Floating Signifiers: Managing Disability Language in Sweden

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ABSTRACT

This paper analyzes the management of intellectual disability language. I will focus specifically on the term *flerfunktionsnedsättning* which is the recommended Swedish equivalent for *Profound intellectual and multiple disabilities* (PIMD). This term reflects how, in Sweden, discourses and practices with an aim to conform language to linguistic, ethical, and political ideals are enacted. The result of such process in relation to disability has been the creation of different co-existing vocabularies that often create confusion. This is especially the case with *flerfunktionsnedsättning* which is hardly used or even recognized in the field among professionals. I will argue that this terminological confusion reflects the normative confusion in disability studies and disability policy.

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INTRODUCTION: TERM BANK

Language management in relation to disability is connected to some fundamental, controversial issues in disability theory. The question of what kind of vocabulary should be used to conceptualize disability and name people with various kinds of impairments has far-reaching significance. That is because language matters, it makes things happen – it does things. To call someone, for example, *a boy*, *a wife*, or *a person with intellectual disability*, makes the identified individual culturally intelligible (Kulick 2022). Language also creates, maintains, and changes institutional responses to disability. To conceptualize disability in terms of individual or societal circumstances guides disability policy and its implementation to correct individuals and/or the social environment (e.g., Oliver 1990).

In Sweden, the National Board of Health and Welfare is responsible for coordinating the terminology in health and social care. This is done by publishing recommended terms and definitions in their 'term bank'.[1] In spring 2019, I was invited to be a member of a working group that had been assigned by the National Board of Health and Welfare to formulate a definition for the Swedish equivalent of *Profound Intellectual and Multiple Disabilities* (PIMD) which is *flerfunktionsnedsättning* (pronounced: flér-funkshionsnedsettning) – a long, complicated word that literally means 'many-functions-reduction'. Having moved to Sweden less than two years earlier, my own command of Swedish was poor, and I was only superficially familiar with the conventions of the local disability language.

I was informed that there was no unified definition for *flerfunktionsnedsättning* and that there continues to be a conceptual ambiguity to this evolved term which was just one of many words used to denote PIMD (Ölund 2021). As a result, there is a great complexity when studying prevalence, programs or virtually anything related to PIMD, as well as when organizing the care work both nationally and locally. In other words, the National Board of Health and Welfare had sanctioned a translation for the already ambiguous diagnostic category of PIMD without clarifying its meaning. The aim of the working group was to standardize terminology, and establish the use of *flerfunktionsnedsättning* by producing a definition for the term as well as a common understanding how it should be understood and used in the service sector (Socialstyrelse 2020).

The working group produced a proposal for the definition that follows the international diagnostic criteria (DSM-V and Gross Motor Function Classification System) of PIMD: that is, the concurrence of significant intellectual and physical impairments. The proposal was circulated for comments but the result was damning (Socialstyrelse 2020). Most of the 86 respondents thought that the term proposal was too narrow and did not reflect its common use as a term simply denoting multiple disabilities, not necessarily including profound intellectual disabilities. The working group admitted that this objection was reasonable and that finding a sufficiently precise Swedish term was difficult. Since the term bank's recommendations should correspond to the common conceptions among healthcare professionals and specialists about appropriate language, the working group's definition was removed. As a result, no definition was produced, but instead, the notes section included merely a short description of the various uses of *flerfunktionsnedsättning*, and a recommendation on how it should be used as synonym for the English term PIMD in order to guarantee clear, coherent communication among the professionals (Socialstyrelse 2020).[2]

My aim in this paper is to make sense of this confusion that reflects not only the Swedish disability discourse but also debates in disability studies about appropriate ways to conceptualize disability. In the next section I will clarify the empirical starting points of this paper; namely how I came to realize the confusion around Swedish intellectual disability language. After that, I will analyze how language is managed in relation to different ideals and requirements, and why disability language matters (or not). In the fourth section I will use the comparison between Sweden and Denmark to enlighten the contextual nature of language and its significance; how conflicting language norms do not necessarily imply conflicting values and policies regarding disability. In the final section, I argue that the terminological confusion of Swedish disability discourse reflects a confusion of a more profound nature in disability theory, namely, the

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1   https://termbank.socialstyrelsen.se.

2   https://termbank.socialstyrelsen.se/?TermId=827&SrcLang=sv.

difficulty to understand and justify what is normatively an appropriate way to communicate different kinds of disability experiences.

FROM VERBAL CONFUSION…

The confusion around intellectual disability terminology in the Swedish disability service sector, especially regarding PIMD, became apparent to me in relation to a telephone survey that was conducted during the COVID-19 pandemic about the living arrangements for persons with PIMD in Sweden, where the interviewer often needed to explain separately the meaning of the term *flerfunktionsnedsättning* to the interviewee.[3] The data consist of 63 mapping interviews and eight in-depth interviews with unit managers. The in-depth interviews were conducted later with persons that had earlier taken part in the mapping interviews. The interviewer did not deliberately ask about the meaning of *flerfunktionsnedsättning* but the issue was brought up by 35 interviewees; 23 respondents were either unaware or uncertain about its meaning and wanted clarification, and 12 thought that it meant simply multiple disabilities. Even in some of the in-depth interviews, the interviewer needed to explain once more the meaning of *flerfunktionsnedsättning*. The following extract is from an interview with Alice, a unit manager in charge of a few group homes.

> Interviewer: Then I wonder how many people with multiple functional impairment or what to call severe intellectual disabilities or something like that, do you have in the group homes that you are responsible for? How many would you estimate you have, approximately?
>
> Alice: Yes … but do you mean with multiple functional variation and or can it be those who only have a cognitive functional variation as well, you think, or should it be that and…[4]

This extract demonstrates confusion with regard to the Swedish PIMD term and disability language in general. When asking about the number of people with PIMD living in group homes, the interviewer separately explains the term *flerfunktionsnedsättning* with the expression *severe intellectual disabilities* (*grava intellektuella funktionsnedsättningar*) which explicitly refers to diagnostical categories based on the severity of limitations in intellectual functioning and adaptive behavior from mild to profound (DSM-5). Regardless of this clarification, Alice the interviewee, clearly felt the need to ensure that she and the interviewer were talking about whether persons with multiple disabilities include people who also have intellectual disabilities. This is understandable since *flerfunktionsnedsättning* translates as *multiple functional disability* (or, literally, *many-functions-reduction*) and it includes no overt reference to intellectual or communicative disability. Therefore, it is often not seen to apply to individuals with (profound) intellectual disabilities. While some of the interviewees seemed to know the meaning of *flerfunktionsnedsättning*, they needed to specify with an outdated term *utvecklingsstörning* (*developmental disorder/interference*) when they talked about persons who had intellectual disabilities in addition to physical disabilities.

As it stands, there is no generally accepted term for PIMD in Swedish which is used commonly and consistently by researchers, policy makers, families, unit managers, care workers in group homes and day centers. In all fairness, it must be remembered that to single out persons with PIMD is difficult regardless of an established, unified intellectual disability terminology. When we recruited research participants with PIMD for our ethnographic study in Finland, we realized that the term that we assumed to be commonly used in the service sector (*syvä kehitysvammaisuus/ profound intellectual disability*) proved to be confusing for unit managers and care workers. Therefore, we decided to use a more uncommon term *vaikeimmin kehitysvammaiset* (*persons*

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3   The survey was part of a research project I directed entitled *A life with dignity for persons with profound and intellectual and multiple disabilities,* funded by the Swedish Research Council. The interviews were conducted by Dr Ida Norberg who took no part in writing this article. Ethical approval was applied for the interviews but the Swedish Ethical Review Authority (Etikprövningsmyndigheten) did not find it necessary: our interview data with the unit managers included no material that would have been subject to review.

4   Interviewer: Sen så undrar jag hur många personer med flerfunktionsnedsättning eller vad man ska grava intellektuella funktionsnedsättningar eller så, liksom har ni i gruppboendena som du är ansvarig för? Hur många skulle du uppskatta att ni har ungefär?
Alice: Ja… men ska vi säga behöver det vara med flerfunktionsvariation och eller kan det vara dem som bara har en kognitiv funktionsvariation också, tänker du, eller ska det vara det och…

with most severe intellectual disabilities) and specify during the recruitment process that we were interested in people who do not have spoken language and are capable of only very rudimentary forms of non-verbal communication (Vehmas & Mietola 2021).

Nevertheless, it is interesting that the term *flerfunktionsnedsättning* has been used, alongside with other terms, at least for some 15 years (Ylven 2015) and that only recently the National Board of Health and Welfare has tried to establish it in order to create linguistic clarity and coherence. The end result seems to be the opposite, however. How such a situation came about is something of a mystery. I have talked to six scholars with long experience in disability research, four healthcare professionals with long clinical and administrative experience in disability services, and three persons representing two disability organizations (FUB, The Swedish National Association for People with Intellectual Disability, and NKA, The National Competence Center for Relatives) about the origins and the motivation for the term *flerfunktionsnedsättning*. These informal discussions took place via email or in person. Nobody that I had contact with knew exactly when, why and by whom the term was advocated and authorized. Some of them speculated that the development of terminology might have been the result of power struggles between healthcare professionals, academics, and disability organizations, while few admitted that they had not thought about the question and therefore really had no idea.

This is somewhat strange especially when considering the linguistic predecessor for *flerfuknstionsnedsättning*, namely, *flerhandikapp* (*multiple handicap*). *Flerhandikapp* referred to the combination of several impairments but included no reference to intellectual disability. Within the Swedish disability movement and disability politics the term was reserved for those persons who necessarily did not have an intellectual disability, but due to the combination of different impairments had more extensive problems and needs (SOU 1980: 46–48). Considering this terminological past, it is safe to assume that *flerfunktionsnedsättning* is largely used as an updated synonym for *flerhandikapp*.

In order to get a larger picture how *flerfunktionsnedsättning* has been used in Sweden, I conducted a search in three databases: the Swedish language corpus *Korp* (83 results), media database *Mediearkivet* (479 results), and Google scholar (250 results). Korp search produced mentions from internet forums such as FamiljeLiv.se (forum on family life) and Flashback. org ('Sweden's largest forum for freedom of expression, opinion and independent thought') as well as parliamentary documents such as motions and plenary session minutes. Some internet forum discussion threads with hundreds of comments included one or two mentions of *flerfunktionsnedsättning* used in a way that the meaning of the word remained unclear. Some of these comments concerned the ethics of publishing pictures on social media of one's children with disabilities, the possibility of a comatose person giving birth, or something completely different with no apparent connection to PIMD. Some search results, on the other hand, included outdated websites that were not accessible. All in all, it became evident very soon that in internet forums and in media websites the term usually remained undefined, or it was implied that it meant *multiple disabilities*. Only those researchers (in academic publications) and policy makers (in reports published by governmental agencies or disability organizations) aware of the official definition of *flerfunktionsnedsättning* use the term in a more or less coherent way to refer to a combination of intellectual and mobility impairments. However, even many students and researchers seem to be unaware of the definition as in many student theses and research reports *flerfunktionsnedsättning* means multiple disabilities.

…TO VERBAL HYGIENE

The reason for the terminological confusion in Sweden probably lies, at least partly, within verbal hygiene or political correctness, in relation to disability. *Verbal hygiene* (Cameron 2012) refers to discourses and practices with an aim to make language conform to linguistic, ethical, and political ideals. Verbal hygiene may include a number of practices such as aspirations to preserve dialects, mocking disparagement of dialects and accents, guidelines on non-sexist language, opposition of such guidelines on the basis of an aim to preserve linguistic traditions, and so on. Simply put, verbal hygiene refers to opinions about correct language use. The aim of ethically and politically motivated verbal hygiene often is to adjust linguistic norms to the prevailing cultural values so that the used language would convey civility and respect (Cameron 2012; Kulick 2022).

People use language to signify social identity, and to differentiate a group of people from other groups. Language has also become an important concern to protect groups of people that have been marginalized on the basis of, for example, ethnicity, sexuality, occupation, or disability from derogatory expressions. Language is such a crucial part of the social world that it seems almost impossible to exaggerate its importance, especially when considering the moral and political standing of various minority groups. The use of appropriate or inappropriate language is often seen to reflect one's mindset regarding, for example, people with disabilities. The use of politically incorrect language thus discloses the politically incorrect views of the speaker. As Geoffrey Hughes (2010: 8) has argued, the most common answer to the question 'What is political correctness?' would be along the lines of 'It means not using words like [the N-word], queer, or cripple,' or 'It means showing respect to all,' or 'It means accepting and promoting diversity.'

Thus, language matters, but it does so in various ways. Not only does language convey information about the surrounding reality, it often shapes it as well. As regards impairment, for example, language can produce very different kind of knowledge about lived realities with impairment as well as different kinds of people with a particular impairment. Depending on the social context (e.g., Denmark versus Sweden, discussed in the next section), it can make a significant difference to refer to a group of people as *persons with cerebral palsy,* rather than *spastics,* or as *people with intellectual disabilities,* instead of *retarded*. This has to do with the way speech acts function as *performatives*, meaning that they change the reality they describe. For example, in many institutional contexts someone has the authority to create a state of affairs merely by representing it as being the case; a chairman can adjourn a meeting by simply saying, 'I adjourn the meeting,' and a judge can pronounce somebody husband and wife by saying, 'I pronounce you husband and wife' (Searle 1995; Hacking 1995).

When the *American Association on Mental Retardation* (AAMR) changed its name in 2007 to *American Association on Intellectual and Developmental Disabilities* (AAIDD), several principles were suggested as regards to naming people on the basis of intellectual disability (Schalock et al. 2007). To begin with, the term should be specific and consistent so that it allows its differentiation from other terms and entities they give name to. It should be used consistently by different stakeholders and represent current research-based knowledge. Also, it should be sufficiently robust to be operationalized for multiple purposes and, importantly, the term should communicate respect towards people with intellectual disabilities instead of devaluing or degrading them (Luckasson & Reeve 2001; Schalock et al. 2007).

In other words, the following questions should be asked when names or terms are considered:

1. Does this term name this and nothing else?
2. Does this term provide consistent nomenclature?
3. Does this term facilitate communication?
4. Does this term incorporate current knowledge and is it likely to incorporate future knowledge?
5. Does this term meet the purposes for which it is being proposed?
6. Does this term contribute positively to the portrayal of people with disability? (Luckasson & Reeve 2001: 48–49)

Names and terms may enhance or inhibit communication, understanding, as well as ethical and political recognition of the lived realities of people with intellectual disabilities. Especially in policy context, the operational value of terms and concepts is crucial; how they facilitate the implementation of policy aims for people with PIMD in terms of their living arrangements, education, spare time activities, social lives, sexuality, and so on. For example, in Finland, concepts like *inclusion* and *participation* refer in policy documents to relations and activities in the mainstream society, outside of group home or day center. However, the lives of people with PIMD take place almost exclusively within intellectual disability services which the current policy discourse ignores and provides no guidance how to create inclusive communities *within* disability service contexts (Vehmas & Mietola 2021).

Disability terminology has other functions than merely to create and maintain institutional order, continuity, and legitimacy. Terms can be tools for social critique like *queer* and *crip* (that originates from *cripple*) which originally were derogatory words but that were later reclaimed by

some activists and scholars to indicate pride of one's sexual or disability identity (e.g., McRuer 2006). Language is inevitably normative as it includes numerous conventions, rules, and value judgments about, for example, spelling, syntax, semantics, and of course, ethics and politics. Although people have different ideas about right, wrong, good, bad, elegant, or appropriate language, 'it is rare to find anyone rejecting altogether the idea that there is *some* legitimate authority in language: We are all of us closet (…) verbal hygienists' (Cameron 2012: 9). With language we express what is polite, respectful, ethically appropriate or politically obligatory in a particular social context regarding, for example, people with intellectual disabilities.

Some terms and phrases may express, perhaps unconsciously, the kind of normative stand that challenges the traditional view of impairment as inherently tragic, negative, or even as having an organic basis. For example, phrases such as 'people who are viewed by others as having some form of impairment' (Oliver 2004: 21) or 'allegedly 'real' impairments' (Tremain 2002: 42) seem to suggests that impairments do not have an objective organic basis. Another example is to place terms like 'learning difficulties' (Goodley 2001) in apostrophes which can be interpreted as a linguistic device with an aim to complicate the taken for granted relationship between an individual's alleged impairment and his or her intellectual and social competence.

Especially poststructuralist and postmodern theories about society and power have emphasized the efficacy of language and discourse, and that words are useful material with which to work for social change (Cameron 2012). In disability studies, poststructuralist scholars in particular have argued how the language used about people with disabilities will affect how they are treated (Feely 2016; Valentine 2002). Although the importance of language is generally acknowledged in disability studies, some critics have accused poststructuralists of overemphasizing the role of language and discourse, and neglecting the ordinary lives of people with disabilities, including their embodied experiences such as pain (Kulick 2022; Shakespeare 2014; Vehmas & Watson 2014).

Concern over disability language appeared already in the 1970s when disability rights organizations in North America and Western Europe launched efforts to educate the media and the public about what one should or should not say when speaking about disability. As a result, words like *handicapped, retarded,* and *spastic* were replaced with *disabled, intellectually disabled/impaired,* and *person with cerebral palsy.* Person first language especially was advocated in order to foreground the person rather than the disability (Halmari 2011; Kulick 2022).

However, regardless of the changes in terminology, the understanding and the resulting definitions of intellectual disability have not changed substantially since the 1960s. In fact, already in early 1900s the major elements of current definitions were used in the United States, namely, limitations in intellectual functioning, behavioral limitations in adapting to environmental demands, and early age of appearance (Schalock et al. 2007). As Schalock et al. (2007: 119) concludes: 'This historical consistency supports the trend in the field and the conclusion of the major organizations that, regardless of the term used to name this disability, the same population has been described.'

SWEDISH VERSUS DANISH VERBAL HYGIENE

It has become the right of any political or social group to choose its own name, and mere civility demands that such preferences ought to be respected. But more is at stake than mere civility; 'at stake is a power structure in which certain people, often without even being conscious of it, just assume the right to tell other people who they are.' (Cameron 2012: 144) Thus, language is an important attribute of power that provides people the means to define and set themselves apart from other people. Language is a crucial part of identity politics where an oppressed group fights for self-determination and recognition. So-called politically correct terminology is often a matter of the clash of two ideological positions as, for example, in the case of *homosexuality*; a term rejected by the gay community because it is 'a clinical description invented by sexologists, whereas *gay* is by origin an in-group label signifying a social or political identity.' (Cameron 2012: 146).

In Sweden, authorities such as The National Board of Health and Welfare and The National Agency for Special Needs Education and Schools (Specialpedagogiska skolmyndigheten, SPSM)

recommend the use of the term *intellektuell funktionsnedsättning* (*intellectual functional reduction*) instead of the earlier *utvecklingstörning* (*developmental disorder/interference*). Two main motivations were presented for this. First was the need to bring Swedish intellectual disability language into accord with international terminology. Secondly, *utvecklingstörning* was seen as a static concept that placed the problem within the individual rather than being something that took place in the relationship between individual and the environment (SOU 2021; SPSM 2019). However, no explanation was offered as for why *utvecklingstörning* conceptualizes intellectual disability as an individual deficit and *intellektuell funktionsnedsättning* as a social phenomenon. There is no *linguistic* reason why either term inherently and necessarily defines intellectual disability either as an individual or social kind. However, both terms do portray intellectual disability in negative terms; either as a disorder/interference (*störning*), or, as a reduction (*nedsättning*).

The only logic that seems to apply regarding disability verbal hygiene is that words become contaminated by stigma over time. Often, this creates an 'euphemism treadmill' where new, polite words are repeatedly introduced to replace offensive ones. This is because words refer to concepts and if those concepts are offensive, new names will inevitably be colored by the concept (Pinker 1994; Stollznow 2020). There is nothing inherently discriminatory or oppressive about, for example, the word *handikapp* (*handicap*). It was introduced to Swedish use in the beginning of 1950s, and it reflected the current notion of disability as an individual pathology. However, in 1970s its meaning changed due to the new conception of disability as a social phenomenon (Gough 2013: 8). In contrast to diagnostic manuals at the time, such as ICIDH, in the Swedish definition *handicap* was seen as a result of the clash between the individual with impairment and the environment: 'It is imperfections in the environment or organized activities that creates handicap' (Söder 1988: 29). *Handicap* does not depend on a person but on the fact that there is something wrong in society that prevents *people with an injury* (*människor med en skada*) to participate (SOU 1980: 8). Therefore, 'handicap is not something constant' and because of this, 'it is also not possible to precisely state the number of disabled people' (SOU 1980: 45). But regardless of this progressive use of the term, *handikapp* became outdated and unacceptable, and was gradually replaced by *funktionsnedsättning* (*functional reduction*) and *funktionshinder* (*functional obstacle*).

The changes in Swedish disability language have followed the logic of verbal hygiene that calls for changes regarding pejorative discourse and terminology because of their damaging potential for thoughts and action (Nordström 2018). Accordingly, we should use:

> words that are neutral with respect to problems, and are positive insofar as they remind us about variability in the world in general and in child development in particular (…) [because] changes in terminology can lead to changes in thinking and action: We can use positive F-words (function, fun, and future) instead of negative D-words (disability, damage, and deficit). (Rosenbaum 2016: 1204)

One manifestation of such seemingly neutral, but in reality, normative conceptualizations in Swedish are terms *funktionsvariation* (*functional variation*) and *normbrytande funktionalitet* (*norm-breaking functionality*). The first is mainly used in media to signal political correctness whereas the latter has been used in some academic dissertations with poststructuralist leaning to signify the cultural and ideological grounds of the disability category (Bylund 2022; Karlsson 2020).

Even within minority groups, there is variation of the preferred terminology that does not always comply with the requirements of the prevailing verbal hygiene. For example, some people refuse to describe themselves as *gay* because they do not want to politicize their sexual preferences (Cameron 2012). And many people with intellectual disabilities continue to refer to themselves with politically incorrect words like *utvecklingsstörning* (*developmental disorder/interference*) and *handikappad* (*handicapped*) – words that cause discomfort in Sweden where 'talk about people with disabilities is one of the most hawkishly policed spheres of language' (Kulick 2022: 128). As a result, disability language is in a constant state of flux.

Language politics in the neighboring Nordic countries differs from the fluctuating Swedish disability discourse. In Finland, the word for intellectual disability has been the same

(*kehitysvammaisuus*, developmental disability) since the 1970s, although regularly questioned and debated (Vehmas & Mietola 2022). Danes, however, have always been less concerned about politically correct language regarding disability.[5] They do choose carefully their words when talking about, for example, immigrants, sex workers or obese people, but with a clear conscience continue to use words like *spastiker* (*spastic*), *dvärg* (*dwarf*) and *mongol* (*mongoloid*). In fact, *mongol* is the most commonly used word in Denmark about people with Down syndrome, which is a more unfamiliar term to the public (Kulick 2022). Also, the name of the advocacy organization of people with cerebral palsy was, until 2019, *Spastikerforeningen* (*Association of Spastics*, now *CP Danmark*), and their magazine was called until 2017 *Spastikeren* (*The Spastic*, now *CP Indblick*).[6]

Should it be the case that politically incorrect language about disability necessarily causes disrespect towards people with disabilities, things ought to be a lot worse for people with disabilities in Denmark compared to Sweden. However, Don Kulick (2022) argues that this is not true, and cites his research with Jens Rydström on sexual politics of disability in Denmark and Sweden. Their main finding was that in Denmark, the land of politically incorrect disability language, the sexuality of people with disabilities is acknowledged and facilitated whereas in Sweden, where strict requirements regarding verbal hygienia prevail, their sexuality is repressed and discouraged (Kulick & Rydström 2015). In fact, Kulick argues that in Sweden right policies and right forms for ethical engagement are forgotten when 'more scrutiny is devoted to how people talk than what they actually say' (Kulick 2022: 134).

The example of Denmark suggests that politically incorrect language does not necessarily cause bad disability policy and general disrespect towards people with disabilities. The normalization principle was developed originally in Denmark and Sweden in the 1960s and 1970s, and these two countries were pioneers in deinstitutionalization and social inclusion of people with intellectual disabilities. Sweden might have been more efficient in its deinstitutionalization process than Denmark but, generally speaking, the conditions of disability services in these two countries are fairly similar (Tøssebro et al. 2012). In other words, Denmark and Sweden have a similar disability policy but different language policy.

TOWARDS NORMATIVELY APPROPRIATE DISABILITY LANGUAGE?

Sweden is an example of a country with an ambition to respectful language regarding various minority groups, such as people with profound intellectual and multiple disabilities. The result of this language correction process, however, has been the creation of various co-existing vocabularies that often create confusion. This is the case with disability language in general, but in particular regarding PIMD. The introduction of the new official term has aggravated terminological confusion – it is not used or even recognized in the field among professionals.

This situation is in line with the terminological diversity and sometimes confusion (e.g., the conflicting uses of 'learning disability' in the US and the UK) in disability theory that is, at least partly, the result of the *normative* confusion in the field of disability studies. This seems a problem especially in poststructuralist accounts that emphasize the importance of language and call for a conceptual eradication of binary distinctions such as male/female, gay/straight and disabled/nondisabled – binaries that are seen to be simplified and maintain dominance of the privileged and powerful (e.g., Campbell 2009; Schildrick 2020). As Mairian Corker (2000) argued, in binary opposites one term is given precedence over the other, and they 'deceive us into valuing one side of the dichotomy more than the other' (Corker 2000: 638). Therefore, political arrangements or ethical conceptualizations that are based on a group identity built upon a binary distinction or difference, are, according to theorists like Schildrick (2020), ethically problematic if not downright morally wrong.

Many poststructuralist accounts of disability seem to oppose group identities but, at the same time, they have been the basis for the conceptualization of disability primarily in terms of marginal identity status. To conceptualize disability as *queerness* (McRuer 2006) or *norm-breaking functionality* (Bylund 2022) is, ultimately, a way to define disability as a phenomenon

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5   In Danish, the official term for intellectual disability is *udviklingshæmning* (*developmental inhibition*) (https://socialstyrelsen.dk/handicap/udviklingshaemning).

6   https://www.cpdanmark.dk.

similar to gender or sexual identity. This conflicts with the traditional people first language tradition where a group of people is defined on the basis of their impairments (people with cerebral palsy, spinal cord injury, etc.). If distinguishing a group of people from other groups on the basis of their impairment is ethically questionable (e.g., Schildrick 2020), justification for impairment-specific group identities and identity politics becomes questionable as well.

From a traditional perspective where an impairment is a core element of disability definition, the criteria presented by, for example, AAIDD (Luckasson & Reeve 2001; Schalock et al. 2007) seem self-evident; the term should be specific, informative, operationalizable, respectful and so on. However, from a poststructuralist viewpoint where disability is often portrayed as an identity and representation issue, terms that identify persons with their *alleged* impairment are problematic, even potentially oppressive. But even if that was the case, one can reasonably ask whether words like *queer* or *norm-breaking functionality* are any better in doing justice to the lived experiences of disability and oppression (which, of course, they necessarily do not need to do if they are meant to be used in academic context to illuminate a particular theoretical position).

Protection from discrimination on the basis of one's physical and mental properties requires the recognition of impairments and their effects. Otherwise, we would not be able to identify groups of people with disabilities that are discriminated against by, for example, inaccessible buildings, transportation, or exclusive educational arrangements; in other words, they have been discriminated by social arrangements that have not been adapted to meet their individual needs/conditions/impairments (Vehmas & Watson 2014; Wolff 2009). The problem with a discourse that centers impairment alongside with relational considerations (like in AAIDD definition) is arguably its liability to medicalization – bearing in mind the critique directed against classification models such as ICF (e.g., Barnes & Mercer 2010). Then again, the problem with a discourse that represents disability primarily in terms of oppressed identity, is its liability to obscurity that has very limited political or administrative value. *Norm-breaking functionality* and *functional variation* are prime examples of verbal hygiene where the end result is an expression that, in its obscurity and vagueness, can virtually mean anything and, thereby, nothing at all. It is difficult to see how such terms would facilitate the implementation of policy, fair distribution of resources, or the protection of moral and political rights.

As I mentioned earlier, the *terminological* confusion within disability services and theory is perhaps related to a *normative* confusion. The arrangements and practices in intellectual disability services, for example, often become estranged from the ethical ideals that are supposed to guide it. As a result, in group homes and day activity centers the central values and aims of disability policy such as autonomy or participation often get lost in the routines of care work (Vehmas & Mietola 2021). The problem in disability studies, on the other hand, is a clear normative orientation which is only rarely acknowledged or analytically developed. In order to do justice to the empirical reality of disablement, the related ethical and political issues would need to be addressed (Vehmas & Watson 2016).

The challenge is to provide normative accounts of disability that are sufficiently complex, nuanced and in tune with practice. In disability studies, normative engagement, or the lack of it, has manifested in the materialist approach as an evaluation of current policies through taken for granted principles such as autonomy and equality, whereas in the post-structuralist approaches normativity is associated with normality and seen as one originator of discrimination against people with disabilities (Van der Weele 2022). Therefore, categories and definitions that support disabled/non-disabled binaries and the ethics of difference are deconstructed with the result that, in post-structuralist accounts, 'normativity is "done" by undoing it' (Van der Weele 2022: 8).

In other words, the normative mission of poststructuralist disability theorists is to erase all norms telling what kinds of beings humans ought to be and how they ought to act. But then again, any kind of norm-critique requires norms as does societal life in general; without norms about health, appropriate behavior, well-being and a good life, the administration of health and social care, education, and disability services would be impossible. In order to explain, justify and implement such norms, we need norms about language as well: 'Values, like languages, are not merely private. Like languages, they need to be shared and recognized to become intelligible to others.' (Kittay 2019: 43) Or, as Nancy Fraser has put it:

> ... the successful performance of any speech act presupposes norms of truth, comprehensibility, truthfulness, and appropriateness. Such norms make communication possible, but only by devaluing and ruling out some possible and actual utterances. They are *what enable* us to speak, at the same time and insofar as they *constrain* us. (Fraser 1981: 285; original emphasis)

It other words, successful communication requires agreement about the meaning of various words and terms, what they mean and what they do not mean. Following Fraser, I would argue that appropriate disability language requires the consideration of disability in its complexity and messiness. This implies the use of words that *enable* rather than *constrain* the engagement with the various intertwining social and individual factors that ultimately constitute, for example, PIMD. This means that we need to talk about things like disability policy, ableist culture and societal arrangements. But none of this makes sense nor does justice to persons with PIMD if impairments, and their effects on one's well-being are pushed aside. The well-meaning verbal hygiene of terms like *functional variation* (*funktionsvariation*) seem to encourage us to avoid uncomfortable realities related to impairments. For example, persons with PIMD often need help in communication, toileting, washing, eating, masturbating – with just about everything (Vehmas & Mietola 2021).

Such tangible issues are not just matters of variation and, as such, something neutral. On the contrary, they are of great importance in relation to human well-being and ethically charged especially regarding people with very limited cognitive and communicative capacities. They are highly relevant concerning social justice as well (e.g., Nussbaum 2006), and social institutions need the kind of disability language that facilitates appropriate ethical engagement with the lives of people with complex needs. Language that dismisses the realities of impairment would be counterproductive in the pursuit of creating personal and institutional responses that respect the *norm-breaking functionalities, variations* and *functional reductions* related to PIMD.

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