

Ten affects of hidden, mental dis/abilities and the act of disclosure

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10 affects of hidden, mental dis/abilities and the act of disclosure

An affect: an ability to affect and be affected

An effect: a change, a result of an influence

Introduction

I am a PhD researcher who lives with similar dis/abilities as those participants I study. My research performance takes this into account and is primarily one of 'noticing'. The notion of visibility and materiality is theoretically relevant because the panoramic spectrum of hidden, mental dis/abilities such as autism, intellectual disability and other mental health problems can typically show no symptoms and so fail to remind us that seeing can be considered a dualist state of presence/absence. In addition to discussing how researchers negotiate their invisible dis/abilities throughout the various stages of research, my aim in this chapter is to explore the challenges and dilemmas I, as a dis/abled researcher face, when conducting research focusing on the questions of disclosure.

First, I will clarify some definitions, the particularities of invisible dis/abilities and the consequences for disclosure. Second, drawing on my personal experiences, explore the opportunities and dilemmas of being a researcher with an invisible dis/ability. Third, I will elaborate on the researcher role and how disclosure might influence the research process looking at mainly the question of neutrality, partnership and reflexivity. Fourth, I offer some pragmatic discussions about the emergence of the 10 affects of the act of disclosure (as noted in the quote above, affect is a capacity to change) in the various stages of research practice.

Definition and terminology

To begin, it seems the lack of agreed terminology is well known in dis/ability research. Therefore, it remains important to explain the approach we have taken (McBrien 2003; United Nations 2005; Bradley 2009; Shakespeare 2014). The notion of visibility and materiality has a central role in the life of people living with various mental and cognitive conditions as firstly, our difficulties are often not apparent to the observers, and secondly, these conditions cannot be readily described by an evident underlying physical anomaly or represented by materials. Brown and Broadman (2010) argue that the visible presence of a wheelchair or an assistance dog are generally accepted signals of a dis/ability and as such provide grounds for negotiating barriers. Disclosure *per se* is rarely a decision to be made when visibility is present. On the other hand, by virtue of the materiality and the visibility of autism, the various mental health conditions or intellectual disability being beyond our reach everything is permitted as anything can be demonstrated (Latour 1993). Many probably would ask at this point the question: is depression or autism a dis/ability at all?

The preferred term by the diagnostic manuals (ICD, World Health Organisation 2016; DSM, American Psychology Association 2013) and various legislation such as The Mental Health Act 1983 (Department of Health 1983) is “disorder”. Disability is the terminology used by the Equality Act 2010 (Government Equalities Office 2010) for a person who has a physical or mental impairment that impacts a person’s ability to carry out normal day-to-day activities. Whilst studies like Mcclimens (2007) Kittelsaa (2014) and Kenny *et al.* (2015) emphasise most dis/abled people probably would prefer to leave behind such differentiation altogether. I use the term dis/ability to signal that the notion of ‘ability’ and ‘disability’ as a binary concept is potentially outmoded and a mistaken view of human differences and their complex representations (Latour 1993 p32; Baudrillard 1994 p133). For example, depression is different from intellectual disability, schizophrenia or autism. However, people who live with the various mental and cognitive conditions also share certain adventures. One of those is the invisible and often misunderstood nature of their performances. And of course, the ambivalent act of disclosure.

The act of disclosure

What does a diagnosis of a dis/ability perform? Disclosure of a dis/ability has the capacity to affect and mediate how others will act. And those actions then affect not only how you feel about yourself, but your research (Latour 2005). The research arena demands many decisions related to disclosure and the everyday performances of dis/ability. You constantly need to make decisions about whether you disclose it to your boss, colleagues, friends, and the people you encounter in your daily life. The feelings of awkwardness, the how to and when to talk about it, to whom are just some of the accompanying difficulties of disclosure. The fear and insecurity of what will happen next? I often say disclosure is like talking dirty, letting out some deeply buried family secrets. And the receiver of disclosure often reinforces this notion: "Thank you for disclosing it, I promise I won't tell anybody." Why not? What is wrong with being autistic? Intellectually disabled? Or depressed?

Most of us in our dis/ability journey will hope for open disclosure, where you can just say something like: “look, I am Autistic, sorry if I say something silly, or my humour bites, or I zone out. I do my best, and you can support me. A dash of humour would be a good start.” But we quickly learn, it rarely works like this. What I have found that most of the time, people have no, limited or very rigid ideas of what Asperger syndrome means and how it might affect you. Talking to participants about the experiences of disclosure and cross member checking typifies the unpredictable nature of disclosure as a shared event between people who have autism, depression, obsessive-compulsive disorder, intellectual disability or bipolar disorder. Our invisible dis/ability itself is a condition of possibilities not a stable, fixed and ordered state. Our dis/ability is constantly perFormed, disSolved and reProduced by diverse actors interacting in complex webs of relations. Networks temporarily stabilise. The labels help

create the impression that hidden, mental dis/abilities are objective, definite and permanent conditions (Goldschmied 2017).

An Actor-Network Theory appreciation of dis/ability and the act of disclosure as personal and connected rather than objective and distant

5 actions of ANT and the act of disclosure:

- 1. Disclosure is more than a say-out-loud ethical or political consideration*
- 2. Disclosure has the capacity to affect and be affected*
- 3. Disclosure should act so as to reframe change not bias*
- 4. Disclosure is action aiming to enable noticing*
- 5. Disclosure recognises its capacity to disrupt conventional research thinking*

When disclosure is not personal, it can appear straightforward and uncomplicated. Yet, the sterility of distance when researchers have attempted to remain objectively removed from their data collection has and is ironically distant itself for my Actor-Network Theory (ANT) approach. To date, in my research practice, I have had many disclosure experiences, some subtle and others more intentional and direct where I have just stated: "I am autistic", and more often than not it has had an observable effect. Sometimes the unpredictability of affects so often anticipated by traditional approaches, so as to encourage distance pushes its way into the frame as informants do any number of things such as terminate all contact, become embarrassed, attempt to hide their lack of faith in my abilities or their relief and admiration in what it is I am trying to do. Others start considering how often I have tantrums and meltdowns. Some ask questions, others don't say a word. They consider scenarios that might have never occurred to them otherwise. "Are you a vulnerable adult?", "Do you have the capacity to consent to sex?", "But you are not dribbling, how come?" just to offer a few. So, if disclosure has an affect of labelling, then with the label comes the support (Ventegodt 2005; Craddock et al. 2008; Reed 2010) but also the launch of a roller-coaster ride (Galasiński 2008; Livingston and Boyd 2010; Frigerio, Montali and Fine 2013). I attended a seminar about research methodology where the established researcher, a reader in health studies, quickly settled the concern of objectivity and reflexivity in research with a statement of "I always state at the beginning of my fieldwork that I'm a nurse so bias could not be a question in my project". I believe she is missing the point.

Disclosure framed as an ethical issue, bias or objectivity in terms of having a distance from your research and the participants might prevent us from exploring the associations it forms and as such study the notion of dis/ability itself. In other words, dis/ability and disclosure offer much more prospects than a one-off announcement at the beginning of research and a sentence or two long reflexive statement at the end of a written account. Examining dis/ability and the act of disclosure through ANT, a semiotic-material approach (e.g. concerned with signs), disclosure is not a question of bias or objectivity but an actor that

enters the research process with the capacity to affect and be affected. In ANT, an actor is always a network of elements, and a network is fully defined by its actors (Law 2004; Latour et al. 2012). In other words, everything is relational including the human actors, such as the researcher and the participants, as well as the non-human actors such as dis/ability and disclosure. There is no overall social, natural or conceptual framework within which dis/ability and the act of disclosure exist as nothing is arranged in advance. Dis/ability itself is an effect of temporally formed associations (Latour 2005). Dis/ability, as well as disclosure, has a “voice”. Disclosure is an actor with the potential to affect other actors and their actions in the associations they form. With the disclosure of a dis/ability researcher and participant, dis and ability, expert discourse and personal stories become entangled providing us with opportunities to reveal the processes that compose dis/ability and how according to Latour and Woolgar (1986) such composition should be ‘discussed, evaluated and negotiated’.

The task of the researcher is then to explore the actions, and their effects such as disclosure perform in the stories they encounter. Dis/ability can enter research through disclosure not as an essence but as an uncertain actor that has the capacity to affect, to change and make a difference. In other words, the act of disclosure shifts the focus from a static position to the processes by which the visibility of a dis/ability might be obtained. Disclosure is no longer a concern about objectivity and contamination but rather can make dis/ability observable, more dimensional, active amongst signs to reveal its connections and its role as a connector (Latour 2013; Bilodeau and Potvin 2016). Something hidden and obscure can become detectable and thus, enhance the interest in how dis/ability is composed and noticed. On the other hand, the danger of disclosure is of course that with visibility, perceived stability and predictability we are risking exchanging a movement for another movement. That is, the shifting nature of dis/ability with apparently fixed, independent and permanent attributes. Every time we disclose, we make some part of us visible but, we also hide, anchor and stabilise whilst subsequently destabilising and highlighting what Law and Urry (2004) suggest are opportunities to make visible different associations and effects in research leading to a particular way of composing knowledge and the concept of dis/ability.

Disclosure blurs the line between the personal and the professional roles

My personal experiences of disclosure showed me that the act of disclosure makes actors do surprising things: they oppose, they separate, they unify. Can we and should we utilise our personal experiences in research? Disclosure appears to blur the line between the personal and the professional roles as it provides a material, semiotic and discursive continuum between the various situations within which I perform. In other words, my researcher role as an ANT researcher is not to assume an *a priori* controlled, ordered and predictable dis/ability independent of us to be discovered by the act of disclosure. On the contrary, as we are learning, the researcher’s dis/ability and the act of disclosure does not shy away from the affects it has on other actors. When those affects produce an effect, a change that we can

notice and thus record we can treat it as potential data shaping our understanding of phenomena, and specifically the notion of dis/ability. The act of disclosure then becomes indispensable from other actors' performance of dis/ability in the various stages of research (Latour 1998; Galis 2011). So having discussed how disclosure is an integral move in engaging, sustaining and promoting data through the affective dynamics of disruption, inseparability and connectivity I will now introduce and discuss 10 potential theoretic of disclosure¹. They operate in specific ways leading to various effects and as such composition of dis/abilities.

10 potential affects of hidden, mental dis/abilities and the act of disclosure

Separation	<i>Disclosure may bring about the binary oppositions of disabled and non-disabled</i>	Simulation	<i>Disclosure can offer reference of one label to another constructing dis/abilities</i>
Apparent objectivity	<i>Disclosure can present dis/ability as an existing thing in its own right</i>	Uncertainty	<i>Disclosure of a dis/ability enters research as an additional unstable factor</i>
Fragmentation	<i>Disclosure may promote the individual labels offering an identity and a sense of self</i>	Composition	<i>Disclosure may reveal that dis/ability is not a given, it is assembled</i>
Enactment	<i>Disclosure does not only narrate dis/ability but also performs it</i>	Agency	<i>Both disclosure and dis/ability can be the effect of other actors' actions</i>
Multiplicity	<i>Disclosure can show how disability presents differently in various contexts</i>	Relationality	<i>Disclosure can make a dis/ability visible revealing its connections and its role as a connector</i>

1. Separation

You are dis/abled, I am not. Some people express relief when you disclose a dis/ability. You are different from me. Me and You, your 'disability' and my 'ability' are now in binary oppositions. Some people obtain self-confidence and power as an effect of disclosure. The structure of differences based on binary oppositions such as neurotypical and atypical is a powerful tool to achieve senses of control. Paradoxically, whilst these people separate your disability from their normality, they seem to be unable to distinguish your skills from your difficulties.

2. Apparent objectivity

People who have set assumptions and fixed ideas about dis/ability finally find a reason, a cause and perceived objectification of the existence of dis/abilities. It is often accompanied by effects of pity like "it must be terrible living with autism" as if dis/ability was a permanent

¹ The development of the 10 affects was inspired by the works of: Baudrillard J. (1993) *Symbolic exchange and death*. London: Sage, Latour B. (1993) *We Have Never Been Modern*. Harvard UP, Baudrillard J. (1994) *Simulacra and simulation*. Ann Arbor: University of Michigan Press, Latour B. (2005) *Reassembling the social: an introduction to actor-network-theory*. Oxford: Oxford University Press and Pawlett W. (2007) *Jean Baudrillard: against banality*. London: Routledge

and justified thing. Their reality has been confirmed by your disclosure. Your label helps build an external reality of dis/abilities. Disclosure, the voice of dis/ability makes it possible to describe and manipulate this reality that seems to exist in its own right.

3. Fragmentation

One of my participants with ADHD expressed she was not dis/abled as her peer from college who has autism needs more support. The proliferation of the labels with the corresponding disciplines, policies and organisations led to a fragmental world. Some people including both dis/abled and non-dis/abled persons will perform such effects as individual labels can offer them an identity at the expense of other labels. It follows, disclosing a dis/ability does not mean automatic access to and acceptance by other dis/abled people, their significant others and other participants.

4. Enactment

You disclose dis/ability to someone who does not want to know about your dis/ability. "Why did you have to tell me? Now I have to do something. I wish you had never told me." And they make you feel as you have just ruined their day. The effects of disclosure are never straightforward as disclosure does not only narrate dis/ability but also performs it. What happens next depends on the complex relations of all the actors that bring about different performances of dis/ability for each person in various context.

5. Multiplicity

Effects of disclosure like "you do not have it", "it may go away", "we are all on the spectrum" or "but you can maintain eye contact" can show that disability is not settled, a fact or a question of perspective but dis/ability itself is multiple. Dis/ability is not merely an 'ability' from one view and a 'disability' from another but, dis/ability is context dependent and performs differently in various settings. Disclosure might reveal that multiplicity is the attribute of dis/ability as well as the actors that compose them, not a question of interpretation.

6. Simulation

People with all sorts of labels and problems can be subject to simulation (a substitution of real for signs) which theoretically at least, has an effect of becoming your best friend and worst enemy, because in ANT research there is still a pressure to produce realistic aims and results, define theory and present pragmatic outcomes. This can be difficult when arguing for the importance of simulated experiences. So, it is important to note here as expressed by one of my participants that Asperger is neither a mental health condition nor autism or an intellectual disability in the real sense. Reference of one label to another can compose dis/abilities and accept them as factual. Stereotyped labels refer to other labels in the system, not to an external reality lapsing into simulation.

7. Uncertainty

People who struggle to manage your disclosure may not know what to say, or how to behave because they either have no experience or lack the skills to handle such acts, but in my experience, they tend to be genuinely concerned and worried that they might say something inappropriate. Research is uncertainty, awkward and therefore rich for disruption. Dis/ability and the act of disclosure bring these additional uncertain factors to the process, whilst also offering opportunities for collaboration and negotiation to compose together the notion of dis/ability as well as the research even if both remain temporary and unstable.

8. Composition

Some people openly acknowledge that the label is just one of your attributes and as an effect aim to learn who you are, what you do and not what the label represents. Whilst in many cases it is possible to reach this seemingly ideal state with your participants, it is rare that the act of disclosure will take you here instantly in research. It is these effects though that reinforce, dis/ability is not a given, a permanent impairment but an assemblage. It has to be performed and noticed each and every time.

9. Agency

Dis/ability is constantly formed and performed; solved and dissolved; produced and reproduced by the complex associations of actors. We, dis/abled researchers are not the only one with an agency. Other actors performing in the research can have agency. They also have the capacity to affect, to mediate, and to change. Disclosure and the making of your invisible dis/ability visible can be the effect of other actors' actions. Our behaviour, an unintentional comment, or our relationship with objects can lead to the noticing of dis/ability without your act of disclosure.

10. Relationality

Human actors in research such as researchers and participants are connected through other actors like objects, ideas and experiences. Some of my participants knew I was dis/abled. I know they knew it without ever disclosing it or saying the word autistic. One of my participants had a diagnosis, but he rejected it. In these cases, there is no disclosure open or otherwise in the traditional sense but rather, it performs through its relations to other actors. Non-disclosure can affect the research and compose dis/ability the same way as an open disclosure leaves it untouched.

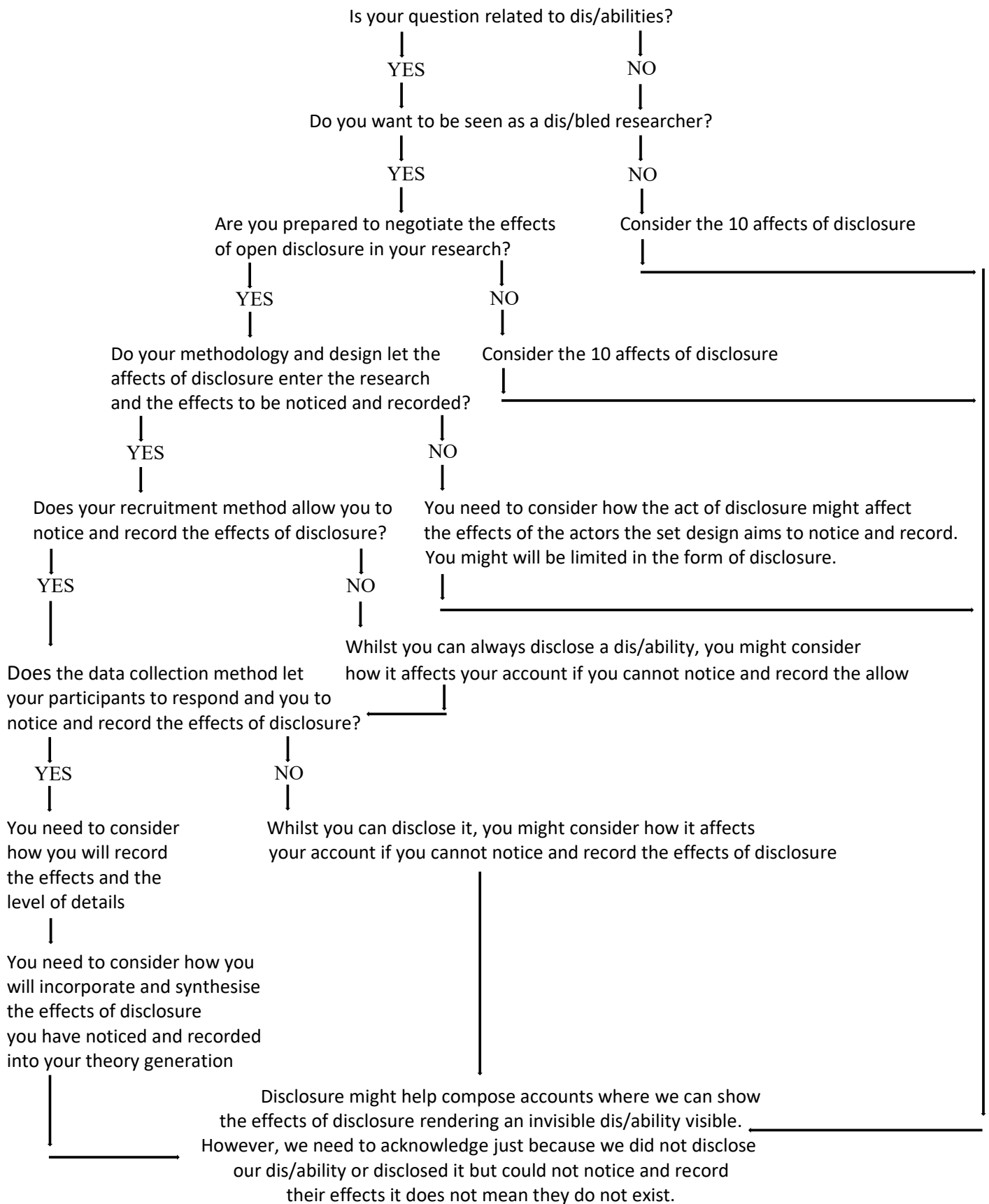
Research as an association of actors, noticing and the act of disclosure at the various stages

The 10 potential affects show us that disclosure promotes an approach to research which has the capacity to generate unexpected effects. It is an uncertain event with the potential to generate controversies about what we mean by a dis/ability. Following on Latour's account (2005 p39) the uncertainty of disclosure is the property of the actors. Disclosure has the

capacity to either transform my label, in other words, modify and change the understanding of dis/ability or merely transport it, that is to say, mirror what I have expected to see without observable effects. The affects of disclosure can only be noticed and thus recorded if it is performed, makes a difference, produces change leaving a visible effect behind. Our concern is to notice those effects and the associations they form at the various stages of research. Noticing is the key activity researchers do. As it is then when a dis/ability and the act of disclosure can become data and an integral part of research (Latour 1996). We should appreciate this as now we do not have to choose between objectivity and subjectivity, between fact and myth any longer. On the contrary, we can show how disclosure has performed on our research, how my dis/ability has affected and was affected by other actors leading to alternative understandings of how the enactment of different worlds lead to particular outcomes (Latour 2004; Law and Mol 2011; Holyoake 2013). It reminds us that nothing is permanent and fixed, that both research as a process and dis/ability as a concept is a temporary state and always context dependent.

In my personal life, I could experiment with disclosure, taking small risks, reflecting on the effects and learning from the experience. In research, we do not necessarily have this freedom. You do not meet with your participants again if you meet at all, build close relationships with them or can flexibly change your approach if it did not go so well. Most of the time we do not have a second opportunity. In sum, we have no overall control over how our dis/ability and disclosure might affect others and the research project. I disclose my diagnosis of Autism throughout the research at various stages, however, the mode and time of disclosure depend on various factors. We, researchers, can make certain decisions about disclosure considering the particular association of actors our methodology advances. On the one hand, a dis/ability and disclosure always have the potential to influence research, and as such the knowledge we bring to light. On the other hand, every methodology, design and method represent a more or less set arrangement of actors and potential relations (Fox and Alldred 2015). In the next section, I will offer some pragmatic considerations how disclosure then might impact in the various stages of research (see also Figure 1).

Figure 1. Research as an association of actors and the act of disclosure at the various stages



The research question, aim and design

The 5 ANT contributions are:

1. *Control is also an affect with a capacity to be disrupted*
2. *Researching the social is always contextual and involves disclosure*
3. *Disclosure is a composition made up of capacity and noticed arrangement*
4. *Disclosure enables flexibility through modes of relationality*
5. *The flow of disclosure is rarely linear (consider your aims and design as ongoing)*

Every research project is a particular arrangement of specific approaches and tools for the exploration of events. It will establish set ways to select, order and notice particular actors, their relations and the effects they perform. The modes of selecting and ordering specify conditions of possibility for noticing, making some associations easier and others difficult or impossible, more or less stable and durable. It is the configuration of the actor-networks of the particular methodology that produces relative stability, durability and a particular outcome (Law 2007). Considering disclosure than in such activities as selecting, ordering and noticing becomes our main concern as once we make certain decisions we set limits to the conditions of possibility of disclosure and the effects we can notice (ibid. 2007). When we establish our research question, the design and the underlying assumptions we need to explore how they intend to manage the various actors, their capacity to affect and be affected and the kind of knowledge it aims to create. Every methodology focuses on aspects of events whilst sacrifices something else in order to reduce complexity into a workable knowledge of phenomena.

In a randomised control trial or pre-test-post-test design, for example, it is a key consideration to keep actors under as much control as possible throughout the research. It follows, we need to consider how the 10 potential affects of disclosure might interact with the set limiters if we disclose our disability to the control group only or after the pre-test but before the post-test. In other words, designs are very specific about the expected *relationality* of the actors and the effects they wish to observe. On the other hand, in ethnography that aims to explore phenomena in the naturalistic environment, disclosure can be an additional *uncertainty* to the recording of events as they happen giving more flexibility to the researcher. In between one of the most limited RCT and one of the less rigid ethnography we find other designs with varying degree and number of limiters. Some questionnaires that only allow set responses have already filtered the events they aim to explore and thus the effects we can record so once again we might have limited opportunities to notice any effects of disclosure. Phenomenology, on the other hand, might provide disclosure with more opportunities to act and the researcher to observe the actions.

We are not concerned by designs *per se* but focusing on the understanding of its limiters, the room they allow for the actors to affect and the researcher to notice those effects. In other

words, most of the time we can disclose a dis/ability being it ethical, moral or political importance for us. This could add to our understanding of the *enactment* of dis/ability but only if we can notice and thus record the effects. In ANT, if no observable mark is left behind, no visible thus recordable effects have been produced, disclosure offers no information for the researcher thus we cannot explore its potential role in our research (Latour 2005 p53). Moreover, the flow of affects is not entirely flexible, linear and logical either even if the design permits variations of disclosure. Firstly, once we start the selecting and ordering, disclosure also begins to stabilise effecting the future decisions and performances of research. Secondly, although designs aim for control, disclosure can have agency. Disclosure can happen as a result of other actors' action. I had participants who had known I was autistic before I could consider disclosing it. Then it became more complex when I attended an event to observe and someone there disclosed my autism to the rest of the group. Such actions might enhance our noticing of events and the various ways people negotiate, compose and influence their world.

In summary, at the early stage of research, our initial strategy of dis/ability and the 10 potential affects of disclosure needs to be considered with the design overall strategy. Credibility, validity and objectivity are then the results of revealing how we attempted to select and order the actors and how we could notice or not the effects of the act disclosure.

Collaboration, sampling, data collection and data analysis

The 5 ANT contributions are:

- 1. Disclosure promotes collaboration and alliance*
- 2. Disclosure means creative methods for contact, engagement and learning*
- 3. Disclosure offers opportunities to notice and record effects*
- 4. Disclosure allows responses to reveal values, ideologies, practices*
- 5. Disclosure can make visible the connections*

Once we have unpacked our particular design, we need to consider how dis/ability and the act of disclosure might enact in the stages of recruitment, data collection and analysis. As with designs, the various sampling techniques will have set limiters for exclusion, and inclusion and disclosure should be considered with their specific approach (Fox and Alldred 2017). Then, we need to think about our communication method with the gatekeepers and potential participants. Are you going to meet with them or send a letter? What is your relationship with them? The question is for ANT what opportunities your sampling strategy, recruitment, and data collection method offer for noticing. The decision of disclosure should not be governed by the notion that it will create order, simplify complexity or end controversies. The 10 potential affects remind us that it is unlikely disclosure will deliver such aspirations. On the contrary, disclosure can add a new, dynamic and uncertain actor to all the other actors in the process revealing the multiplicity of dis/ability (Latour 2005 p30,45.). When our sampling,

recruitment and data collection method allow the effects of disclosure to be noticed, it reveals values, ideologies, and performances of dis/abilities and dis/abled researchers. From all the stages of research, it is data collection that can show best the *multiplicity* of disability, how it is composed differently in various context when we have direct interaction with our participants.

We might consider how likely it is that your participants will meet and talk to each other, how many times they will meet with you, or whether they can have any information about your dis/ability. What can make a difference between accounts at this stage is the level of details and analysis we intend to explore. Actors are constantly positioning themselves, establishing their relations to others and things, form and reject connections. How much we wish to explore about the effects of disclosure and all the actors' action in a given situation: legislation, personal experiences, cultural expectations, or a movie our participant watched the day before. Disclosure of a dis/ability to participants encourages the researcher to observe the effects, how they compose and make visible the connections and disclosure as a connector. On one occasion we were talking about the age of diagnosis. One of my participants in the group had a late diagnosis like me, and he was also generally older than others closer to my age. I disclosed my diagnosis linked to the topic. He changed. There were observable effects. He did not engage with me for the rest of the day. It took me a few occasions to interact with him again. Fragmentation as proposed affects of my disclosure, as our similarity has at least two dimensions as alluded to by Pawlett (2013 p132) which was not only an advantage but dangerous. Whilst others in the group have continued to talk about the diagnosis as the most natural thing. Ask yourself: will your data collection method permit such noticing?

The 10 potential affects of disclosure showed us that the researcher is not the only actor with potential agency in research as dis/ability performs in relation to others and things. For example, when I was interviewing talking about ideal employment, I spontaneously responded: "yes, being a lecturer is good for autistic people, too, when I mark and research I don't have to interact with others". Her laughing and the comments followed made it noticeable that my response transformed the situation. When you do research with people who are either autistic themselves, have some other hidden, mental dis/abilities, care for or work with them, you have to be ready they have the skills and experience to detect the smallest signs of differences without such obvious comments. This is often confirmed immediately or later on. Participants either ask you, "are you autistic"? or when you disclose it they will respond, "yes, I know it from the moment we met".

In summary, controversies arise as a result of disclosure as the examples illustrate and drawing on such tensions are essential if we to better understand dis/ability and how many ways it can be composed. It opens up opportunities to collaborate and learn from each other. It reminds us of the uncertain and temperamental nature of research.

Theory and discussion generation

The 5 ANT contributions are:

- 1. Disclosure provides opportunities to explore the participants' world-making activities*
- 2. Shared experiences can help notice what might otherwise go unnoticed*
- 3. Disclosure supports reflexive accounts*
- 4. The uncertainty of disclosure offers diverse translations of experiences*
- 5. The more performances, the more visible it becomes how dis/ability is composed*

In the previous paragraphs, we have considered whether we will introduce ourselves as an autistic researcher or a researcher? Does the topic have a direct reference to dis/ability? We have explored how the designs might affect whether we can notice the effects of disclosure through set arrangements only or somewhat flexibly (see also Figure 2). We have discussed, a one-off purposeful disclosure built into the design might appear as an act of keeping the research assemblage under our control to achieve neutrality and objectivity. The 10 affects showed us, it probably will not and should not deliver such aspirations. Instead, we should embrace the uncertainty and potential mediating effect of disclosure in research, thus appreciating the opportunities to compose different translation of experiences in our theory generation. One way to synthesise our dis/ability and the act of disclosure into our research is to follow the actions of the actors and notice when and how they mediate if they do at all. This way we can analyse more openly what might have influenced and composed our findings. Research seen as a habitual, normative, and a set way of doing things might not allow such discussions. And this is the mistaken view our researcher has taken at the beginning of the chapter; that reflexivity and in this case, disclosure is an unconnected, independent event that can somehow be resolved not for a moment but all along the research process.

Disclosure is a continuously unfolding story rather than a one-off announcement. All researchers regardless of the presence or absence of dis/ability will select, order and notice specific actions whilst let slip others. The question for ANT is not which account reflects the notion of dis/ability best. Different approaches allow us to explore the various enactments of dis/abilities that might overlap at certain parts and will be different at others. And then we can ask the question how we negotiate the diverse outcomes? To negotiate, I argue the more performances we explore, the more visible it becomes how dis/ability has been composed, the better the chance we have to find temporally closure and solution (Latour and Weibel 2002). This can be particularly significant in dis/ability studies where the shared experiences can help notice what might otherwise go unnoticed. However, instead of looking at dis/abled researchers and disclosure as distinctive actors from all the other personal attributes researchers possess that in fact may accentuate stigma (McClimens 2003; Gernsbacher 2017) we can use the opportunities to reveal different accounts.

Equality, inclusivity, social justice to mention a few aims disabled as well as non-dis/abled people wish for is not a pre-existing state we can simply demand. We, researchers and participants, with and without a dis/ability have to compose it together. Reflexivity then means our participants are allowed to express their world making activities (Serres and Latour 1995 p173). Research in most textbooks demands for rigour, control, and predictability just to mention a few key attributes. Paradoxically, giving a voice to dis/ability, disclosure, an unstable and dubious actor will make the network, and as such the research process not only more transparent and reflexive but better managed and inclusive. Partnership now is not just a symbolic act expected in contemporary research but becomes an active, dynamic and expressive association. Disclosure is a way of connecting as there is always something between a researcher and a participant. When we apply Actor-Network Theory in the spirit of Law (1999) and Latour (1999) we recognise that in the act of disclosure, 'dis' and 'ability', expert discourse and personal experience become entangled to potentially increase our understanding of phenomena to be discussed, evaluated and negotiated.

We aim to compose accounts where the effects of hidden, mental dis/abilities and disclosure are visible. However, we need to acknowledge just because we did not disclose our dis/ability or disclosed it but could not notice and record their effects it does not mean they do not exist. Eventually, we need to reduce both complexity and uncertainty if we aim to compose pragmatic messages but doing it at a too early stage of research might miss opportunities to more subtle explorations.

Figure 2: 10 questions to notice the potential effects of the act of disclosure in research

1. List the ways disclosure noticeably impacts upon your methodology and design.
2. How open are you about your dis/ability and what effects are you prepared to negotiate? Disclosure or non-disclosure?
3. What kind of limiters are built in the sampling for disclosure to affect and the noticing of such effects?
4. How does the recruitment and data collection method allow your participants to respond? Can you notice, observe and discuss the effects of disclosure?
5. How often will you meet with your participants? Do you have more opportunities for disclosure and/or to follow the effects? Will your participant meet?
6. How does the data analysis method allow for the effects of disclosure to be entered, coded and analysed as data?
7. How do you intend to notice and record the effects of disclosure and how much details are you prepared to record?
8. How will the noticing, recording and analysing of effects of disclosure contribute to your topic and contribution?
9. How will the effects of disclosure be synthesised and transformed in your discussion?
10. How might the effects of disclosure affect your audience, discipline and the sharing of knowledge? Can you and will you notice and record the effects?

Summary

In summary, disclosure of a dis/ability offers potential to enrich our research culture and enhance collaboration. First, disclosure might compose entangled accounts and help reveal and notice actions and their effects that a non-disabled researcher might not envisage. Second, disclosure does not act alone. Disclosure adds to the complexity of living with a dis/ability as it interacts with other actors providing us with opportunities for more profound understanding of accounts. Third, not giving voice to our dis/ability does not automatically lead to non-effect. Other actors can make our dis/ability enact and perform without our disclosure. Fourth, being a dis/abled researcher and disclosing a dis/ability to dis/abled and non-disabled participants will not result in a more faithful reflection of reality. It does, however, compose a different account to advance our understanding of phenomena, values and expectations. Fifth, disclosure and the enactment of dis/ability connects the researcher contextually to the participants as well as other actors. Research itself should arise from these enacted practices of fieldwork.

Conclusion

As opposed to conventional views, dis/ability is not a fixed condition, and disclosure is not a single act of achieving neutrality. Dis/ability affects, and the effects of disclosure are not a concern of perspective; it is dis/ability that multiple and will enact and perform differently in various context. Disclosure impacts on other actions. It might evoke unity or resistance, rejection or support; it affects other enacted actors. Disclosure becomes indispensable from other actors in the performance of dis/ability in research. Researchers regardless of their chosen design and methodology should consider the potential affects of their dis/ability and other identity signifiers be it ethnicity, gender or accent as these all have the capacity to affect and be affected. An invisible dis/ability can be given a voice through disclosure making it visible thus detectable offering opportunities to negotiate our values, ideals and expectations of dis/abilities. My research as a dis/abled person no more or less objective, no more or less justified to make a dis/abled world visible. It is a different way of composing our concerns. The more accounts we reveal, by disabled and non-disabled researchers about dis/ability the better position we might be in to discuss the complex and ethically charged question of what sort of society we live in.

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