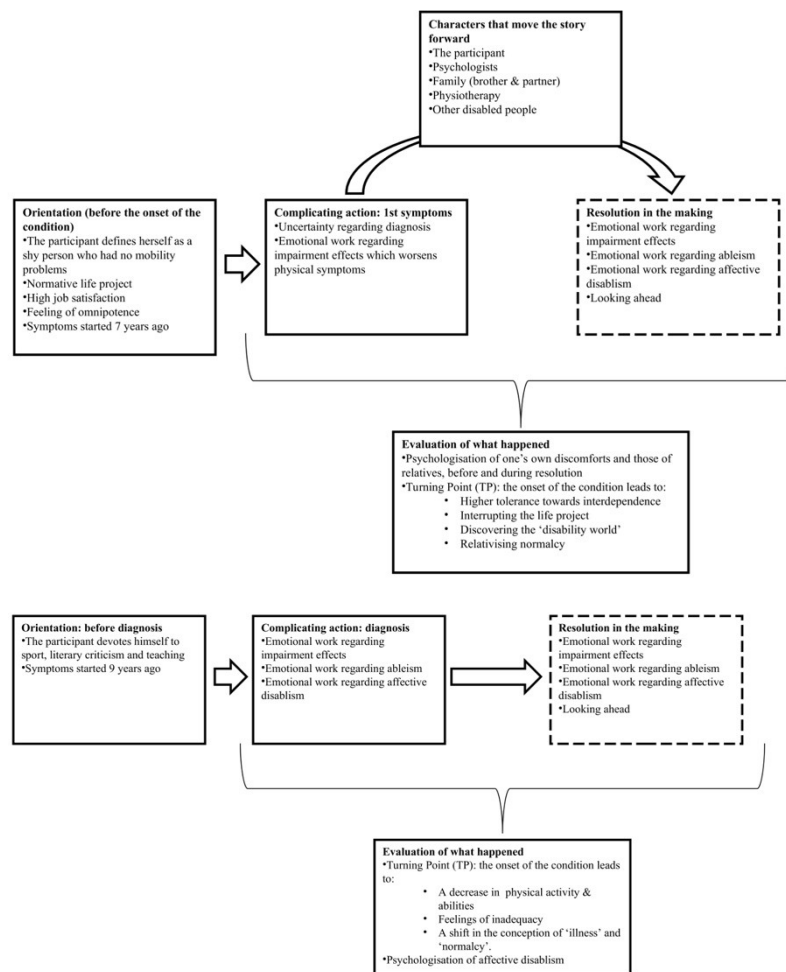


Figure captions

Figure 1. Horizontal dimension in *A Tailored Suit for Every Human Being: Vindicating Equality in Diversity*, by J. C.

Figure 2. Horizontal dimension in *Diverse Paces in Competitive Times: Placing Life at the Centre*, by Montserrat Garcia.

Figure 3. Horizontal dimension in *A New Stage: Constructing New Identities and New Normalcies*, by Abril.

Figure 4. Horizontal dimension in *The Challenge of Living*, by Arnau Renom.