

TOOLS FOR CONSTRUCTIVE DISABILITY MANAGEMENT

A Pragmatic Approach to Label Use within Disability Discourse

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Introduction

‘Labels go on soup cans, not people’ – an expression either playfully or forcefully thrown into both private and public conversations on disability. After all, it could be clamoured, are human differences not more deserving of celebration than medicalisation or stigmatisation through label use? In reducing people experiencing any form of impediment to their abnormalities, labels suppress people’s potential and therefore their level of functioning. New participation laws passed in 2015 even demand employers make use of this potential in people with disabilities and offer them appropriate job opportunities. It is therefore hard to see what would be the added value of using labels – either medical or social – within disability discourse.

Political correctness to further inclusion, however, does not necessarily diminish experience of impediment that may be negatively impacting people’s functioning.¹ Neither does analysing or researching how disability is understood or represented in language make a negative connotation shift to a positive one; the words do not carry the connotation with them, it is put into them by the way people interpret and use them.² Discarding labels before exploring alternative usage would therefore be rather premature.

In this thesis I will argue that labels *do* have an added value within disability discourse. I consider labels indispensable for improving personal functioning of people with disabilities, but only if they are used as practical action filters as opposed to identity descriptions. Since this is a pragmatic proposal, I will not be engaging in the debate on the nature of disability. My claims will be supported using varying examples mostly referring to experiences associated with physical disabilities, neurodevelopmental and mental disorders. In Chapter 1 I will use Neil van Leeuwen’s concept of Matrix happiness to illustrate the unlikelihood of decreasing experience of impediment by aiming for normal functioning, therewith emphasising the importance of focusing on personal functioning. Here I will be introducing my concept of need substantiation and constructive action and support this with my ‘Coat metaphor’, which will be carried on throughout this thesis. Problems in establishing a link between label and individual when employing labels as identity descriptions will be discussed in Chapter 2, for which I will take much of my inspiration from Ian Hacking’s view on human kinds. In Chapter 3 I will explain how using labels as need-dedicated action filters is more conducive to constructive action. Since this approach to labels allows for a phenomenological link between individual and label without having to commit to an essentialist view of disability, it is more conducive to constructive action aimed at optimising personal functioning.

¹ Anita Silvers, “Chapter 7: Feminism and Disability”, *The Blackwell Guide to Feminist Philosophy*, ed. Linda Martín Alcoff and Eva Feder Kittay, (Oxford: Blackwell Publishing Ltd., 2007), p. 131-142, here: p.135-136.

² Tom Shakespeare, *Disability: Rights and Wrongs Revisited*, (London: Taylor and Francis, 2013), p.55.

Chapter 1

Experience of Impediment, Matrix-happiness and Constructive Action

In this chapter I will address what I consider to be the issues people with disabilities face on a day-to-day basis in order to underscore the importance of personal functioning over the appearance of normal functioning when dealing with experiences of impediment. I will use Neil van Leeuwen's account of Matrix-happiness in order to argue that maintaining a standard of normal functioning for people with or without disabilities inhibits constructive action aimed to optimise personal functioning. I will then proceed to draw out the process of personal need substantiation underlying constructive action to then point out the importance of acknowledging any experience of impediment, especially for people with disabilities.

1.1 Experience of Impediment

It can be said people manifest themselves as embodied individuals among others through action.³ It is through performance that a person becomes aware of her⁴ capabilities and consequently her incapacities.⁵ What it is like to live with the awareness of what she is not entirely capable of when comparing herself to her peers or to what she conceives of as 'normally functioning' people, however, is another matter. Performing specific tasks or interacting with people may be indeed quite impossible or at least come at a great personal cost in terms of energy, physical health/comfort and emotional resilience.⁶

Choosing to maintain the appearance of optimal functionality despite certain incapacities would therefore be quite paradoxical if 'optimal' functionality amounts to performance of action - and/or cognitive processes necessary for smooth execution of this action - at the lowest personal cost possible. When a process runs smoothly, I understand 'smooth' to mean that the energy put in equals or at least closely approximates the intended productive energy coming out with the least amount of energy 'leakage'. If someone has to put great effort into endeavours others may find quite effortless, her personal circumstance may leave her feeling highly constrained. If she would be required to meet the same demands as people who do not have to put in the effort she does, maintaining the same level of productivity would come at a great personal cost, which may or may not be outwardly visible.

Experiencing either physical or mental disabilities in a sense that one feels heavily impeded in performing daily tasks in both professional and personal settings, can thus be said to greatly affect one's overall functioning. Throughout this thesis I will be using 'impediment' and 'disability' interchangeably. I do not intend to offer a definition for disability, since I will focus on the *experience of impediment*. Since 'disability' is often used to allude to this, whether it be within medical or social context, the term should be read with the same neutrality. To name a few examples: manoeuvring through a crowd on a busy street can be frightening, even dangerous for someone who cannot see; taking the stairs without the use of one's legs can face one with an impossible challenge; interacting with people without being able to clearly understand figurative speech or translate verbal instruction to appropriate action can be confusing and stressful for people with autism; and living

³ Shaun Gallagher and Anthony J. Marcel, "The Self in Contextualized Action", in *Models of the Self*, ed. Shaun Gallagher and Jonathan Shear, (Thorverton: Imprint Academic, 1999), 273-301, here: 296.

⁴ For simplicity's sake I will only use the female pronoun all throughout this thesis. No gender discrimination is intended.

⁵ Shaun Gallagher and Anthony J. Marcel, "The Self in Contextualized Action", 293.

⁶ Tom Shakespeare, *Disability: Rights and Wrongs Revisited*, p.86.

independently is certainly not a given for people with learning disabilities or severe anxiety disorders.

Aside from encountering practical challenges, people with disabilities are also prone to judgement from their environment.⁷ Being considered 'the person who cannot (do) x' leads both her and others to identifying her (self) with her inability to (do) x. She could seem not to be more than her disability. Therefore, she may not be *treated* as more than her disability, which may also account for many people not speaking to someone with a disability directly.⁸ Moreover, seeing someone struggle, seemingly because of an inability to (do) x, often confronts people with their own humanity.⁹ Possible anxieties of 'catching' the disability or other undesirable feelings this may provoke are often attributed to the person with a disability, branding her as 'something that should be avoided, ignored or patronised'.¹⁰ Consequently, this kind of social devaluation or stigmatisation often gives rise to debates on disability rights, in which people with disabilities hope to judiciously gain the respect they are not afforded in their daily lives. Having to go to these lengths in order to be acknowledged, respected and treated as equal is what can make a disabled life even more of a struggle than it may already be. What needs mentioning is that there being a causal relationship between someone's experience of impediment, its manifestation and possible social barriers coinciding with these is highly controversial.¹¹ However, a causal relation tends to be assumed when the environment is aware of someone's disability.

This unification of person and their label of disability also tends to be a reason for employers not to hire people with either physical or mental disabilities. They may not know how and if a disabled employee's limitations can be compensated for without putting financial and practical pressure on their colleagues and management.¹² For people with disabilities, being unable to manage 'regular' tasks independently often means being at the mercy of health professionals, home care services, partner, friends, family - sometimes even strangers. People with disabilities may constantly feel as if their vulnerabilities are on show for anyone to see, look at, comment on, inquire about or intervene in without invitation.¹³ Not only does this discount the capabilities people with disabilities may have, it also shows a disregard for various compensatory coping skills they may have developed themselves. Martin Milligan in his letter to Bryan Magee on his disability, for instance, mentions how he was once passed over for a job, because the prospective employer assumed Milligan's blindness prevented him from walking up and down the stairs within the building. He would have been perfectly fine, Milligan mentioned, managing the stairs by moving slowly and guiding himself with his hands.¹⁴ Generalised assumptions on what someone with a particular disability can or cannot do can thus lead to chronic over- or underestimation, apparent in, for example, 'tough love' attitudes meant to encourage overcoming an incapability or in overly

⁷ Shakespeare, *Disability: Rights and Wrongs Revisited*, p.98.

⁸ Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, (Englewood Cliffs: Prentice Hall Inc., 1963), p. 5-7.

⁹ N. Ann Davis, "Invisible Disability", *Ethics*, Vol. 116, No. 1, (Chicago: The University of Chicago Press, 2005), p. 153-213, here: p. 213.

¹⁰ Erin Martz, "Acceptance of Imperfection", *Disability Studies Quarterly*, Vol. 1, Issue 3, (The Ohio State University Libraries, 2001), p. 160-165. Accessed online on November 18, 2015, <http://www.ds-q-sds.org/article/view/302/353>; Davis, "Invisible Disability", p. 192-193.

¹¹ David Wasserman et al., "Disability: Definitions, Models, Experience", *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Winter 2015 Edition.

¹² Shakespeare, *Disability: Rights and Wrongs Revisited*, p. 31.

¹³ Goffman, *Stigma*, p. 5-6.

¹⁴ Bryan Magee and Martin Milligan, *On Blindness: Letters between Bryan Magee and Martin Milligan*, (Oxford, Oxford University Press, 1995), p. 43.

considerate gestures that border on patronising.¹⁵ The rationale towards disability labels could then become something like: 'If you do not want to be the man with the hat, do not wear a hat.' If a label is associated with an image that does not feel like it properly represents the entire person wearing it, not wearing it – if possible – would be more preferable.

What can make living with a disability even more strenuous is that the experience of impediment is not always outwardly visible in appearance or behaviour.¹⁶ Pain, discomfort, confusion, compulsive thought patterns, panic or sensory overload need not manifest outwardly, but are no less part of life with certain impediments. Still, disclosure of experience related to any kind of invisible disability can meet with (professional) incredulity or hesitation to regard it as anything serious. As such, the burden of proof is placed on the disabled person whenever the situation demands it.¹⁷ Furthermore, stereotypical understanding of certain disabilities may play into possible disregard of someone's experience of impediment.¹⁸ Statements exemplifying this may take the shape of 'You cannot possibly be/have x, because if you were/did, you would do y or look z and would not be able to do w.'

Not only do preconceived notions of disability surface in grading someone's experience of impediment in relation to its visibility, but also in determining whether someone copes as well with her life as she could. Admirable athletic performances of people without legs or wheelchair users, for instance, could put considerable pressure on non-athletes experiencing similar impediments if their environment expects the same level of skill. Thanks to *Youtube*, many are familiar with reports of blind people orienting themselves through clicking sounds; Stephen Hawking – the world-famous physicist and mathematician - writing brilliant works despite his ALS through use of a speech device; and even of someone with cerebral palsy like Paul Smith, who despite his severely limited mobility creates masterful art pieces using only ten keys of his typewriter.¹⁹ People with mental disorders also meet with unrealistic expectations based on exceptional talents people with similar impediments may have: Stephen Fry - a highly eloquent British comedian, writer and actor - claims the manic periods he goes through offer him much of the creativity he needs to come up with great new ideas and storylines;²⁰ and Kim Peek - an autistic savant on whom 'Rainman' was based - was famous for his awe-inspiring photographic memory.²¹ What seems to be greatly overlooked is that even personal areas of excellence possibly (partially) attributable to someone's disability do not cancel out any difficulties she may have in coping herself. Assuming that talent points to overall well-being is therefore also known as the 'halo effect'.²² Maintaining such a narrow view "may perpetuate our culture's devaluing of dependency and inflating of the importance of self-sufficiency",²³ thereby putting steep demands on people with disabilities.

¹⁵ Goffman, *Stigma: Notes on the Management of Spoiled Identity*, p.5.

¹⁶ Davis, "Invisible Disability", p. 153-154.

¹⁷ Davis, "Invisible Disability", p.154-155.

¹⁸ Davis, "Invisible Disability", p.205.

¹⁹ John Stofflet, "Typewriter Artist", *Youtube* video, posted December, 2013, <https://www.youtube.com/watch?v=svzPm8IT36o>.

²⁰ Finnbuster, "Stephen Fry on Manic Depression", *Youtube* video, October, 2010, <https://www.youtube.com/watch?v=cKiAz6ndUbU>.

²¹ Chuck Brown, "Kim Peek: Idiot Savant ("Rain Man")", *Youtube* video, posted May, 2007, https://www.youtube.com/watch?v=dhcQG_KItZM.

²² Davis, "Invisible Disability", p.160.

²³ Anita Silvers, "Feminism and Disability", p.134.

1.2. Happiness and Constructive Action

It is safe to assume that both people with and without disabilities aim for leading a happy life or at least undertake steps that they consider conducive to happiness in the end.²⁴ If someone feels that their idea of happiness is threatened by difficulties concerning the realisation of that idea, it seems plausible that they will want to secure their path to happiness. How this translates into action, depends on what someone considers a threat to her idea of happiness and what she thinks needs to be done in order to assuage or evade it. I will assume a Humean account of motivation here, since in this thesis the focus lies on valuing one's actions with the aim of dealing with the *subjective* experience of impediment.²⁵ In view of this, several decision stages can be distinguished: defining the conceived problem or threat, defining the desired state or goal, sorting out options for action, and lastly, adapting actions to serve this particular goal. First, it is important to clarify what I understand happiness to be before making any other claims concerning it. In this thesis I will side myself with Neil van Leeuwen's understanding of happiness used in his article "Self-Deception Won't Make You Happy" in which he "contests the idea that maintaining an overly self-flattering belief about one's capabilities as a policy does not result in "choice-worthy happiness".²⁶ I understand 'self-flattering' rather broadly, in that it refers to a particular preference for a false belief of a life without the physical and emotional impediments someone finds too disconsolate. Van Leeuwen understands genuine happiness to be the state in which you have "genuine external goods and positive sentiments"²⁷ and he opposes this with Matrix happiness, which he understands as the state in which you have overly positive sentiments that are not supported by or genuinely increase external facts or goods. He argues that, since self-deception produces false beliefs, it "undermines one's ability to satisfy one's desires",²⁸ even if it temporarily offers the *sense* of happiness and self-management in areas of insecurity. In order to make optimal choices in compensation for your limitations and the insecurity stemming from them, knowing and acknowledging them is essential."²⁹ The Matrix happiness, furthermore, is more of a cumulative happiness in which the focus lies on building up the *appearance* of being more successful in life in terms of means, status or inner peace.

Van Leeuwen's emphasis on satisfaction of desires, however, could better be construed as *need* satisfaction when considering compensation for any limitations. What he understands as self-deceiving is "making self and situation out to be better than frank appraisal would support".³⁰ What this would practically come down to is "attempting to form beliefs that are contrary to negative information about the self *that one already possesses*"³¹ (his italics).³² The needs that stem from the self-deceptive self-conception could in this light be better understood as desires themselves,

²⁴ Richard Kraut, "Aristotle's Ethics", *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Summer 2014 edition.

²⁵ This specific theory of action can of course be disputed. I do not, however, want to side with an externalist theory in this thesis, since doing so would open the door to a cumulative understanding of happiness that I am greatly opposed to. In section 1.2 I will elaborate more on the problems of this understanding.

²⁶ Van Leeuwen, "Self-Deception Won't Make You Happy", p.109, quoted in Marin Kaufmann, "The 'Ought' in Disability Management", final essay for *Ethical and Political Implications of Human Nature*, June 25, 2015, p.1.

²⁷ Van Leeuwen, "Self-Deception Won't Make You Happy", p.109.

²⁸ Van Leeuwen, "Self-Deception Won't Make You Happy", 108, quoted in Kaufmann, "The 'Ought' in Disability Management", p.1.

²⁹ Kaufmann, "The 'Ought' in Disability Management", p. 1.

³⁰ Van Leeuwen, "Self-Deception Won't Make You Happy", p. 108.

³¹ This assumes one is capable of accurate self-assessment and putting a self-assertion against it. Thanks to Joel Anderson for pointing me to his article on self-assessment to clarify this point. I would not go as far as say that lower cognitive abilities make accurate self-assessment and therefore self-deception impossible. This would have to be determined on a case-by-case basis. For more on self-assessment, see Joel Anderson and Warren Lux, "Knowing Your Own Strength: Accurate Self-Assessment as a Requirement for Personal Autonomy", *Philosophy, Psychiatry & Psychology*, Vol 11, No. 4, (John Hopkins University Press, 2004/5), p. 279-294.

³² Van Leeuwen, "Self-Deception Won't Make You Happy", p. 107.

because they flow from a narrative one prefers over real life. For people with disabilities, ‘frank appraisal’ could therefore be understood as the acknowledgement of one’s limitations and the *need* that arises from the desire to practically compensate for them. Opting for a self-narrative that is more desirable, less frightening, less impeded and therefore less *needy* would, Van Leeuwen claims, not lead to genuine external goods and positive sentiments, because it would not be based on the person whose life it is supposed to represent.³³ The belief one is not impeded does not actually decrease experience of impediment, but merely muffles it. Also, provided one ventures out from an environment that does not intrude upon the self-deceptive belief, there is bound to be frequent confrontation with the situation/reality one is trying to mentally shift away from.³⁴ It only takes someone without sight to trip over numerous objects to realise maintaining the belief she is sighted would be rather difficult. Moreover, since self-deceptive beliefs are often used to make the uncontrollable feel controllable, self-deceiving blurs the distinction between the two.³⁵

In order to generate genuine external goods and positive sentiments action would then have to be based on an individual’s substantiated need in order to be constructive. For if the need is satisfied, the experience of impediment would decrease and personal functioning would consequently improve. To take my example from the previous paragraph: would someone without sight wish to move around more safely, she would need something to help her do so. Using a white cane or guide dog could satisfy this need and would consequently make her feel less impeded.

The concept of constructive action can best be illustrated by using what I would like to call ‘the Coat metaphor’. During winter time it can get awfully cold out. Sitting by the radiator all day with a hot beverage, however, does not constitute a particularly productive day: going to work or into town requires exposing oneself to the cold. Here being cold refers to someone experiencing some kind of impediment, assuming being cold can negatively influence one’s functioning. If there is a desire of not wanting to be cold, donning a coat would be the best approach to keep the cold out. Putting on an appropriate coat in this scenario would then be analogous to undertaking constructive action towards improving personal functioning, because it acknowledges the experience of being cold through practical compensation. A trip to Matrix-happiness would then be like going out insufficiently clothed while simultaneously denying one is cold. In this case, someone would not be acknowledging any experience of impediment and thus not practically compensating for it in a constructive manner. Somehow, whether one is wearing a particular coat or not seems to be more important than whether someone needs to be warmer or not. Looking out of odds is here seen as less threatening than feeling cold.

The scenarios I sketched out in section 1.1 could be taken to illustrate conceived threats such as emotional and/or physical pain, exclusion, lack of control and (social) insignificance.³⁶ What is considered threatening is tightly bound to perceptions people have of their imperfections: “Individuals with congenital or sudden-onset disabilities may internalize the stigma that “disability means imperfection” (Smart, 2001). They may view disability as “a constant reminder of imperfection” (Bicknell, 1983). These highly laden, negative connotations of having a disability is one reason why some may argue that an individual should not “accept” the disabled aspect of his or her mental or physical life.”³⁷ The idea may be that functionality entails action and that no action follows from the things someone cannot do. Focusing on one’s capabilities would be more productive instead. This kind of reasoning thereby enables the mental shift away from one’s disabilities onto possible coping strategies in order to decrease the experience of impediment. This attitude is of course quite understandable, since it offers a sense of control and perhaps even the determination

³³ Van Leeuwen, “Self-Deception Won’t Make You Happy”, p. 120.

³⁴ Van Leeuwen, “Self-Deception Won’t Make You Happy”, p. 120.

³⁵ Van Leeuwen, “Self-Deception Won’t Make You Happy”, p. 120.

³⁶ Though distinguishing these threats facilitates their connection to specific scenarios like the ones described in section 1.1, I take them to be interrelated. For example, a lack of control can be painful, so can exclusion. Pain can also exclude people by virtue of its limiting effect, which is also the case for insignificance.

³⁷ Martz, “Acceptance of Imperfection”.

to prove one's worth by not letting oneself acquiesce in impotence.³⁸ While I understand this mind set is often considered the only way to keep pessimism and depression at bay, I argue that it tends to have the opposite effect as a policy held long-term in that it is *not likely* to facilitate anything more than Matrix happiness. While Van Leeuwen does recognise that there could be cases in which overly self-flattering beliefs lead someone to do something which happens to be constructive in terms of securing genuine external goods and positive sentiments, he does not find this undermines his arguments against self-deception as a policy: "Suppose someone argues that it is bad to give sharp knives to children under the age of four. Would it refute this argument to show *one possible case* [his italics] of a three-year-old child who did something good with a knife, for example, cut carrots? Or is that an exceptional behavior that in no way justifies the practice of giving children knives?"³⁹

As shortly described above, action concerning management of the experience of impediment requires at a least a conception of the threat to one's happiness, the desired goal and the options for getting there. Functioning well by one's own light does not seem to be the preferred goal if it means feeling or being seen as worth less than people who do not have the same experience of impediment. If my understanding of personal functioning translates to not being cold and 'normal functioning' to wearing a particular coat, say, a beige trench coat, sticking to wearing the trench coat despite being extremely cold does not suggest the cold is considered much of a threat. Rather, wearing anything *other than that beige trench coat* seems to be the problem: looking like one functions normally is paramount. Not being able to pull off the trench coat could make someone stand out like a sore thumb, leading someone to (wish to) change their appearance to improve their fit. In short, aiming for wearing that beige trench coat successfully draws attention away from the possibility that the desired coat could still leave one cold if it is not the coat one needs. Employing practical compensation strategies to satisfy personal needs may interfere with maintaining the appearance of normal functioning. Trying to come across less impeded could therefore make need substantiation unappealing, because it requires acknowledgement of experience of impediment.

1.3. Disability Management

People with disabilities may claim to have accepted their impediment and not strive for normality, but the means available for disability management do seem to be used and appropriated with optimal normal or *societal* functionality in mind instead of personal functionality. It could be said functionality is measured quantitatively in, for instance, the amount of hours someone can work, someone's cost-to-benefit ratio, and the overall state of independence in terms of living quarters and income. Someone's personal situation or experience of any impediments that affect the *quality* of functioning are matters 'behind the scenes' that need not reach the big screen. Quantifying personal experience of impediment and determining its cause, either medically or socially, could possibly offer a sense of control, but would in light of my understanding of constructive action be more conducive to Matrix-happiness than it would secure genuine external goods and positive sentiments.

From a medical perspective, the most straightforward approach to alleviation of disability symptoms would be to resort to medication.⁴⁰ (Psycho) pharmaceutical intervention often plays into the conception of disability as a disease that needs to be cured or at least treated medically.⁴¹ Yet, it can offer someone the compensation needed to, say, be able to work longer hours, engage in social interaction and perform daily tasks more successfully than before. Physical pain can be dulled and over-active emotions can be tempered - one's label of disability merely a reference to a disease entity as a "key organizing principle around which particular clinical decisions could rationally be

³⁸ Shakespeare, *Disability: Rights and Wrongs Revisited*, p.108.

³⁹ Van Leeuwen, "Self-Deception Won't Make You Happy", 111.

⁴⁰ Shakespeare, *Disability: Rights and Wrongs Revisited*, p.60.

⁴¹ Wasserman, "Disability: Definitions, Models, Experience".

made.”⁴² Over all, it can create more favourable conditions for personal functioning. What is problematic about using medication in order to function to a normal standard, is that it inhibits direct response to impeding stimuli, but it does not necessarily remove the impediment.⁴³ Moreover, muffling physical or mental signals that would otherwise motivate someone to pay heed to their body or mind’s need for something like rest, nourishment or even a general overhaul of one’s working and/or living conditions, could possibly be deteriorating to one’s health.⁴⁴ Furthermore, aside from the fact that along with the therapeutic effect come many undesirable side effects that could form a problem in themselves,⁴⁵ there are many things medication cannot do. It does not offer directives for dealing with one’s impediment outside of its use. Therefore, medication use alone does not stimulate someone to look beyond the short-term compensation of psychical or emotional pain into practical ways to support oneself more independently, wielding medication as one of *many* tools.

Socially, a way to fit in would be to mainly focus on barrier removal, thereby compensating for limitations to a 'normal' level of operation. Compensation often comes in the form of practical solutions employed by the individual or made available by the environment: e.g. white canes, wheelchairs, prosthetics, sensory-friendly offices, or braille on the buttons of an ATM. The experience of impediment is then seen as a mere result of the way social situations are set up,⁴⁶ and disability in general something outside the individual body.⁴⁷ The idea would then be that the impediment vanishes as social barriers do.⁴⁸ Because this approach puts a lot of responsibility on society, it can be very liberating for people with disabilities to feel justified in thinking that their functionality does not depend on them alone or even not at all.⁴⁹ Putting the blame for someone’s impeded situation somewhere else can be very satisfactory in the moment, but, unfortunately, it does not necessarily decrease personal experience of impediment by meeting any needs.⁵⁰ It temporarily projects the non-acceptance of one’s impediment on the environment with the aim of lightening the emotional load. This is not to say that there are no issues resulting partially from social arrangements nor to contradict any social criticism that may be due. Neither is it to suggest one’s impediment should not be a bother to anyone but oneself. Still, as was the case with medication use, barrier removal on its own does not guarantee improvement, nor can it dissolve experience of impediment.⁵¹ “The ambition to minimise illness and impairment should be balanced with the need to accept limitations and find ways of living with them. (...) Obsession with normality

⁴² Charles Rosenberg, “The Tyranny of Diagnosis: Specific Entities and Individual Experience”, *The Millbank Quarterly*, Vol. 80, No. 2, (Oxford: Blackwell Publishing Ltd., 2002), 237-260, here: p. 239.

⁴³ Research with rodents suggests that active coping behaviour in response to inescapable stress does alleviate anxiety symptoms due to displacement, but it does not seem linked with decreasing stress hormones. Though the experiment did not include administering ‘tail shock’ to humans, the results could prompt some interesting insights into human behaviour. See Dana L. Helmreich et al., “Active behavioral coping alters the behavioral but not the endocrine response to stress”, *Psychoneuroendocrinology*, Vol. 37, Issue 12, (2012), p.1941-1948, accessed on November 18, 2015. [doi:10.1016/j.psyneuen.2012.04.005](https://doi.org/10.1016/j.psyneuen.2012.04.005); Shakespeare, *Disability: Rights and Wrongs Revisited*, p.85.

⁴⁴ Davis, “Invisible Disability”, p.194.

⁴⁵ Antidepressants are an excellent example: many are known to, for example, increase the appetite, disturb sleep patterns and curb sexual desire. See: Farmacotherapeutisch Kompas, “Paroxetine”, *Zorginstituut Nederland* (2015), Accessed November 17, 2015, <https://www.farmacotherapeutischkompas.nl/Preparaatteksten/P/paroxetine.asp>.

⁴⁶ Tom Shakespeare, *Disability: Rights and Wrongs Revisited*, p.12.

⁴⁷ Shakespeare, *Disability: Rights and Wrongs Revisited*, p.50.

⁴⁸ Shakespeare, *Disability: Rights and Wrongs Revisited*, p.12.

⁴⁹ Shakespeare, *Disability: Rights and Wrongs Revisited*, p. 13.

⁵⁰ Shakespeare, *Disability: Rights and Wrongs Revisited*, p. 18.

⁵¹ Shakespeare, *Disability: Rights and Wrongs Revisited*, p. 40-41.

and perfection, ultimately unattainable or false goals, is harmful to well-being and self-esteem.”⁵²

1.4. Constructive Coping

The question inevitably rises what *would* be a better approach to coping with disability in order to optimise personal functioning. Much has already been hinted at in section 1.2 in describing how constructive action requires one to acknowledge any limitation one wants to practically compensate for. Basing actions on the needs resulting from this acknowledgement is what is more likely to optimise personal functioning, because it aids in securing genuine external goods and positive sentiments. However, personal functioning can only be improved if it is what is aimed towards. Moreover, measuring oneself to an able-bodied standard when experiencing impediment on a daily basis seems counterproductive. “By continuing to assign so much importance to meeting (and appearing to meet) able-bodied standards, we run the risk of both neglecting and subverting other elements of our human paradigm, including some that there are now more compelling reasons for us to value more than people did several generations ago. Thus, if we continue to assign primacy to meeting able-bodied standards, there is reason to think that this will result in our living lives that are less good by our own lights.”⁵³

Yet, even if limitations are being fully acknowledged, this in itself does not offer up any practical tools for people who experience those specific limitations. It only tells someone what needs she has. In terms of the coat metaphor I used, it could be said that the assertion one needs a coat to keep out the cold does not clarify what coat will be adequate.

There is, in my opinion, no need to throw the baby out with the bath water and discount the labels people so associate with any social discomfort resulting from label disclosure. Yes, the scenarios described in section 1.1 could be indicative of the negative effect of categorising people based on their limitations. I do not agree, however, that the categories under labels *themselves* are a direct cause of stigma and consequent exclusion or possible maltreatment. If the goal is *personal* functioning instead of ‘normal’ functioning, labels need not be understood as markers of anomalies people supposedly carry around with or inside of them.⁵⁴ A pragmatic approach to label use would give an answer to Rosenberg’s paradox of “the unavoidable use of reductionist means to achieve cultural and behavioural – necessarily holistic, multidimensional, and contingent – ends”.⁵⁵ When labels are taken as the ‘reductionist means’ in question, in that they reduce people to their deviant properties, it leads one to wonder about the workings and effects of this reduction. Chapter 2 will be dealing with human categorisation to pinpoint what I believe is the main issue concerning label use and signification. In Chapter 3 the pragmatic approach to labels I have in mind will be explained in detail.

⁵² Erin Martz, “Acceptance of Imperfection”, *Disability Studies Quarterly*, Vol. 1, Issue 3, (The Ohio State University Libraries, 2001), p. 160-165.

⁵³ Davis, “Invisible Disability”, p. 160.

⁵⁴ Ann Davis makes an excellent case against maintaining an able-bodied standard in “Invisible Disability”, which is why I leave elaboration on that argument to her. It is my intention to offer a practical account for optimising personal functionality.

⁵⁵ Rosenberg, “The Tyranny of Diagnosis”, p. 252.

Chapter 2

Problems in Categorising Individuals under Labels

Being arbitrary and dependent on power structures due to its “looping effect”, categorisation creates people’s identities for them rather than that it offers insight into what they are for the purpose of ameliorating their lives. Consequently, people can become stigmatised because of an imposed label denoting deviancy. In this chapter, however, I will elucidate how maintaining the link between category and identity makes labels seem intrinsically disadvantaging. First, I will focus on explaining the purpose and dynamics to category formation. Secondly, I will employ a Foucauldian analysis of categories to point out their inability to capture an entire person. Lastly, I will show how possible stigma attached to labels can be explained by pointing out its reliance on labels as identity descriptions.

2.1 Action under a Description

As mentioned in Chapter 1, assuming a Humean account of motivation, intentional action requires an agent to decide on the action considered most conducive to the intended goal. This decision presupposes both an understanding of the world and a conception of one’s capabilities and incapacities. Someone who cannot see, for example, understands herself as a human being who does not have full vision at her disposal amongst a majority that does. She places herself within a world in which phenomena can be seen and value is attached to this possibility. This self-conception in turn determines what one considers to be part of one’s identity - understood as a sense of one’s subjective ontology – in the sense one is ‘someone who...’. The capabilities or states of being someone then assigns to herself fill in the blanks. Applied to my former example, this person may conceive of herself as ‘someone who is blind’ and perhaps therefore as ‘someone who does not frequent the cinema’, or even as ‘someone who is defective’. As such, a self-conception could also be seen as a specific narrative one identifies with or chooses to identify with. Action would then happen under a description of one’s conceived identity. It is the coherency of this description, or the rationale behind it, that makes both one’s present and past self intelligible to oneself.⁵⁶ Imagine that the person from our example became blind at a later stage in her life. If she were to conceive of herself in the present as ‘someone who does not frequent the cinema, because of her blindness’, she could then understand her past self as ‘someone who did go to the cinema, because she could see.’ The way she understands herself now affects the way she understands herself from back then. The same goes for some diagnosed with Post Traumatic Stress Disorder (PTSD): the newly ascribed traumatised state supposes a traumatic experience she might not even have considered traumatising at the time. Were she to notice herself doing things inconsistent with the actions (or lack thereof) of a PTSD sufferer, this would lead her to either tweak or overhaul her self-conception to fit her current state.⁵⁷ Insofar this conception manifests itself in actions, it could also be called an “act identity”.⁵⁸ However, I am not claiming the self-conception is the root of all behaviour. It is my intention to show how self-conception can account for the actions one consciously considers possible to be performed. So understood, action happens under the description someone thinks captures her identity.

⁵⁶ Ian Hacking, “Chapter 12: The Looping Effects of Human Kinds”, *Causal Recognition: A Multidisciplinary Debate*, ed. Dan Sperber, David Premack and Ann James-Premack, (New York: Oxford University Press, 1995), p. 351-383, here: p. 369; J. David Velleman, “From Self Psychology to Moral Philosophy”, *Philosophical Perspectives*, Vol. 14, (Wiley Periodicals Inc., 2000), p. 349-377, here: p. 349.

⁵⁷ Velleman, “From Self Psychology to Moral Philosophy”, p.351.

⁵⁸ Velleman, “From Self Psychology to Moral Philosophy”, p. 368.

2.2 Category Feedback

If acting happens under a description,⁵⁹ then it makes sense for people to want to define all elements within a certain context in order to know how to subsequently deal with them. Particular disabilities could be the particular elements one would wish defined. Though definition and subsequent categorisation mainly serves to offer direction to the person in need of it, it depends on the type of category whether this has impact on its content. In “The Looping Effects of Human Kinds” Ian Hacking distinguishes two types of category: natural and human kinds. The goal underlying both types of categorisation is to be able to clarify, understand and predict the behaviour of the category content to then determine what kind of – if any – intervention is called for. The organisms, objects and phenomena categorised as natural kinds are not affected in the slightest by what they are labelled as;⁶⁰ what is prone to change is the human acknowledgement and conception of them. Humans ‘filing’ themselves under human kinds, however, does not only mirror the conception, inception and acknowledgement of certain types of people. What sets human kinds apart from natural kinds is that human kinds have a moral element to them, in that to be of one particular kind is considered positive while being of another is considered negative.⁶¹ Given the choice, most people would rather be able to walk than to be dependent on a wheelchair to get around. Because of this “intrinsic moral value”,⁶² being labelled as of a certain kind influences someone’s life on different levels. Adjusting to a new narrative means that not only she herself, but others too will view her and her potential differently and therefore act differently towards her.⁶³ Certain assumptions about the extent of her capabilities are then made, that could potentially put her at a disadvantage, as was the case with Martin Milligan in section 1.1.

The realisation of how one is defined by others shapes the self-conception in such a way, that one acts under a different description and relates to others accordingly. This response to categorisation and the interaction between category and the categorised is what Hacking refers to as the so-called ‘feedback effect’.⁶⁴ The interaction between category and the categorised is what over time continually shapes and reforms the category content and the attitude towards that content. Categories change people’s self-conception and this in turn changes the kinds the categories are supposed to describe, which consequently requires adaptations to the categories’ scope.⁶⁵ This process is what Hacking calls the ‘looping effect’: “Kinds are modified, revised classifications are formed, and the classified change again, loop upon loop.”⁶⁶ While intended to create oversight, labels thus continually influence people’s understanding of themselves and each other in terms of social significance. Therefore, the social and ontological implications of human categorisation in kinds and/or labels referring to these kinds could prove to be quite problematic.

Since categorisation or labelling presupposes a decision on division lines between categories, the question arises as to who determines the grounds for division and the criteria someone has to meet in order to be placed in a particular category. Also, the ‘looping effect’ calls into question to what extent categories can accurately describe people if both their form and content are subject to change over time. This in turn demands clarification on what exactly is being

⁵⁹ Ian Hacking, “Making Up People”, *The Science Studies Reader*, (New York: Routledge, 1999), p. 161-171, here: p.166.

⁶⁰ Hacking, “Making Up People”, p.166.

⁶¹ Hacking, “The Looping Effects of Human Kinds”, p. 367.

⁶² Hacking, “The Looping Effects of Human Kinds”, p. 367.

⁶³ Hacking, “The Looping Effects of Human Kinds”, p. 368.

⁶⁴ Hacking, “The Looping Effects of Human Kinds”, p.370.

⁶⁵ Hacking, “The Looping Effects of Human Kinds”, p. 370.

⁶⁶ Hacking, “The Looping Effects of Human Kinds”, p. 370.

categorised. The perceived social consequences to human categorisation, such as stigmatisation and segregation, are not matters to be overlooked either. What is most interesting to consider for this thesis, however, is whether these implications actually point to the risks to categorisation itself. Matters of power structures, foundational arbitrariness and stigmatisation are not to be taken lightly with regards to the lives of people with disabilities. Yet, I would argue that it is the manner in which these categories – and labels referring to these categories - are *used* and what they are taken or expected to signify that may be causing problems.

2.3 Dynamics of Categorisation

In both medically and socially describing human behaviour in order to better predict and reform it, a standard is assumed to then define normalcy and deviancy. Whether normalcy describes what is most common or what is most desired for establishing social and political balance is difficult to capture, since the term is applied to both. It could be said that the idea of a standard need not describe anything in itself, but rather functions as a semantic background for whatever is held against it. What deviates from this standard, however, is highly changeable as well as the practical attitude towards it.

The example Hacking uses to illustrate the dynamics behind terms like ‘normalcy’ and ‘deviancy’ is what he calls “the making and molding of child abuse”.⁶⁷ It is hard to imagine there ever being a time the current conception of child abuse did not even exist. It is even harder to stomach the idea that, at one point, maltreating children was not considered deviant behaviour to the extent the abuser was considered mentally ill.⁶⁸ The professions associated with responding to these new kinds of behaviour then become responsible for dealing with whoever is behaving under a description relevant to their field. This suggests that deviant behaviour is something that needs to be dealt with and managed. If the behaviour is considered highly morally objectionable, all would be expected to work in unison to prevent it. If child abuse was considered the product of a diseased mind, it was up to medical professionals to come up with and administer medical treatment. Referring to child abuse with a phrase like “battered-child syndrome”,⁶⁹ would reflect its medicalisation. If the abuse and the psychologically damaged children as its consequence was a social phenomenon, changes in environmental support would have the most priority.⁷⁰ The approach to and conception of child abuse has been “in constant flux”⁷¹ for several decades; the scope of the term widening to encompass almost all morally questionable interaction with children, with a heavy focus on sexual relations.⁷² As a result, the abused child has often been identified under labels varying from and fluctuating between victim, damaged goods, juvenile delinquent and predestined abuser.⁷³ Likewise, the abuser would be known as offender, mental patient, victim-turned-perpetrator, and so on.⁷⁴ What seems to be assumed in labelling the children and adults in question is that it is not normal to want to beat or sexually approach children; it is not normal to act out as a child to the extent of committing petty crimes; and it is not normal for a child to experience and display any distress from past events. It is the label on the distinguished phenomenon and the people involved that marks them as an abnormality to be dealt with.

⁶⁷ Ian Hacking, “The Making and Molding of Child Abuse”, *Critical Inquiry*, Vol. 17, No. 2, (University of Chicago Press, 1991), p.253-288, here: p.258.

⁶⁸ Hacking, “The Making and Molding of Child Abuse”, p.253, 265.

⁶⁹ Hacking, “The Making and Molding of Child Abuse”, p.270.

⁷⁰ Hacking, “The Making and Molding of Child Abuse”, p.265-266, 280.

⁷¹ Hacking, “The Making and Molding of Child Abuse”, p.253.

⁷² Hacking, “The Making and Molding of Child Abuse”, p.274.

⁷³ Hacking, “The Making and Molding of Child Abuse”, p.265.

⁷⁴ Hacking, “The Making and Molding of Child Abuse”, p.267-268.

Interestingly, shifts in focus and attitude regarding social norms and consequent inception of new kinds of people are often preceded by certain scientific developments,⁷⁵ research direction is likewise influenced by public focus on certain issues in human behaviour.⁷⁶ The natural and social sciences are mostly considered and *expected* to respectively approximate truths about the human brain, body and life events impacting both. In their pursuit to aptly describe human behaviour, scientific findings on human ‘anomalies’ therefore often give rise to revised social norms and understanding of sound minds and able bodies.⁷⁷ From a medical perspective, what is treatable is conceivably correctable to a state of what is – in that particular society and time- considered perfect health. New conceptions and categorisation of medical problems that need to be ironed out then tend to prime the way people falling into the revised category are perceived by others and themselves.

Within a Foucauldian model, this normalisation process is considered a “distinctive feature of modern power”, in that it allows for social control and reform through correction – what Foucault generally termed as ‘discipline’.⁷⁸ Categories then are not employed to further understanding so as to ameliorate people’s lives, but are used to divide and conquer, as it were, under the guise of altruistic revisionist knowledge pursuits. They would just have to be “consistent with the bureaucratic imperative, not only in hospital management, but also in a variety of contexts ranging from life and health insurance to epidemiological and related public health and policy debates.”⁷⁹

One strategy to quiet down the cynic “suspect[ing] there is no knowledge to be had”⁸⁰ could be to point out that it is not the correction of people themselves that is sought after, but the eradication of crippling disease entities causing any experience of impediment.⁸¹ Whether there is a direct causal link between this presumed entity and experience of impediment is subject of heated discussions within the field of disability studies,⁸² but will not be focused on here. What is important to note about postulating disease entities is that doing so could still be conceived as a dominating practice. The difference would be that a person’s alleged faultiness would only be implied. Also, symptoms would then, circularly, be turned into causes themselves.⁸³ Someone may be diagnosed with, for instance, depression, because she is depressed, but she is to understand she is depressed because of her depression. Here the label ‘depressed’ serves both to elucidate the medical issue in need of treatment –therewith re-establishing dominance– and to justify the medical profession.

While this may be the case, having a sort of mechanical objectivity of standardised procedures⁸⁴ to fall back to does have its benefits, in that it offers society a sense of safety in ‘knowing’ what and who is what. However, it would only offer clarity insofar the category criteria remain constant, the categorised only fall into one category and the attitude towards the category does not change. It is hard to figure out the puzzle of one’s identity when it is not clear how to understand the pieces already lying there and the pieces one can choose from keep piling up, changing or vanishing altogether.

⁷⁵ Hacking, “The Making and Molding of Child Abuse”, p.259.

⁷⁶ Hacking, “The Looping Effects of Human Kinds”, p. 359-363.

⁷⁷ Davis, “Invisible Disability”, 163.

⁷⁸ Gary Gutting, “Michel Foucault”, *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Winter 2014 Edition.

⁷⁹ Rosenberg, “The Tyranny of Diagnosis”, p. 246.

⁸⁰ Hacking, “The Looping Effects of Human Kinds”, p.360.

⁸¹ Rosenberg, “The Tyranny of Diagnosis”, p.237.

⁸² Wasserman, “Disability: Definitions, Models, Experience”.

⁸³ Trudy Dehue, Radboud Reflects lecture on *Betere Mensen: Gezondheid als Keuze en Koopwaar*, October 2014, *Youtube*. Accessed December 8, 2015, https://www.youtube.com/watch?v=fj_xUKs6GcE.

⁸⁴ Trudy Dehue, *Betere Mensen: Over Gezondheid als Keuze en Koopwaar*, (Amsterdam: Uitgeverij Augustus, 2014), p. 17.

2.4 Correspondence between Category and Identity

Within the context as described above, someone's identity is defined and therefore constituted in virtue of meeting specific normalcy or deviancy requirements.⁸⁵ Categories determine what someone is understood to be because the categorisation shapes one's self-conception, which in turn influences the category content. However, if the framework for this content depends on what division is considered socio-politically and/or medically advantageous, the content will only reflect this particular consideration. The narrative of a person's life is an artefact in such a sense, that it reveals more about the narrator than the person.⁸⁶ However, choosing one's own label in order to escape this imposition⁸⁷ would not dissolve nor redefine the division, for it would still be a restricted choice between set interpretations. If the semantic background does not alter, the meaning of a self-chosen label will not stretch beyond it.

If the category or label creates or, 'makes up'⁸⁸ people rather than reveal their essence or lack thereof, the question rises as to what the category should then be taken to refer to. How making up people or "dynamic nominalism" "affect[s] the concept of the individual person" can, according to Hacking, be understood in terms of possibility.⁸⁹

Who we are is not only what we did, do and will do but also what we might have done and may do. Making up people changes the space of possibilities for personhood. Even the dead are more that their deeds, for we make sense of a finished life only within its sphere of former possibilities.⁹⁰

Equating 'being' with 'action', however, would not adequately grasp the nuances between person and personhood. I do think *the way* people are and *who* they are, in terms of their relation to others in certain contexts, manifests in action. Yet, the changeable character of both points to the difference between the individual as an existing entity and the way in which that entity is conceived within a certain socio-temporal context. I do not want to make any metaphysical claims here, but I would like to point out the difficulties in making statements from within a highly changeable conceptual framework about what may well lie outside it.

It then seems plausible to think that there is no way of knowing whether the concept corresponds accurately with what it is conceiving. Neither can it be established how far off the concept is in its attempt to capture the entire person. Also, as is illustrated in Figure 1, there are many aspects to a person, none of which entirely define a person, merely part of her. Would one serve to subordinate the others and if so, which one? Could someone be questioned per aspect to such an extent that the answers accumulate to form a person's biography? In my opinion, one can never ask all the different kinds of questions pertaining to all the different kinds of contexts of which the combined answers accurately describe an entire person at t_1 , let alone at t_n . Even if this were possible, the questions would only be relevant to the particular standard being used. For if there is a standard x in context y and someone is not x but a in context y , what is this someone in context z ?

⁸⁵ Liggett, "Stars Are Not Born", p. 180-181.

⁸⁶ Dehue, *Betere Mensen*, p. 16.

⁸⁷ Mike Oliver and Colin Barnes, *The New Politics of Disablement*, (Basingstoke: Macmillan, 2012), p. 21, quoted in Shakespeare, *Disability: Rights and Wrongs Revisited*, p.18.

⁸⁸ Hacking, "Making Up People", p.162.

⁸⁹ Hacking, "Making Up People", p.165.

⁹⁰ Hacking, "Making Up People", p. 165.

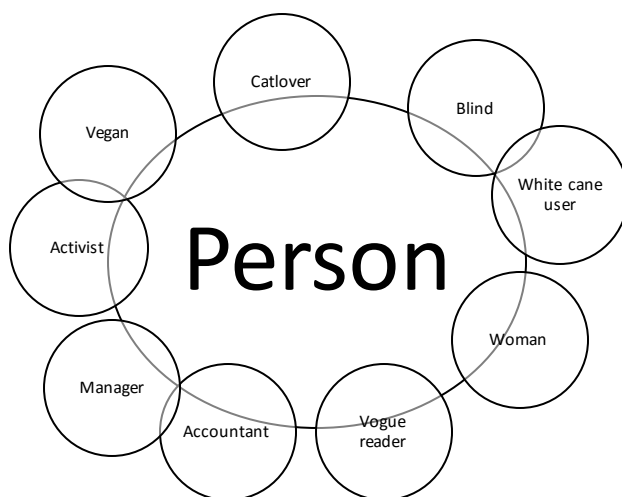


Figure 1: Visual representation of the difficulties in encompassing an individual in one category.

2.5 Labels and Stigmatisation

“The inescapable terms of everyday life, in this model of society, [however,] are [still] organized in terms of various distinctions between normal and deviant identities.”⁹¹ Individuals carrying a label of disability could find themselves the object of stigmatisation when they are being “disqualified from full social acceptance”⁹² in any given situation. Therefore, “the ascription of group membership – in the form of labelling – is generally viewed negatively in the disability community”:⁹³

Opposition to labelling arises from an awareness of the stigma that can be a consequence of particular labels or diagnoses. When someone is given a label – for example, of learning disability or mental illness – this may trigger other negative associations. The phenomenon of ‘identity spread’ means that the person’s individuality – both their personality, but also other aspects of their identity such as gender, sexuality and ethnicity – can be ignored. As the impairment label becomes the most prominent and relevant feature of their lives, dominating interactions.⁹⁴

People with disabilities are left with a social identity they may not (want) to personally identify with,⁹⁵ even though they would with any experience of impediment.⁹⁶ A label of disability would send out personal information they might not want others to know or notice, especially not when the social identity it creates – the accumulation of salient social characteristics – would clash with the image they maintain of themselves. Being stigmatised can make life with disabilities amongst others without highly distressing, as the scenarios depicted in section 1.1 clearly show. A wide gap between social and personal identity leaves someone with three information management options: concealing any signs of deviancy as much as possible, volunteering personal information⁹⁷, or using other personal features as a cover if she would like to minimise information salience. Sometimes, someone’s appearance carries the stigma for her. Practicing information control would only make a difference concerning the details surrounding her perceived deviancy, so her best bet may be

⁹¹ Liggett, “Stars Are Not Born”, p. 181.

⁹² Goffman, preface to *Stigma*.

⁹³ Shakespeare, *Disability: Rights and Wrongs Revisited*, p. 95.

⁹⁴ Shakespeare, *Disability: Rights and Wrongs Revisited*, p. 95.

⁹⁵ Goffman, *Stigma*, p.64.

⁹⁶ Shakespeare, *Disability: Rights and Wrong Revisited*, p.98.

⁹⁷ Goffman, *Stigma*, p.64.

adopting a policy of 'normification': "the effort on the part of stigmatized individual to present [herself] (...) as an ordinary person, although not necessarily making a secret of [her] (...) failing."⁹⁸

Overall, there seems to be a social information imbalance between people carrying a disability label and non-labelled people. Still, the argument that categorisation does not log any information about the individual herself is applicable to stigmatisation as well. Deviancy is formulated based on a highly changeable standard of normalcy, of which no-one ever seems to have a solid definition.⁹⁹ Categories only offer fragmented information about this standard and the way the categorised relate to it. Therefore, if categorisation alters social understanding to the point that people are stigmatised and segregated, what would be the added value of maintaining use of arbitrary social 'filing tags'?

2.6 Labels as Identity Descriptions

Categories can be understood as tools of dominance in that they impose identities on people they themselves have not chosen. A label of disability would then be forced upon someone, who, seemingly because of the label, will suffer stigmatisation and segregation. Labels would decide people's worth for them to then make their lack of it a public matter. Labels may be taken to reduce people to their disabilities, without even taking their assets into consideration. If the vending machine is broken, it needs a sign saying it is no longer reliable nor useful. Apparently, if someone lacks in the capabilities department, both she herself and society need to be informed that her social and economic output will never be up to standard. An understandable conclusion would be that not wearing a label would then lift this yoke of inferiority. If labels suggesting defectiveness are that disadvantaging, using them would not be constructive.

The question whether categorisation under labels dominates and stigmatises people and should not happen because of this, however, presupposes labels as identity descriptions. Since their criteria are selective of particular features of people's lives, categories cannot encompass an entire person. Labels would thus be nothing more than arbitrarily chosen and highly disadvantaging language constructions. In light of this, categories are not fulfilling their purpose of clarifying human behaviour by dividing it up into manageable chunks, because they create rather than reveal. It is understanding labels as identity description that makes "the unavoidable use of reductionist means to achieve cultural and behavioural – necessarily holistic, multidimensional, and contingent - ends"¹⁰⁰ paradoxical.

Using labels as identity descriptions does not establish an adequate link between individual and label, since the narrative the label suggests need not be entirely applicable to the person it is supposed to capture. Neither do the needs associated with the label necessarily follow from that person's particular experience of impediment, since incapacities do not impact everyone in the same ways.¹⁰¹ Consistently relying on a self-conception attached to a label does therefore not facilitate constructive action, because it does not reliably incite *personal* need substantiation.

Unfortunately, with the normalcy-deviancy distinction being so heavily ingrained within social practice, merely saying labels cannot describe people would not automatically undo and prevent any stigma attached to labels. While I do think shedding light on the impact of stigmatisation and underlying societal structures of dominance is of import, doing so does not help people with disabilities optimise their personal functioning. Moreover, it can stifle any feelings of autonomy essential for constructive action, since labels are used to tell them what they are and

⁹⁸ Goffman, *Stigma*, p.31.

⁹⁹ Davis, "Invisible Disability", p.156.

¹⁰⁰ Rosenberg, "The Tyranny of Diagnosis", p. 252.

¹⁰¹ Davis, "Invisible Disability", p. 173.

what their place is. In chapter 3 I will argue for a pragmatic approach to labels, so they fulfil the purpose they were intended for: creating oversight by categorising what can actually be categorised so as to help people with any experience of impediment live their lives constructively.

Chapter 3

Labels as Constructive Action Filters

Using labels as identity descriptions has little to no merit when trying to improve personal functioning, because they do not facilitate personal need substantiation. However, they *can* be used to filter out practical strategies people with particular needs could benefit from. In this chapter I will first explain why making use of filters is necessary in order to decide on what action is most likely to serve its purpose. Since a link between need and dedicated action is crucial for improving personal functioning, I will argue for using experience as a starting point. Secondly, I will illustrate how labels can function as filters for cohesive sets of actions that are most likely to satisfy the needs one has substantiated after acknowledging any experience of impediment. Lastly, I will argue that it is not necessary to assume an essentialist position when trying to find out what label would be most constructive to someone's particular situation, because action ownership offers sufficient awareness of oneself to substantiate needs. Furthermore, I will claim that trying to objectively assess or authenticate subjective experience and one's responsibility in optimising personal functioning would not be fruitful in the least. However, this need not discourage people with disabilities from decreasing their experience of impediment. In addition, I would like to note that I will *not* be offering a new vocabulary, but selecting from existing label content the practical coping strategies associated with that label; e.g. 'using a white cane' from 'blind' or 'applying deep pressure' from 'autism'. So while I am suggesting a *Gestalt*-switch, the term 'label' need not be abandoned.

3.1 Action Filtering

In section 1.2 I described the relationship between constructive action and optimal personal functioning. What makes action based on genuine experience acknowledgement constructive is that it offers the opportunity of satisfying underlying needs. Yet, it remains unclear how labels would contribute to constructive action, if they cannot offer a personal narrative suggesting what course of action would be right for someone intended at optimising *personal* functioning. Especially when someone finds herself having substantiated many needs in varying areas of her life, the appeal to a cut-and-dried 'act identity' –deceptive or not - becomes that much greater.

Not knowing what identity and the actions it entails fits the bill leaves one with an overabundance of actions to choose from. The appeal, therefore, does not necessarily lie in having a clear sense of one's identity, but in knowing what to do, seeing as that the narrative limits the options one has to choose from. Deciding on an action becomes easier when one has a comprehensive set of options to weigh, just as settling on a cuisine would greatly facilitate deciding on what dish to cook. The type of cuisine then 'filters' out all the irrelevant recipes that do not need any consideration. Making use of a certain filter does not only aid the decision process, it can also help rule out the actions that would be of no use to the situation. Nobody has to think twice about whether to pack a sun dress for a trip to Alaska, for instance. The destination, in this case Alaska, helps to filter out any unsuitable clothing when deciding what to bring along.

While in some cases a useful filter can be inferred from the situation and the outcome the action is supposed to further, unfamiliar settings could potentially leave someone with nothing to fall back to. When someone 'knows' what kind of person she is, this could of course offer a sense of direction and a short-term relief from a momentary decision 'freeze'. An action would be the practical answer to the question what a particular kind of person would do in a given situation. However, since this 'act identity' cannot correspond with her entire way of being –as was shown in Chapter 2 – and as such has no particular traction on her personally, it is not likely to establish an outcome that promotes her personal functioning. A set identity would then not do as a link between

individual and action.

The link I suggested in section 1.2 takes a more phenomenological approach to action, in that the individual chooses to respond to an *experience* of impediment by substantiating needs for practical compensation. Whether an action turns out constructively depends on whether it successfully satisfies any needs. Filters used in determining suitable action would have to focus on making the link between need and action a successful one, in the sense that the filtered actions are most likely to satisfy the needs in question. Acting without this link would not likely serve the purpose of optimising personal functioning, because it would not be aimed at satisfying underlying needs of the person in question. I say 'not likely', since it is possible that someone improves her functioning by 'accidentally' performing a need-satisfying action. Although as a policy, a filter is most constructively applied when it picks out action options relevant to someone's needs. To take my cooking example again: deciding on a recipe becomes increasingly difficult if the filter would be 'eaten with knife and fork' instead of, say, 'Italian food'. The former would simply not filter out a manageable amount of recipes, whereas the latter could.

Of course, in managing experience of impediment culinary clarity is generally not what is most needed. Filtering actions becomes especially important when someone experiences many impediments and wants to delve into practical management options. Someone with autism, for instance, may not *only* feel awkward in social situations and will therefore not be 'relieved' of her experience of impediment if she merely practices her social skills. If sensory overload causes her a lot of stress in addition, either through environmental or inner stimuli, social skills alone do not decrease her experience of impediment. Therefore, she would greatly benefit from learning about various strategies, aside from social skill training, that others with similar needs have employed or use currently to decrease their experience of impediment on a larger scale.

3.2 Labels as Filters

Thus, a filter, as a description of a set of action possibilities, has to be employed before action aimed at fulfilling a purpose can occur. This description, however, need not apply to the nature of the individual acting under it, merely to the selection of actions it labels. I concluded in Chapter 2 that labels cannot describe all aspects to a person's life in which constructive action is called for. Exploring what labels do have to offer if used as filters for need-dedicated action would be more beneficial nonetheless. Not being able to hear, for instance, can leave one feeling heavily impeded in varying situations, such as engaging in social interaction and operating safely in traffic. The inability to hear being the only information available, it can be hard to think up of different practical solutions for decreasing the experience of impediment. 'Deaf' as a label, however, has many ties to practical techniques and tools for catering to people who feel impeded by their inability to hear: sign language, deaf schools, deaf communities, cochlear implants, etcetera. Practical techniques need not be limited to the application of certain devices or communicational aids. Actively searching for and utilising human support - such as cognitive/physical therapy, home care, or coaching - would be an equally practical response.

While using labels - denoting ailments of any sort - for selecting a suitable course of action is common within medical practice,¹⁰² the label is taken to refer to a condition of the person herself. My aim is to change the question from 'what label describes the patient's condition?' to 'what label offers the practical tools capable of satisfying this person's needs?'. By not referring to a *condition*, a label, when used constructively, would be more likely to incite an active attitude towards any experience of impediment, because it can only be used for practically optimising personal functioning. So even when someone does not 'qualify' for having a certain condition due to lack of

¹⁰² Rosenberg, "The Tyranny of Diagnosis", p. 246-247.

symptom manifestation, but still has experience of impediment similar to what people who do show the 'required' symptoms might have, a label can be used to filter out strategies that could help her regardless.

In section 1.2 I used my Coat metaphor to illustrate the unlikelihood of optimising personal functioning when striving towards normal functioning regardless of any present experience of impediment. Analogous to aiming for normal functioning instead of personal functioning and thus not sufficiently acknowledging experience of impediment, wearing too thin a coat would not adequately keep the cold out. It would stand to reason that if one does not desire to be cold, one would have to wear the coat one needs as opposed to a coat one would like to fit. However, the coat in this metaphor does not signify the label someone would 'wear', but the practical techniques employed to optimise personal functioning. Therefore, a label should not be understood as a mold covering its wearer, but as a voucher for a specific coat store, carrying coats likely to fit the customer.

Since owning a whole host of coats for every occasion is not unheard of, this raises an interesting point concerning multiple and superfluous label appropriation. What if people take an eclectic approach to labels and use a label not for its specific cohesion but for merely one of its practical elements? What if people would use a label to fulfil needs they do not have? Considering the nuisance of people rolling around trolleys in a busy crowd and efficiently tackling unwitting passers-by, using a white cane to free the way could seem like an attractive solution even if it were not needed to compensate for visual difficulties. Yet, people could get used to white canes not signifying a specific adjustment to one's spatial conduct around someone who has difficulty seeing where she is going. In this case, the cane could potentially lose its specific alerting function. Since the effect of the tool on the user's environment attributes greatly to its function, maintaining this effect would then be crucial. Also, people without sight limitations would not lose their ability for visual orientation if the cane were not available. The degree of dependency on the practical strategy thus determines to what extent personal functioning would diminish in its absence. Furthermore, the question of 'how can I prevent myself from tripping over people's trolleys?' does not rely on the label 'Blind' to filter out a possible practical solution. Also, to come back to the coat again; while being cold would be heavily impeding, being too warm wearing a ski jacket where a trench coat would do can be quite cumbersome as well.

This implies a label exists in virtue of its ability to filter out compensational strategies for acting constructively. Since a label is only useful insofar as its content aids in constructive action, expanding or adapting the practical measures it filters to suit this purpose is not only fruitful, but necessary as well. The fairly newfound possible¹⁰³ benefits of assistance dogs to people with PTSD and Autism,¹⁰⁴ for instance, have enabled many to increase their personal functioning, even though assistance dogs were formerly only associated with visual impairments.¹⁰⁵ So while there is also a distinguishable looping effect to be expected in label formation, labels do not overstep their boundaries by describing and dividing people. Instead, here a looping effect would help keep their

¹⁰³ There has not yet been done sufficient research to clinically underwrite positive effects of assistance dogs on mental health, though positive experiences have been reported. See A. Berry, M. Borgi, N. Francia, E. Alleva, and F. Cirulli, "Use of assistance and therapy dogs for children with autism spectrum disorders: a critical review of the current evidence", *Journal of Alternative and Complementary Medicine*, Vol. 19, No. 2, (2013), Accessed January 2016, PubMed: <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0055043/>.

¹⁰⁴ Berry et al., "Use of assistance and therapy dogs for children with autism spectrum disorders".

¹⁰⁵ "Types of Assistance Dogs", Assistance Dogs International, accessed January 2016, <http://www.assistedogsinternational.org/about-us/types-of-assistance-dogs/>.

content up to date by adjusting practical strategies to better fit their purpose within changing contexts.

3.3 Fitting Individual and Label

Using labels pragmatically, in the sense that their function determines their usefulness, raises questions as to their relation to the user. What does the tool say about the person wielding it? My pragmatic account of label use may have given a rather mechanic impression of human beings as social input/output systems,¹⁰⁶ without sufficiently accounting for people's specific and varying phenomenal states. Understandably, it could be questioned whether acting in response to experience of impediment towards optimal personal functioning would not assume and require awareness of one's own nature¹⁰⁷ and as such an essentialist account of disability. Securing a fit between label and individual would then be a matter of substantiating someone's nature to determine her needs.

One of the ideas that may still linger could be that at least *a* sense of identity is needed for action, which leads one to question to what extent someone should know her identity in order to further her specific interests. This awareness could conceivably be measured by the personal content one can report when reflecting on one's sense of self and by the correspondence between report and appearance. The resulting rationale could then potentially influence future action. I would say this only applies to the action one consciously connects to and performs on the basis of an earlier formed narrative of oneself, but not necessarily to all intentional action.¹⁰⁸ If this were the case, my emphasis on action over identity could be taken as tarring people with the same brush if an action is considered a better vehicle for describing an entire person. This may then suggest I am claiming action interpretation could possibly do what an identity-describing category cannot, namely encompass an entire person. Nevertheless, even if purported to do so, actions would not be able to describe an entire person either, in part because not all aspects to someone is expressed in action. If her actions would encompass anything, it would be her *personhood*, since -again- it only describes *the way* she lives her life.

Moreover, "pre-reflective phenomenal states can be expressible without being reportable. (...) This suggests that insofar as there is a contextualized self (a self contextualized in and by perception and action) it is something which can be expressed in action, emotion or in certain attitudes, but not necessarily something which can be reported."¹⁰⁹ I want to point out that I consider action to be a way of relating oneself to the environment and that for this an agent need only understand herself, pre-reflexively, as the individual perspective from which actions are performed. Her actions thus only reflect upon her insofar she is the owner of the action. As such, action ownership is sufficient sense of identity for acting in response to experience of impediment.

A second issue could be that the approach I propose seems to imply that not only are people with disabilities capable of underlying need substantiation and applying action filters, there is a right way to do this constructively by using the right label. To the extent that someone is cognitively and emotionally capable of registering experience of impediment, I consider her capable of need substantiation. Applying action filters may be necessary for deciding what to do, but this does not mean it is done consciously and deliberately to improve personal functioning. Also, being capable of both need substantiation and conscious filter application, does not suggest someone would do either, nor does it imply it is done with ease and/or instant success. I do not wish to claim a

¹⁰⁶ Gallagher & Marcel, "The Self in Contextualised Action", p. 290.

¹⁰⁷ I consider someone's nature to refer to the conceived objective constitution of a person as a thing-in-itself. Identity would then be the idea someone has of her nature and what she considers herself to be capable of.

¹⁰⁸ Velleman, "From Self Psychology to Moral Philosophy", p. 367-368.

¹⁰⁹ Gallagher & Marcel, "The Self in Contextualised Action", p. 290.

successful fit between label and person and can be objectively determined. Considering this, I do not believe there is such a thing as a 'right' label for every person experiencing impediment. The idea of confirming genuine personal functionality increase from a third-person-perspective could, in my opinion, strongly promote Matrix-happiness, because what looks like a flourishing individual may well be someone doing a great job of keeping up appearances. It needs to be said that this individual need not see this endeavour in a negative light. Participating in disability activism, for example, can make someone feel she is both accepting of her experience of impediment and that she is proving it is in no way a lower standard of functioning, because being an activist can be empowering. Her situation may be perfectly tailored so as not to incite any negative associations, but this does not imply acknowledgement of any impediment she may have. Were she to leave her activist endeavours behind and try to measure up to the expectations outside of her previous position, she may well be confronted with situations she would have to find practical tools for in order to manage them at all.

What could be argued against this reluctance to accept someone's self-professed state of happiness is that it assumes an objective view of what happiness consists in. This would be highly problematic for my stance, since the emphasis lies on *personal* and therefore subjective functioning. It raises the question how any subjective account of happiness can ever give someone the affirmation that one's happiness is *true* nor others the means of authenticating that individual's happiness and deeming it deception-free. The reply I would give to this justified critique is that I believe being reluctant shows more respect to a person as a whole than accepting her happiness at face-value, for it acknowledges that a thorough evaluation of one's experiences demands attention to and close scrutiny of *all* aspects to one's life over a longer period of time and in varying conditions. For people with disabilities this would mean taking stock of their attitude towards their impediment in more areas than one. Withholding judgement need not mean that one can never claim to be happy; it can offer someone the room to develop through trial and error and remind her that what way of living works for her at one point need not be held firm through all her future undertakings.

It is hard to resist leaning towards an essentialist approach when considering that labels do group together people with similar needs. Having one need over another may suggest a specific intrinsic feature accounting for this need as for the will to compensate for it. A possible claim could be that an anxious nature, for instance, makes someone more prone to experiencing intense anxiety, thus more likely to be in need of Cognitive Therapy. Nature or character then underlies specific experience of impediment and subsequent need substantiation.

This would leave the anti-essentialist with the burden of proving there is no such thing as character, therewith veering the discussion onto the question whether disabled people are impaired by nature and how a label can be fitted to this nature. For if experience of impediment is decided by nature, the label denoting the impediment would then be taken to say something about the person experiencing it. Moreover, the experience would have to be authenticated, by determining what someone's nature *really* is. If this were the case, constructive action would not be aimed at optimising personal functioning directly, but through intrinsic personality changes.

The underlying issue lies in knowing where to draw the line between the controllable and the uncontrollable so as to determine the extent of one's responsibility in having certain experiences. When no causal link between someone's nature and her experience of impediment can be established, it is assumed the cause must lie in individual volition.

In its crudest form, this view embodies what [Davis refers to as] "the myth of the world-transcendent will": the view that what we think or feel is essentially up to us. Many of those who embrace such a view will probably concede that there are cases in which an individual simply cannot control his or her thoughts or feelings, cases of force majeure in which the person's will has been overborne by physical factors that lie outside of his or her control. But whenever there are no such causes, it is thought, it is reasonable to suppose that individuals can alter their thoughts or feelings. For example, when there are no clearly identifiable physical causes of an individual's feeling extremely anxious or depressed, then his or her continuing to feel that way must be viewed as a matter of choice, or as something that is changeable by decision.¹¹⁰

The desire for this knowledge may be pressing, but attempting to objectively determine subjective experiences by distinguishing between what is controllable and what is not will not likely satisfy it. For lack of a definite answer on the responsibility one *has*, I would say that starting from one's experiences, making the choice for a particular need-substantiation procedure that requires someone to acknowledge any experience of impediment is the responsibility one can *take* to see how far it reaches. It depends on someone's needs whether the use of a label can be justified in light of its capability to filter the actions most likely to satisfy those needs, but this is something only determined through trial and error. For practical purposes, the only relevance lies in employing a label to explore its contribution to someone's personal functioning. After all, questioning the source of one's experience still leaves one with the experience to deal with. When labels enable people with disabilities to decrease their experience of impediment constructively if used as action filters instead of identity descriptions, I would say using them thusly is a responsibility worth taking.

¹¹⁰ Davis, "Invisible Disability", p. 186.

Conclusion

It is understandable people with disabilities may prefer not to focus on their experience of impediment in an attempt to prevent feelings of limitation or inferiority. However, acknowledging experience of impediment is crucial for finding practical compensation strategies that may help to decrease this experience by satisfying someone's particular practical needs. Action dedicated to satisfying these needs would then be constructive to someone's personal functioning. If one were to focus on maintaining the appearance of normal functioning instead, experience of impediment would not be sufficiently acknowledged to substantiate compensatory needs, making genuine improvement to personal functioning unlikely. Though need substantiation alone does not direct someone to the appropriate actions, relying on a category to find out what actions would make sense for someone who belongs to this category would not ensure a link between someone's specific needs and her actions. After all, the category only describes that part of a person which is considered to deviate from a particular standard. Thus, a label referring to a category cannot describe all aspects of a person, because it could only refer to someone's relation to her environment in terms of a highly changeable and selective understanding of normalcy and deviancy. Therefore, using labels as identity descriptions would not be constructive to personal functioning. Were they to be employed as filter systems for sets of actions most likely to satisfy particular needs for practical compensation, however, people experiencing many impediments could efficiently link personal needs with appropriate actions to improve their personal functioning. Moreover, awareness of possible natural tendencies towards certain experiences is not necessary, since need-dedicated action only requires someone to be pre-reflexively aware of herself as owning the action and the experience it responds to.

Even though I have not attempted to offer a normative theory on label use, some may take issue with my reliance on self-assessment, in that it cannot be objectively ascertained whether someone is acting constructively, whether she has even substantiated her 'actual' needs or is able to do so at all. I would like to mention, as I did in section 3.3, that I did not claim self-assessment necessary for need substantiation is always *possible* nor that there is such a thing as the 'right' label for someone who experiences impediment. People with disabilities may never find answers to questions such as 'Who am I really and how can I use this information to gain control over myself?'.¹¹¹ A pragmatic attitude change towards labels could at least incite people with disabilities to prioritise employing practical ways to adequately decrease their experience of impediment.

What I do think would be a challenge in light of subjective assessment of functioning and overall well-being, is setting up a social theory of justice for controlled and adequate practical resource distribution. Since most accounts of justice aim to buttress their understanding of efficient and economical resource distribution with more or less objective principles, there is bound to be a clash of private and public interests. If someone cannot prove she has a certain experience, for instance, determining whether she has more need of a particular resource than someone else would not be possible. This would also raise the question whether a greater need for compensation determines the right for certain resources, which would be another attempt to objectify subjective experience by grading the need for compensation.

Also, it would be interesting to inquire into the added value of pragmatic label use within psychiatric practice and possible implications for patient policy. While there is always the risk a patient adopts her doctor's view on her inner workings rather than tries to focus on her experience of impediment, possible introduction of need substantiation procedures could be worth looking into nonetheless.

¹¹¹ Of course, neither will people without disabilities, but my focus is on people *with* disabilities.

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