

Danes call people with Down syndrome ‘mongol’: politically incorrect language and ethical engagement

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In the course of fieldwork in 2011 in Denmark and Sweden, investigating how these two Scandinavian welfare countries facilitate the sexual lives of people with significant disabilities, I stumbled across an unanticipated phenomenon. In Denmark, I discovered, there is little or no political correctness when it comes to the language used to talk about disability.

I quickly learned that Danes refer to physical and intellectual impairments as *handicap*, using a word that has been rejected in most other European countries for a very long time. And very early on, when I was just getting started, I visited a group home for people with cerebral palsy in order to explain my project to them. I sat with ten residents, and I asked them what word I should use to talk about them. *Spastiker* (spastics), they answered in unison, without blinking.

“Really?”, I said, surprised. “Everywhere else I know of, that word is absolutely taboo”.

“Really?”, they said, surprised. “Well, what else would you call us? We call each other ‘*spasser*’ (‘spazzes’), but you can call us ‘*spastiker*’”.

Another experience was even more jolting. In a group home for people with intellectual disabilities that I lived in during my fieldwork, I was sitting outside chatting with female social worker in her 60s, who had worked in that group home for twenty years. She was devoted to her job and she was clearly much loved by the young men and women who lived in the group home. In between puffs of her cigarette, she turned to me to tell me a story about a young woman who lived there. “*Og så har vi den lille mongol*” she said: ‘We have this little mongoloid’. As soon as this woman said “*den lille mongol*”, she stopped and apologized, perhaps because she noticed that I had nearly choked on my coffee.

“Oh, *undskyld*”, she said. “Sorry, I know I shouldn’t say ‘little’. She’s an adult”.

The longer I worked in Denmark, I came to understand that language like this exists, in part, because of a much-beloved and much-fondled self image in Denmark that Danes are honest, forthright people who *kalder en spade for en spade* – ‘call a spade a spade’ – and have no patience with what is often presented as the silliness, and the American-ness, of politically correct language.

But this self-satisfied stereotype is not the whole picture. For the fact is, political correctness in language does exist in Danish. Words having to do with immigration and immigrants, for example, have politically correct forms that most people who aren’t racists – or who aren’t really old – are careful to use. The word *perker* – ‘paki’ in English – is avoided, as is *neger* (negro). People speak, and journalists write, in Denmark of *nydansker* (‘new Danes’), avoiding the politically incorrect *indvandrer* (‘immigrant’), which had already replaced *gæstarbejder* (‘guest worker’), which had replaced *fremmedarbejder* (‘foreign worker’). Other words also index politically progressive positions are *sexarbejder* (‘sex worker’) instead of *prostitueret*, *delebørn* (‘shared child’) instead of *skillmissebørn* (‘divorce child’), *ældre* (‘older’) instead of *gammel* (‘old’). The Danish Council of Ethics (*Det Ethiske Råd*), a government-appointed body that advises the government about ethical issues involving medicine and the environment, began a public campaign in March 2012, concerning politically correct language in the health sector – the difference it makes, for example, if you say *tyk* (‘fat’) or *overvægtig* (‘overweight’), or if you say *barmhjertighedsdrab* (‘mercy killing’) or *aktiv dødsbælp* (‘active help to die’). All this is to say that it isn’t as though Denmark is completely isolated from a world of discussion about politically correct language.

It is, however, or it seems to be, when it comes to disability. The rest of the world long ago eschewed a word like ‘handicap’, and the rest of the world contorts itself over whether it should say ‘disabled person’ or ‘person with a disability’ or ‘differently abled’ or ‘physically challenged’ or some other such formulation. Danes, however – including Danes with disabilities and including Danes who work with people with disabilities – seem blithely unaware of those debates, and the overwhelming majority of Danish speakers merrily go on using words and expressions about disability that are guaranteed to cause shock and offense outside Denmark.

This paper poses the question of what that means. It will examine the phenomenon of politically incorrect language in Denmark in order to ask the larger question: What exactly does politically incorrect language tell us about non-linguistic practice? What is the whole point of advocating politically *correct* language to talk about something like disability, and what are the consequences for people with disabilities when speakers don't talk that talk?

The context of the study

The context in which the following issues arose out of a comparative study of Denmark and Sweden.¹ The Swedish historian, Jens Rydström, and I compared how these two Scandinavian welfare states treat the topic of sexuality and disability.² The reason for the focus on sexuality and disability is partly because this is an area of life that has been profoundly neglected practically, politically and academically. Some reasons for this neglect are understandable, such as the fact that disability rights organizations have prioritized the public domain over the private, and focused their struggles on issues like access, employment, and discrimination. Other reasons are less defensible, and have to do with unease that many non-disabled people feel when thinking about disabled people having sex. But the most important reason to focus on sexuality is that we believe that the capacity to form erotic relations with other people is a fundamental entitlement that is central to human flourishing. The possibility to engage in sexual relations is a decisive marker of adult status in our society, and it is one of the fundamental entitlements that we expect as citizens. If it turns out that if a society systematically disregards, neglects, inhibits or obstructs the sexual needs and desires of people with disabilities, then that society is not just a society that discriminates, it is a society that is fundamentally unjust.

¹ The fieldwork on which this paper is based consists of 98 interviews with a wide range of people – people with various forms of impairments (both physical and intellectual); parents; academics; social workers; sex workers; people who work in group homes or as personal assistants; and Danish 'sexual advisors'. Fieldwork also consisted of attendance at various conferences and retreats, and participant observation in two group homes: for a month in a group home for adults with intellectual impairments, and for two weeks in a group home for adults with cerebral palsy.

² Our book, *Fucked: Sex, Disability and the Ethics of Engagement*, will be published by Duke University Press in 2014.

From this perspective, men and women with significant congenital disabilities such as some forms of cerebral palsy or some forms of Down syndrome are the most problematic people of all, because while many non-disabled people find it possible to express understanding and sympathy towards the sexual desires of a good-looking 23 year-old hockey player who breaks his neck and ends up a paraplegic in a wheelchair, fewer people have comparable levels of understanding and sympathy when the person with sexual desires is a 54 year-old man with Down syndrome, or a person born with cerebral palsy so severe that he or she has no verbal language, drools occasionally, and has arms and legs that are strapped to a wheelchair to help control spasticity. That a person like that might have a sexuality that they need assistance in understanding and living is a thought that disturbs many people, who would much rather prefer not to have to think about such things. This group of severely disabled adults are the ones who need most help in realizing their sexuality. They are the ones who present the biggest challenge to the way we think about things like entitlement and justice.

The reason to research this issue in Scandinavia is because Scandinavian welfare societies are usually portrayed as progressive and at the forefront of rights for people with disabilities. In terms of phenomena such as state-sponsored care and access, this is true. In other ways, however, the situation for people with disabilities in Scandinavia is anything but straightforwardly positive. A crucial difference between Scandinavian nations is precisely how the sexuality of people with disabilities is treated. Although they are similar in many ways, Denmark and Sweden have strikingly different policies and practices regarding the erotic lives of people with disabilities. This difference is the reason why my colleague and I decided to study them, and I will return to this difference below. But I want to get there by way of examining politically correct language.

Why is politically correct language thought to be important?

Most people are familiar with the history of political correctness in language – that the term comes from Maoist Communist doctrine meaning conforming to the party line, and that it was picked up in the 1970s by leftist activists in the United States and the UK. There was a

brief period when the term actually meant doctrinaire correctness on the left, but as soon as the term began to be used in leftist circles, it also acquired an ironic meaning *in those same circles* of holier-than-thou sanctimoniousness, and it – especially in its abbreviated form, “PC” – was used to make jokes and to make fun of earnest individuals who towed the party line too eagerly and mindlessly (Hughes 2010).

The ironic meanings of ‘politically correct’ became displaced when the phrase was picked up by politically conservative commentators in the 1980s, who very successfully repackaged the term as a one that named a crazy leftist obsession with enforcing “orthodox (‘politically correct’) views on class, race, gender and other forms of sociocultural diversity” (Cameron 1995: 124).

In the discussions about politically correct language since the 1980s, disability has always figured prominently, just as much – if not more – than class, race and gender. Of course, the language for referring to physical and intellectual impairments changed before political correctness was heard of. An example is the name changes that have occurred over the past 130 years for the organization that, when it was founded in 1876, was called the ‘American Association of Medical Officers of Institutions for the Idiotic and Feebleminded Persons’. That name persisted until 1933, when the Association was renamed the ‘American Association on Mental Deficiency’. In 1987, it became the ‘American Association on Mental Retardation’. And in 2006, the Association changed its name again to the ‘American Association on Intellectual and Developmental Disabilities’ (Halmari 2011: 829).

Scandinavian examples of this kind of development are words like the Swedish *krympling* or the Danish *kerøbling* (both mean “cripple”), which are no longer used. The Swedish word, *vanför*, “crippled”, was abandoned by groups who worked on behalf of people with disabilities already in the mid-1960s, before debates about political correctness even existed. Those groups began using “handicap” in all contexts – a word that is now considered unacceptable in Sweden. (Interestingly, the Danish disability movement continued using the Danish equivalent, *vanfør*, until 1988).

Concerted efforts to revise how the media and the public in North America and Western Europe spoke about disability really only took off in the 1970s, which was the decade that disability rights organizations – modeled on the civil rights, anti-Vietnam war, and

feminist movements – began to reject charity models of social welfare and achieve real political and social influence. The 1970s was when what is called ‘person first’ language began to be used and advocated. In English, speakers and writers were urged to stop using terms like ‘the disabled’ or ‘the handicapped’, and start putting the person first and saying ‘people with disabilities’ – the idea being that one should see the person, not the disability. Words like ‘handicapped’, ‘cripple’, ‘retarded’, ‘spastic’ and ‘dwarf’ became stigmatized, and were replaced with ‘disabled’, ‘physically impaired’, ‘intellectually impaired’, ‘person with cerebral palsy’ and ‘person of short stature’ or ‘little person’.

Disability rights organizations regularly distribute material that educates the public about what one should or should not say. The National Center on Disability and Journalism, for example, has produced a “style guide” for journalists. It lists commonly occurring words like ‘cerebral palsy’ and ‘dwarf’ and discusses their acceptability.

Another widely cited manual is titled *Language is more than a trivial concern!* (note the chastising exclamation mark), by June Isaacson Kailes, published in the United States by the Center for Health and Disability Policy. This text is a 27-page booklet that offers advice and guidance about how to speak about disability. The beginning of the booklet contains a language quiz so that readers can test themselves to discover they unknowingly are “perpetuating negative attitudes and false stereotypes of people with disabilities”. The quiz lists terms such as ‘invalid’, ‘disfigured’, ‘imbecile’, ‘retarded’, ‘humpback’, ‘wheelchair user’ and ‘midget’ and asks readers to place an “A” before those terms that are acceptable, and a “U” before the unacceptable ones. The end of the booklet provides the correct answers to the quiz. Those answers tell us that words like ‘handicapped’ and ‘spastic’ are ‘Unacceptable’. The booklet also advises English speakers to avoid certain metaphors, such as ‘dumb luck’, ‘blind ambition’ and ‘paralyzed by fear’. The author feels that expressions like these “reinforce common misconceptions, stereotypes and negative thinking about disability”. The booklet also contains lists of Unacceptable and Offensive formulations paired with their Acceptable or Neutral alternatives. Here one learns that a phrase like ‘He has arthritis’ is acceptable or neutral, but ‘He is arthritic’ is unacceptable. A word like ‘mongoloid’ is so off-the-charts outrageous that it isn’t even printed on this list.

Efforts like this to get people to use what in-group members regard as respectful language are a textbook case of what Deborah Cameron (1995) has labeled 'verbal hygiene'. And like all instances of verbal hygiene, words and expressions about disability occasion profoundly affect-laden disagreement. Some words that non-disabled people who think they are being PC-use to talk about people with disabilities are dismissed by people who actually are disabled. The pious phrases 'physically challenged' and 'differently abled' are held in particular contempt by people who have disabilities. Other expressions are more contentious. 'Person first' language itself, which many people argue expresses respect, is rejected by increasing numbers of disabled people because they think it is both denigrating and patronizing: they point out that the postponed nouns or noun phrases mandated by 'person first' language have negative connotations ('person with cancer', 'person with a mobility impairment'), and they like to ask how a black person would react if she or he was referred to as a 'person with blackness', or how a woman would respond to being called a 'person with femaleness' (Mackelprang and Salsgiver 2009: 20; also Linton 1998: 8-33, Snow 2007, Wendell 1996: 77-81). Many people with disabilities also resent what they see as the implication of 'person first' language that there is a person imprisoned inside the unhappy shell of disability who is somehow detachable from the disability. Author Nancy Mairs, who has multiple sclerosis, expresses this sentiment succinctly in her memoir *Waist-high in the world*. "Who would I be if I didn't have MS?", she asks. And her answer: "Literally no body. I am not "Nancy + MS", and no simple subtraction can render me whole" (Mairs 1996: 8). Instead of 'person with a disability', Mairs prefers to call herself a cripple.

Political correctness in Scandinavia

This brief short historical and linguistic contextualization brings us to Scandinavia. As I've mentioned, political correctness regarding disability never really arrived in Denmark. Even so, though, some words, like *krøbling* ('cripple') are gone. Another example is the once-popular words *evnesvag* and *åndssvag*, both of which mean 'feeble minded'. These words have largely passed into the realm of schoolyard abuse and descriptions of really imbecilic behavior. But *åndssvag* lived on in official contexts until 1980, for example in *Statens Åndssvageforsorg*

(Department of Support for Feeble-Minded People) the name of the national administration of what we now call people with intellectual and psychological disabilities. As I mentioned above, the Danish word for ‘cripple’, *vanfør*, also lasted a long time – it was only in 1988 that the Danish *Landsforeningen af Vanføre* (Crippled People’s Union) changed its name to *Dansk Handicap Forbund* (Danish Handicap Association).

But even today, official documents and mass media reports continue to use words like ‘handicap’ and ‘handicapped’. When Danes – and I stress that this includes people who are disabled and people who work with them and advocate for them – talk about people with disabilities (‘the handicapped’), the contrast they draw is with *normale mennesker*, ‘normal people’. There is a politically correct word, *udviklingshæmmet*, (‘developmentally hampered’) that has replaced *evnesvag* (‘feeble minded’) as the name for people with a range of intellectual disabilities. But *mongol* (mongoloid) is the word most commonly used to describe people with Down syndrome. It is used in the press, for example, to help readers understand the more unfamiliar expression ‘Down syndrome’ – so the words *downs syndrom* will sometimes be followed by a parenthesis containing the explanatory word *mongol*.

Another example of this Danish political incorrectness is *spastiker*, which as I said earlier, is the word of choice for people with cerebral palsy; so much so that the name of their advocacy organization is *Spastikerforeningen* (‘Association of Spastics’), and their bi-monthly magazine is called *Spastikeren* (‘The Spastic’).

But the case that most succinctly sums up Denmark’s unique relationship to politically correct language regarding disability is what happened to the Danish Association for People with Restricted Growth, *Landsforening for Væktsbæmmede*. In June 2007, by a vote of its members, the Association for People with Restricted Growth officially changed its name to *Dværgeforeningen*, ‘The Association of Dwarves’. Their members’ magazine is titled *Kort og Godt*, ‘Short and Sweet’.

Now contrast this kind of language use with the situation we find over on the other side of the Öresund sound. Sweden is heavily influenced by American and British discussions, and talk about people with disabilities is one of the most hawkishly policed spheres of language. The slightest lapse – saying, for example, *en funktionshindrad*

(‘a functionally-impeded [person]’) instead of the much more cumbersome but politically correct, ‘person first’ *person med funktionsnedsättning* (‘person with a functional reduction’) – will often elicit a sharp disapproving correction from anyone who knows better, conveyed in a tone suggesting that if you don’t know the right words, you have no business speaking at all. I was chastised during a public lecture in Stockholm in 2011 because I used the politically correct term *funktionsnedsättning*, but one of my fellow speakers knew an even *more* politically correct term – *funktionsvariation* (so ‘functional variety’, rather than ‘functional reduction’, what I said) – and she publicly criticized me for using what she considered to be an outdated, denigrating term. This kind of interaction illustrates what Steven Pinker has called the ‘euphemism treadmill’ – where a politically correct term comes to take on the offensive connotations of the offensive word it was coined to replace.

Words like *spastiker*, *mongol* or *dvärg* (dwarf) are out of the question in Sweden, as is the word ‘handicap’, which has been replaced by *funktionsbinder* (‘functional obstacle’), on the principle (inspired by the British ‘social model of disability’) that a person’s physical or intellectual impairments only result in a handicap when that person is confronted by an unaccommodating environment. In 2007, the same year that the Danish Association for People with Restricted Growth changed its name to the Association of Dwarves, The Swedish National Board of Health and Welfare (*Socialstyrelsen*), issued new guidelines about language relating to disability. Everything relating to disability was reformulated in ‘person-first’ language, and the term *person med funktionsnedsättning* (‘person with a functional reduction’) was declared to be the new recommended term.

In this context of heightened awareness about language, two words stand out as being a bit inconsistent or jarring in Sweden. One is most commonly used word for people with intellectual disabilities: *utvecklingsstörd*. This word literally means ‘developmentally disturbed’ or ‘developmentally disordered’. The other word that jars a bit with an otherwise highly policed culture of political correctness in Sweden is *cp-skada* (‘cp-damage’ or ‘cp-injury’), which is the way most Swedes refer to cerebral palsy. So a person with cerebral palsy is *cp-skadad* – ‘cp-damaged’. Both *utvecklingsstörd* and *cp-skadad* have recently acquired politically correct versions, however, in ‘person-first’ language. So an

acceptable way of designating people with intellectual disabilities or cerebral palsy is to say *person med* (or ‘*som har*’) *en utvecklingsstörning* (‘person with – or ‘who has’ – a developmental disturbance’) and *person med en cp-skada* – ‘a person with cp-injury’. Despite the fact that words like ‘disturbance’ and ‘injury’ would not pass muster in disability activist contexts in the English-speaking world, in Sweden, these expressions remain largely unremarked on, as long as they occur in a ‘person-first’ formulation. If they don’t, and a speaker uses *cp-skadad* instead of *person med en cp-skada*, then risk is great that that speaker will be upbraided by anyone who knows better.

Why use politically correct language?

What is the point of politically correct language? Why do people who advocate it argue that speakers should use it? What does politically correct language do? The simplest answer usually given to that question is that politically correct language conveys civility and respect. If a group of people declares that they would prefer to be called ‘African-American’ instead of ‘black’, or ‘gay’ instead of ‘homosexual’, then the polite thing to do is accommodate them and call them by the name they prefer. But politically correct language is about more than etiquette – it isn’t called ‘politically correct’ for nothing. It is believed to result in non-linguistic consequences in the real world. But how exactly is politically correct language imagined to do that? What is the theory of language that underlies the conviction that politically correct language is better than politically incorrect language?

This is articulated in slightly different ways by different writers. The Danish Council of Ethics (*Det Ethiske Råd*), for example, that I mentioned earlier, motivates its 2011 brochure, titled ‘Ethics and Language Use: from cradle to grave’ (*Etik og Sprogbrug: fra vugge til grav*), with the explanation that “language use can influence both attitudes and actions among people” (*sprogbrug kan påvirke både holdninger og handlinger blandt mennesker*; 2011:6). This is a version of the common argument that appears in perhaps its pithiest form in a little, greeting-card-like text in the manual I cited earlier, *Language is more than just a trivial concern!* (Kailes 2010: 4). Attributed to a woman named Shirley Devol VanLieu, the point of using politically correct language, this manual says, is as follows:

Our words affect our thoughts,
Our thoughts affect our beliefs,
Our beliefs affect our feelings,
Our feelings affect our behavior,
Our behavior affects the world!

This view of the relationship between language and social action is Whorfian, Orwellian and Austinian, all at once. Language shapes thought, which affects feelings, which result in the performance of felicitous speech acts involving sincerity, correctness of form, and propriety of context. The idea is that the use of certain words will result in mental, affective and behavioral changes in the speaker. And cumulatively, those changes will result in a greater degree of respect for diversity and in a better, more empathetic, more just society.

Now an implication of this theory of language in relation to the case I am discussing is that people with disabilities in Denmark, where words like 'handicap', 'mongoloid', 'spastic' and 'dwarf' that have been stigmatized in other Western countries, are still widely used – this understanding of language implies that disabled people in Denmark will be treated with less respect and with less dignity than is the case in a place like Sweden, where political correctness reigns supreme.

Let's put that hypothesis to a test. Is it true?

Policies and practices relating to sexuality and disability

We can address this by returning now to the topic that my colleague and I have researched, sexuality and disability. Denmark and Sweden are both considered to be representative of what sociologists and political scientists call a "Nordic model of disability protection". This model, which also includes Finland and Norway, is characterized by a high percentage of the expenditure (nearly 4% of the Gross Domestic Product, on average) on people with impairments, a consequently high level of income maintenance for those people, and a higher percentage of people with disabilities in paid work. There are differences between the Nordic countries, for example, Denmark has a higher percentage of people with impairments living in institutions or service housing, such as group homes, than Sweden, which grants more subsidies for

personal assistants (Hvinden 2004:173-74). But compared to other countries in Europe, the Nordic model is fairly coherent.

One significant difference not captured by political scientists who compare the Nordic countries on the basis of factors like expenditure and employment statistics concerns policies, understandings and practices regarding the sexuality of people with disabilities. On this point, the difference between two Nordic countries, Sweden and Denmark, is extreme. Put as starkly as possible, the difference is this: In Denmark, the sexuality of people with disabilities is acknowledged, discussed and facilitated. In Sweden, in contrast, the sexuality of people with disabilities is denied, repressed and discouraged. Denmark has a set of policies that acknowledge the sexuality of people with disabilities, and that express that acknowledgement as an entitlement. In other words, Denmark explicitly recognizes that people with disabilities are entitled to a sexual life. In Sweden, we find pretty much the opposite situation. There, the idea that sex might be a right is roundly and universally condemned, and the idea that someone – for example a social worker or a personal assistant – might actually help a disabled person have sex is utterly out of the question.

In practice, this means that, in Denmark, people like the 54 year-old man with Down syndrome or the person with severe cerebral palsy that I mentioned at the beginning of this paper may well have a sex life. In Sweden, the chances are very great that they wouldn't – ever. The 23-year-old hockey player I mentioned earlier might well have sex in Sweden, because if you have an acquired disability, and especially if you are young and already have a partner, then you are supplied with information and support to help you rehabilitate your sexual life. But if you have a congenital impairment, especially a severe one, or if you are single, then you are out of luck.

Denmark has a set of guidelines that advise social workers and others who work in group homes and homes for senior citizens how to deal with sexuality. The document first appeared in 1988, and it has been revised twice, once in 2001 and again in a new version that just appeared in 2012, published by the Danish National Board of Social Services (Socialministeriet 2001, Socialstyrelsen 2012). There are important differences between these different versions of the document, and the latest version has markedly watered-down formulations that in previous versions were much more affirmative of

disabled people's sexual rights. But even the latest, watered-down version of the guidelines document affirms that people with disabilities have a right to a sexual life, and that social workers and others have a responsibility to advise and guide people with disabilities who want help understanding, exploring and living their sexuality.

How this works in practice for disabled people living in group homes varies between different homes. Many group homes ignore and discourage sexuality, in ways that we know is the default stance on sexuality taken by many such institutions around the world. But since 1990, Denmark has had an educational certification on sexuality and disability that social workers can earn as a specialization. The certification is awarded after the completion of twenty days of meetings and coursework spread over one and a half years, during which time students complete practical assignments and initiate projects at their places of work. The course results in a certification as what is called a *seksualvejleder*, or a 'sexual advisor'. There are currently over 300 certified sexual advisors in Denmark, and two more diploma programs have recently been instituted in Copenhagen and at a college in Hans Christian Andersen's birthplace, Odense.

If one or more social workers with a certification as sexual advisors work in a group home, that home is likely to have open and progressive policies regarding sexuality. Sexual advisors provide information and education, they make practical arrangements to accommodate sex between disabled lovers, they help people with mobility impairments masturbate, and they help individuals who want to contact sex workers.

Here is an example of what all this means in practice. Here is what is called a "plan of action" (*handleplan*) written by a social worker for a woman in her twenties who we can call Helle. Helle lives in a group home for people with cerebral palsy. She is unable to move anything but her head, and she has no verbal language. She communicates with her eyes, by smiling and making a variety of sounds, and also with the help of a laser that is strapped to her head and that she can use to point to symbols on what is known as a BLISS board. The following plan of action was handwritten in Danish by a sexual advisor and dated March 2011.

Plan of action for Helle Rasmussen

Helle would like help in positioning her sex aide. Helle is laid naked on her bed. A large mirror is placed at one end of Helle's bed, so that she can see herself. A pillow under her knees, legs spread. Put lubricant on the sex aide, Helle's hands and on her privates. Place the sex aide on her privates. The helper asks Helle how long she would like to lie alone, 5 min. or 10 min. or 15 min. Helle will nod at the exact number of minutes she wants. The helper goes back in when the agreed upon minutes are up and asks Helle if she is done. If she says no, ask again how much longer Helle would like to lie in bed. When Helle is finished, wash the sex aide and ask Helle if everything is OK.

This text is interesting linguistically for how it breaks down a sexual act like masturbation into its component acts, in a way that allows a helper to facilitate sex without performing it or without intruding any more than necessary on the privacy of the person who needs the help to have sex. It exemplifies a fundamental feature of the help that sex advisors provide: they help individuals have sex, but they don't *have sex* with them – in fact, they are explicitly prohibited by their code of ethics from having sex with them. So sex advisors are not sex workers or sex surrogates. They are social workers with special training and competence. Notice how a text like this 'plan of action' helps guard against abuse of the relationship between the sexual advisor and the person with a disability. If a contract like this exists, the person with a disability has grounds for saying "You transgressed our agreement" if the helper does something not in the agreement. And the person providing the help knows exactly what she or he is agreeing to – she or he can also refuse to do anything beyond what is made explicit in the agreement.

Nothing even vaguely similar to a contract like this exists in Sweden. There, the picture is unrelentingly bleak. The situation in Sweden for people with severe disabilities is characterized by a number of features that differentiate it from Denmark – there are no 'sexual advisors', for example, nor are there any guidelines regarding sex and disability. But a particularly significant feature that

distinguishes Sweden from Denmark is the steadfast assertion in Sweden that sex is not a right.

The Danish guidelines mentioned above declare sexuality in the sense of sexual relations to be a right. This is in keeping with both United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities and the World Health Organization's working definition of sexuality. In Sweden, however, the suggestion that sex in the sense of sexual relations or sexual activity might be a right is met with sharp denial and unanimous condemnation. A comment like the following one is typical. This text appeared in an article titled "Sex is not a right" (*Sex är ingen rättighet*). The author is Mattias Kvik (2004), a man who identifies himself as a '*habiliteringspersonal*' (habilitation facilitator); in other words, as someone whose profession is to work with people with disabilities.

In my view it is completely impossible (*helt omöjligt*) to attempt to find guidelines for how this kind of help [that is, help with sex] might occur in ways that prevent every conceivable risk for abuse and/or humiliation in relation to any of the people involved.

Mattias Kvik's remarks are a concentrated version of the kind of commentary that saturates Swedish public debate on this topic. Particularly striking is the language: the proclamation, not that it is difficult, or challenging – no, it is "completely impossible" to even *attempt* to try to find guidelines for assisting people with disabilities to have a sexual life. An assertion like that does its best to preempt discussion and shut it down firmly before it can even begin. Also striking is the standard of morality to which persons with disabilities who need help are held: they can't have help with sex, Kvik declares, because he doesn't believe that it is possible "to prevent every conceivable risk for abuse and/or feelings of humiliation in relation to any of the people involved". A question one might well ask upon reading that concern is how much sex *anyone* would have if we were permitted to engage in sexual relations only after every imaginable precaution had been taken to prevent "every *conceivable* risk for abuse and/or feelings of humiliation in relation to any of the people involved"? Weekend nights after the clubs close would be very lonely

times indeed.

Politically correct language and the ethics of engagement

The sort of response offered by Mattias Kvick is what meets anyone in Sweden who discusses the issue of sexuality and disability in terms of rights. So returning now to the issue of political correctness in language, it should be clear that we have a contrasting and counter-intuitive situation. On the one hand we have Denmark, where politically wildly-incorrect language about disability co-exists with policies and practices that are both politically radical (for what they mean for the rights of people with disabilities as citizens) and ethically progressive (for what they imply about how disabled and non-disabled people might imagine and engage with one another). This contrasts starkly with Denmark's neighbor, Sweden. There, *language* about disability is constantly monitored and uncompromisingly judged. But policies and practices relating to the 'sexual lives of people with disabilities are politically retrogressive and ethically arrested. How are we to account for this contrast?

In national terms, it is possible that the Danish ideology of *frisind* might provide some kind of explanation as to why Danes are so relatively unconcerned with politically correct language in regard to disability. Danish sociologist Henning Bech has called *frisind*, a word that literally means 'free mind' or 'free spirit', a "national peculiarity". He has defined it as a cultural ideology of "enlightened tolerance in matters of personal belief and moral conduct, combined with a social commitment to establish the conditions for individuals to think and live as they prefer" (1992:147). Bech says that this ideology of tolerance has played an important role in Danish national identity for the past 150 years, and he invokes it in his work to explain both Danish progressiveness in relation to issues relating to sexuality (such as the legalization of pornography in 1967 and the establishment of 'registered partnerships' for homosexuals in 1989), and also the upsurge in the 1990s of anti-immigrant sentiment (the argument there being that many Danes who express that sentiment perceive Muslim immigrants to threaten this ideology of tolerance, 2002:69). Although Bech does not link the ideology of *frisind* to language and linguistic ideologies, his insistence that one of its defining characteristics is that "it is not moralistic: it doesn't lay out norms for how people should or

shouldn't live their lives" (2002:55) suggests that it may be a factor in explaining Danes' apparent disinterest in engaging with discussions that have the explicit agenda of stigmatizing some forms of language as morally faulty or wrong. Sweden, on the other hand, as Bech points out, not only has no ideology similar to *frisind*; it also has a strong history of state intervention into citizens' lives and a robust tradition of prohibitions and state-issued moral guidelines that instruct people how they ought to live.

Whatever the specific reasons for these national differences might plausibly be, a general theoretical point that can be made from these two contrasting countries concerns the way that language can become hypostasized in discussions about diversity. In those discussions, it can happen that so much attention gets paid to the right *language* that the right *policies* or the right *forms for ethical engagement* can get displaced or forgotten, as more scrutiny is devoted to how people talk than what they actually say. Talk here becomes a substitute for action. This, of course, is similar to what conservative critics of political correctness claim – they argue that what they call the 'Looney Left' has so fetishized language that it believes that an orthodox regimentation of labels people use for others is enough to change the world.

My point is slightly different. My point, which is similar to what the philosopher Judith Butler (1997) has argued in relation to hate speech, is that language can become misrecognized as the site where speakers satisfy themselves that action takes place. Language can become the arena where speakers can congratulate themselves for taking action – in ways that may make action in other arenas seem less necessary or urgent. So when a Swede polices the language of other speakers and swiftly corrects a word that he or she perceives to be out-of-date or offensive, that person can congratulate himself or herself that he or she has acted in a progressive, empathetic manner. By correcting another person's politically incorrect language, an individual can feel as though he or she has made a concrete contribution to the betterment of people with disabilities in society. Where language is perceived to be the site of progressive action, action is taken in language. Actions taken in other spheres can become less urgent and less necessary.

So this case study between Denmark and Sweden does two things. First, it disproves the relation that many people feel hold, or ought to

hold, between politically correct language and behavior. Language about disability in Denmark is politically incorrect to a massive degree. Although nondisabled Danes who use a word like *spastiker* may not feel that they are being politically incorrect, the theory of language behind political correctness is not relativistic. Not knowing that a word or phrase is politically incorrect is not an excuse – or it is an excuse that only works once. People committed to political correctness in language, such as the author of *Language is more than just a trivial concern!*, or Swedes who work with people with disabilities, would not, I suspect, be terribly receptive to the argument that in Denmark it is perfectly fine to call a person with Down syndrome a *mongol*. On the contrary, they would seek to educate Danes why it *isn't* perfectly fine at all. It is offensive, they would argue, it is demeaning, and it is wrong.

But despite the politically incorrect language, the policies and practices in Denmark that relate to the erotic lives of people with disabilities allow even people with profound impairments to flourish. Those policies and practices facilitate disabled individuals' access to experiences, relationships, emotions and sensations that are life enriching and that non-disabled people take for granted – and that also are fundamental entitlements in a just society.

The opposite is the case in Sweden. There, people are careful to use language that they believe expresses respect for disabled people, but their ethical buck stops at language. That they should extend their engagement with disabled women and men beyond language, to try to find ways to help those women and men experience dimensions of life that they take for granted for themselves and for other adults – this is not considered – or if it is considered, it is declared to be “completely impossible”. Severely disabled individuals' access to sex is actively blocked, by the same people who would be the first to correct you if you said ‘handicap’ instead of ‘disability’. Severely disabled individuals receive no practical help with sex. Sex, Swedes like to tell one another, is not a right. And therefore any disabled person who wants help with masturbation, or rolling on a condom, or inserting a vibrator, or help with positioning their body and that of their partner in such a way that they can experience erotic pleasure – those individuals are informed that they are infringing on the rights of their helpers or assistants, or even harassing them.

The Swedish case suggests that politically correct language may actually hinder progressive change rather than facilitate it. To the extent that we too unthinkingly or too completely collapse the distinction between speaking and other forms of acting; to the extent that we misrecognize language as a primary site of action, then the consequences for the lives of disadvantaged people – such as people with disabilities – can be profound and negative. And Danish political incorrectness does something theoretically interesting: it invites us to problematize the space that exists between language and action, and it pushes us to acknowledge that speech acts, for all their performative power, are not the same as, and cannot substitute for, concrete ethical practices of awareness, engagement, care and justice.

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