

The remarkable everyday lives of people with hidden dis/ability: a material-semiotic analysis

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ABSTRACT

My research concentrates on conditions including autism, intellectual disability and mental health. I explore the ways they are used to establish the divisions required by diagnostic criteria in the separated health and social approaches to care. Defining conditions rather than performances has resulted in a neglect of the consideration of connectivity.

My project employs Actor-Network-Theory, and Latour's and Baudrillard's philosophy, to reconsider the specific metaphysical and ontological issues of how, when and why we judge hidden dis/ability as a universal and essential thing, rather than one constantly formed and performed (perFormed), solved and dissolved (disSolved), produced and reproduced (reProduced) by diverse human and non-human actors in complex webs of connections. I composed the 6D material-semiotic network practice to offer a new ontological 'seeing' of how the associations and significations of hidden dis/ability are produced, represented and thus consumed.

I found that exploring the everyday performances of hidden dis/ability with the 6D material-semiotic network practice might not verify the apparently universal, fragmented and permanent notions that the distinct categories imply. I conclude that hidden dis/ability can be considered as in a constant state of transformation which, when people are left to their own devices, composes capacities for shared cultural experiences and practices dismantling long-held ideas, and will be one of the benefits giving opportunities to rethink how we provide apposite care, services and inclusion for the conditions.

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LIST OF ABBREVIATIONS

ADHD – Attention Deficit Hyperactivity Disorder
ANT – Actor-Network-Theory
APA – American Psychological Association
ASD – Autism Spectrum Disorder
BILD – British Institute of Learning Disabilities
BPD – Borderline Personality Disorder
BPS – British Psychological Society
BSA – British Sociological Association
CCG – Clinical Commissioning Group
CQC – Care Quality Commission
DIG – Disablement Income Group
DSM – Diagnostic and Statistical Manual
HCPC – Health and Care Professions Council
HMSO – Her Majesty's Stationery Office
ICD – International Classification of Mental and Behavioural Disorders
ICF – International Classification of Functioning, Disability and Health
ICIDH – International Classification of Impairments, Disability and Health
NGO – Non-Governmental Organisation
NHS – National Health Service
NMC – Nursing and Midwifery Council
OCD – Obsessive-Compulsive Disorder
SCIE – Social Care Institute for Excellence
SRV – Social Role Valorisation
STS – Science and Technology Studies
UPIAS – Union of the Physically Impaired Against Segregation
WHO – World Health Organisation

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CHAPTER 1

Hidden dis/ability in everyday performances

1.1. The terrain of hidden dis/ability

This thesis uses case studies of people living with hidden mental and cognitive dis/ability to contribute to a vibrant theoretical debate. Specifically, my contention is that hidden dis/ability is not a stable, fixed and ordered reality, but one constantly formed and performed (perFormed), solved and dissolved (disSolved), produced and reproduced (reProduced) by diverse human and non-human actors in complex webs of associations. One connecting and temporarily stabilising apparently 'universal' and 'essential' categories of the conditions to create the impression that hidden dis/ability is a definite and a permanent state.

This study challenges conventional health and social care approaches to everyday performances of hidden mental and cognitive dis/ability. In particular, the ideas of nature-culture, medical-social, able-disable binaries and the apparently universal differences between various performances, that are deployed to strengthen the notion that the terrain of the hidden is justified, objective and an essential thing. That is to say, I reconsider hidden disability in everyday life as performances, relational possibilities composing capacities for transformations rather than set arrangements that need to be ordered, controlled and predicted.

Therefore, unlike much earlier work in hidden dis/ability research, this thesis explores how we could turn our attention towards complexity and connectivity in the temporary composition of hidden dis/ability by the application of Baudrillard's and Latour's philosophy,

and in particular Actor-Network-Theory. I aim to bring to the forefront the complex everyday performances of hidden dis/ability where many actors, humans, non-humans, objects and dialogues, are in continuous connections with one another. Where a 'dis' and an 'ability' are not in a binary opposition but are seen as an effect of connectivity awaiting the next transformation like in this scenario.

Once we all settled, Jane made a cup of tea for her friends, a coffee for me and offered us biscuits to feel welcomed. The group of friends soon started having discussions about the art of everyday living. Jane shared her experiences of supporting another common friend earlier that morning, Mick. She detailed how much money Mick spent and that he really should know better. "Silly Mick" added Eric worrying about Mick's not so good money management practices. One topic after another, then Eric started telling his story of moving around the West Midlands in the past 30 years or so and how many places he had lived. Nick dropped a comment this time, "Eric is like a gipsy, he travels around", which made the group laugh out loud. One joke followed the other, Jane ended up tickling Nick to the point that he could hardly hold it together, whilst Barbara slowly started to snooze out on the sofa until Eric grabbed an Ipad and started teaching Barbara how to play a game. Two hours or so passed by gossiping, laughing and storying in the company of hot drinks and biscuits that positioned the actors somewhat differently from the universal narrative of the hidden disability, the diagnosis that all of them had.

Many contemporary theorists and methodologies, especially post-structural and post-modern movements, have attempted to move away from the binary of normal and abnormal, 'disabled' and 'abled', nature and culture and questioned the role of these categories. I argue, in the case of hidden mental and cognitive dis/ability, those oppositions remain mostly ill-suited in understanding and working with everyday performances in the time spent

together by Jane and her friends: the ordinary, the mundane and the specific. Such descriptions reveal that the assembled actors and their connections that compose the everyday performances of hidden dis/ability are crucial to our understanding, rather than the apparently distinct and permanent categories embedded in a universal narrative.

The theories of Baudrillard and Latour, including the tenets of Actor-Network-Theory, are radically different from the mainstream health and social care practices of hidden dis/ability. Baudrillard and Latour are not dis/ability scholars as such and are marginal in many ways. Baudrillard wrote extensively about modern society, culture and media, whilst Latour explored sciences and technology. They are often considered as two conflicting figures. However, I argue that they express analogous conceptualisation in their arguments. Baudrillard, a cultural-semiotic thinker, and Latour, a material-semiotic scholar, both argue in their work, albeit differently, that preceding theories of totality are no longer plausible as nothing can be said to exist in isolation but always in relation to multiple others and things.

Baudrillard's cultural-semiotic approach of mirroring, proliferation, simulation and Latour's material-semiotic empiricism on separation, purification and proliferation are the main concepts I reframe to reconsider the everyday performances of hidden dis/ability, and to offer a novel approach outside the conventional health and social domain not yet available to practitioners. Thus, this thesis explores what alternatives might be possible in working with hidden dis/ability in everyday performances other than applying ready-made frameworks, one-sided concepts, predefined tests and rigid interventions mostly based on the categories (so fundamental to the field) once we shift our focus towards the complex connections of actors composing various performances and realities of hidden dis/ability.

1.2. What is hidden dis/ability?

It seems the lack of agreed terminology is well known in disability research (McBrien 2003; United Nations 2005; Bradley 2009; Shakespeare 2014). Therefore, it remains important to explain the approach I have taken. I have assembled six significant matters linked to my later theorising before deciding on the terminology.

To *begin*, the notion of visibility and materiality has a central role in the life of people living with mental and cognitive conditions. First, the difficulties are often not apparent to the observers and second, these conditions cannot be readily described by an underlying physical anomaly or represented by materials. Brown and Broadman (2011) argue that the visible presence of a wheelchair or an assistance dog are generally accepted signs of a dis/ability and as such, provide grounds for negotiating barriers. The performance of a dis/ability *per se* is rarely in question when such visibility and materiality 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 uncertainty reigns: everything is permitted as anything can be demonstrated (Baudrillard 1993 p19; Baudrillard 1994 p6; Baudrillard 2005a p67; Latour 1993 p37; Latour 2005a p163; Latour 2011 p475).

Second, the preferred term of the two official manuals the ICD (International Classification of Diseases) (World Health Organisation (WHO) 2015) and the DSM (Diagnostic and Statistical Manual) (American Psychological Association (APA) 2013), and legislation such as the Mental Health Act 1983 (Department of Health 1983) is 'disorder'. However, the word disorder tends to denote mental health problems only. Specifically, the Mental Health Act 1983 defines it as "any disability of the mind", but "a person with a learning disability shall not be considered by reason of that disability" unless "associated with abnormally aggressive or seriously irresponsible conduct on his part" (Department of Health 1983

s1.2,1.2A). Disability is the terminology used by the Equality Act 2010 (Government Equalities Office 2010 s6.1) for a person who has a physical or mental impairment that impacts on a person's ability to carry out normal day-to-day activities.

Third, research and practice to date have primarily focused on individual conditions, as defined by the medical practices and the above-mentioned manuals, rather than the shared experiences and practices of hidden dis/ability. One major drawback is that these conditions remain separated not only in the classifications and related professional practices, but in everyday performances that might adversely affect people living with hidden dis/ability. Besides, if we focus only on the medical categories permitting the existence of set differences, rather than the multiple realities of people connecting with and within performances, then how can we decide which conditions need more attention and in what circumstances we feel safe? I argue, it is important to conduct research that includes people with various conditions to attempt to move away from the somewhat limiting specific diagnosis.

Fourth, the conceptualisation of hidden dis/ability has been the space of an ongoing debate for many years. For example, Grönvik (2009) proposed that instead of having one definition, we might work with various concepts at different levels 1) to enable research and services - the functional aspect of definitions, 2) to create policies and legislation - the administrative aspect of terminologies and 3) the subjective and theoretical definitions that involve the people with a dis/ability as well as thinkers' contemplations of dis/ability. Likewise, Alman (2001) and Ellis (2013) agree that there is no single or correct way to think about dis/ability. It is validated and defined by various professions, social strata and citizens, at least partly, in their values, expertise, experiences, and insight into the condition and the services they provide.

Fifth, the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006) made an important contribution to the core concepts of disability rights by embodying universal aspirations for equal participation, justice and individual ambitions. It moves away from a vulnerability perspective to a rights-based approach grouped around 13 core concepts including non-discrimination, individualised services, autonomy and privacy (Bartlett 2012; Mannan *et al.* 2012; Sherlaw and Hudebine 2014). Disability is conceptualised within the Convention preamble as resulting from the interaction between persons with impairments and attitudinal and environmental barriers recognising the complex nature of disability in line with the International Classification of Functioning, Disability and Health (ICF) (WHO 2001, 2002).

Sixth, participatory research with disabled people is needed to explore and recognise not only the complexity of dis/ability but the various stakeholders who have a key role in community participation. This aspiration has not been fully realised yet as research, especially with people with hidden mental and cognitive dis/ability and people who lack capacity, remains a highly problematic field with increasing emphasis on ethical issues (Parker *et al.* 2010; Carlson 2013; Thomson *et al.* 2014; Northway *et al.* 2015) reinforcing the tendency to exclude people with hidden dis/ability and particularly people who lack capacity (Dixon-Woods and Angell 2009; Shepherd 2016) and foster a culture of protection and paternalism on behalf of the gatekeepers (Jepson 2015; Hamilton *et al.* 2017). Oliver and Barnes (2006 p1) point out that “legal rights do not mean that they will be enforced”, whilst Mladenov argued (2012 p71) the active involvement of disabled collectives could bridge the gap between abstract rights and actual inequalities experienced by disabled people. What studies like McClimens (2007), Kittelsaa (2013) and Kenny and colleagues (2016) emphasise is that most disabled people probably would prefer to leave behind such differentiation altogether.

Following extensive research on the topic summarised through the previous six points, I decided that the terminology hidden mental and cognitive dis/ability, or in short, hidden dis/ability, could serve best the purposes of the present study, and also denote the participants.

1.2.1. Deciding on terminology

First, the word *hidden* will be used to stress how cognitive and mental health conditions, while not apparent to observers, challenge both the medical and social constructions of dis/ability and influence the person as well as other actors in the everyday performances of hidden dis/ability (Fitzgerald and Paterson 1995; Fitzgerald 2000; Valeras 2010). My major concern is that it remains challenging to render the invisible visible to understand and represent people's needs and interests who live with such conditions to raise awareness and to develop a culture of understanding and active support as defined by Davis (2005), Home (2008), Roud (2013) and Williams and colleagues (2015).

Second, the term *cognitive and mental* refer to the broad conditions of behavioural and mental disorders such as neurodevelopmental conditions (Autism Spectrum Disorder, Intellectual Disability, ADHD), neurocognitive conditions (Alzheimer's, Dementia) and mental health conditions (Schizophrenia, Depression, Mood, Anxiety and Obsessive-Compulsive Disorders) as classified by the DSM-5 (APA 2013) and the ICD-10 (WHO 2015). Depression might be different from Intellectual Disability, Schizophrenia or Autism in the diagnostic manuals. However, my practice and knowledge of the field suggest that people who live with various mental and cognitive conditions also share many experiences. One of those is the hidden and often misunderstood aspect of their complex performances.

Third, the term *dis/ability* signals the notion of 'ability' and 'disability' as a binary concept that is potentially an outmoded and a mistaken view of human differences and their complex performances (Latour 1993 p32; Baudrillard 1994 p133). The slash also aims to reflect my hesitancy. How can I decide between 'ability' and 'disability'? How do I manoeuvre between 'ability' and 'disability'? And what connects 'dis' and 'ability'? How and in what situation?

1.2.2. A brief discussion of the language used

The literature suggests that there is an on-going debate not only about the 'correct' definition and terminology of hidden dis/ability but 'respectful' language too (Maio 2001; Moir and Alexander 2008; McDermott and Turk 2014): in short, what we can and cannot use when we address dis/abled people or people with dis/abilities. One of the most striking examples in disability studies are the 'rules' of using the words impairment and disability. According to Barnes (1991 p2) "impairment is a physical, mental or sensory functional limitation within the individual. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers". In support, it is later argued by Lennard (2013), Samaha (2007) and Hughes (2010) that an impairment expresses an inner medical condition, whilst disability expresses the outer social barriers of the impairments reinstating the Cartesian dualism as noted by Jones (2002) and Anastasiou and Kauffman (2013). Such is the troublesome nature of not being able to see metaphysical souls.

Studies by Swain (2004), Barnes and Mercer (2005) and Oliver (2013) emphasise how dis/abled people think in this way. The argument extends well beyond the words impairment and disability to the use of 'non-disabled' instead of 'able-bodied', 'have impairments' instead of 'with disabilities', whilst others suggest using 'with a disability' instead of 'the disabled', 'live with' instead of 'suffer from', and this prescriptive list is growing (Miller *et al.*

2004; Department of Communities 2010; BPS 2015; Department for Work and Pensions 2018). Binary oppositions are made between body and persons, and between persons and environment (Owens and Cassell 2010 p205); all entities may experience impairments of function, but only persons can make sense of such consequences of impairments.

Bickford (2004), Pate and others (2014) and Bedell and colleagues (2018) claim 'people-first language' can fight negative stereotypes because they emphasise the person and not the dis/ability itself. Others like Lynch and colleagues (1994), Linton (2013) and Peers and colleagues (2014) ask what if someone prefers disability-first language and alternative terminologies. Such a question is not out of place, but highlights how networks, connections and dynamics contribute to signs, symbols and signals. I wonder how it is different from terminologies referring to being gay, Jewish or gifted. As it would be odd to say I am a person with, or I have, or I live with gayness, Jewishness or giftedness. So even though I am sympathetic to these notions of equality, I am equally drawn to Gernsbacher (2017) who noted that person-first language is mostly used to describe dis/abled people in scholarly articles as opposed to consequently using it for all people and their various attributes and that, in fact, this may accentuate stigma. As my data and subsequent analysis explore, many of my respondents did not seem to care for such political correctness.

Autism, for example, is a noun naming dis/abilities and a short-cut for complex lists of things representing a set of distinctions. Such debates regarding normalising tendencies may appear to be medically speaking 'common sense', but for my study remain an entirely symbolic act as discussed by Jette (2006), Croucher (2017) and Crocker and Smith (2019). These authors argue that expressions of equality and pragmatic sentiment will not solve the many issues facing dis/ability studies because language does not mirror the world or passively reflect an objective reality (Halliday 2003; McClimens 2007). Likewise, others reject such views altogether, including person-first language, as autism and hidden

dis/ability form an integral part of people's identities (Silberman and Sacks 2015; Hennessey 2017). Identifying people with autism as different is not the experience Kenny and others observed. People with autism expressed that "autism is not a disability, disorder or syndrome, more a different way of perceiving the world" (2016 p448).

Having noted these equality issues, my professional practice has shown that the language of dis/ability is a primary actor in the network of disability studies. It is even more complicated in everyday performances and narratives. These days, the preferred terminology in official documents is 'service user' (SCIE 2004; Beresford 2005; McLaughlin 2009). However, I have worked with these 'so-called' service users (who had a diagnosis of intellectual disability, mental health or autism) and they hated the phrase service users. They said, "we all use services". They adopted the word 'client'. For another group I was involved with, the preferred term, when they were unwell, was 'patient', a term that many dis/ability professionals, including most of my colleagues, reject. They added also that they were not 'our' clients, in need of our generous assistance. They called themselves 'partners' or 'members'. Whilst some said 'autistic' or 'aspie' and, as noted by Kenny and colleagues (2016), a terminology preferred by the majority of autistic people as opposed to professionals who endorse the term person with autism.

These issues of language and representation point up a key theoretical concern of my work. The problem with such modernist and essentialist views, grounded in binary oppositions, is that bodies, persons and societies are easily perceived as existing separately, as reflected in mainstream medical and social approaches. Context and, as shown in my later analysis, issues such as details, dynamics and dimensions are easily disregarded when considering how people (be they service users, clients, patients or members) perform these composed roles of hidden dis/ability in everyday practices. Such distinctions might acknowledge that a person and a dis/ability exist in relation to others and things, but the natural and the

cultural composing them remain separated (Latour 1993 p41, 2007 p17). In a Baudrillardian (1994 p13) analogy, such debates are used to demonstrate our care and justice for people with hidden dis/ability and to hide the complexities and subtleties of everyday performances. Impairment and disability, 'ability' and 'disability' reinforce the notion of a binary concept (Rogers and Swadener 2001 p4) and maintain the realities of an objective and permanent hidden dis/ability (Baudrillard 1994 p13).

In summary, both the definition and language of dis/ability is an unavoidable actor in my work, but one with which I remain sceptical and at arm's-length. My work is up-close, and the arguments mentioned above demonstrate that, whether I wish to join such debates or not, I am affected to do so in clarifying my position. Latour (1993, 1994, 2005a) aims to overcome such issues of language by writing accounts that place the actions within a particular actor-network without referring to an *a priori* distinction between nature, culture and discourse. My aim is then to describe events using words which, as much as possible, do not imply a specific field but complex performances.

1.3. Research area and the focus of inquiry

My research started with an interest in providing people with hidden dis/ability with apposite care, services and inclusion. My professional practice experience in hidden dis/abilities amounts to a dual qualification as a learning disability nurse and social worker about which I have written (Goldschmied Z 2014; Goldschmied Z and McClimens 2015). During the course of my work, I have eventually come to selecting three concerns contributing to the predicaments present in the everyday performances of hidden dis/ability resulting in the research proposal of this study. The following 3 theoretical schema continued to inform and guide my study:

1. Apparent binary oppositions provide a means to explore both theory and practice concerning hidden dis/ability, in particular:

- Nature/culture, normal/abnormal, medical/social model of dis/ability
- Health/social professionals, NHS/Local Authority, Expert/Service user

2. Apparent separated practices are actors in the everyday performances of hidden dis/ability, including:

- Separated conditions and disciplines
- Distinctive training, policies and practices for the many conditions

3. Apparent fragmentation helps with the exploration of connecting conditions in the everyday performance of hidden dis/ability, including:

- Shared experiences and complex performances are often overlooked
- Condition-specific groups and services

1.3.1. The central argument and approach of the thesis

The grounding argument of the thesis has been developed by abduction. A central theme in the study of human reasoning is the construction of explanations that give us an understanding of the world we live in. The field of logic and reasoning, and particularly the place of abduction in it, is far from settled. It is beyond the scope of the thesis to explore the subtleties of such philosophical and scientific arguments, so I introduce my positioning in a vibrant on-going debate (Mill 1856; Simon 1977; Popper 1979; Walton 2001; Weintraub 2013). Abductive reasoning is a crucial skill for practitioners as well as researchers, as we are often confronted with surprising and unexpected performances in our practice. Often in everyday life, we are not in the position to deduct what the performance is about, or even to induce probable theories, but we propose that something may be the case. One of the

classical examples of abduction in everyday life is when a practitioner, a learning disability nurse or social worker like me, for example, observes a behaviour in a client (performance). To be able to respond with a solution, the practitioner hypothesises about the possible causes and contributing (f)actors (case) based on the available information usually in the form of complex networks of signs, experiences and knowledge of the potential relations between the (f)actors (premiss). Similarly, abduction was crucial in more theoretical and scientific contexts such as the discovery of penicillin, handwashing to prevent the spread of infections or the elliptical orbit of the Mars (Aliseda 2006; Haig 2008; Rahlm 2010; Kodama 2016).

All three types of major inference (deductive, inductive and abductive) work with one or more premisses, cases and performances (other terminologies are often used such as major and minor premise, rule, fact, observation, result, conclusion). The difference does not lie in the terminologies applied but derives from which two are used to arrive to the third, an inference. In deductive reasoning the performance is a necessarily true inference from the premiss and the case. Therefore, such approaches cannot increase human knowledge and contribute to originality as the conclusions (performances) are *tautologies*, practically self-evident from the premiss and the case. In inductive reasoning, we will arrive to a probable premiss from a case and a performance. Therefore, most scientific research (both fixed and flexible designs) is carried out by the inductive method to explain what is seen (performance) and to accumulate evidence (cases) to arrive to a believable or adequate certainty (theory) confirmed eventually by deduction. Abductive reasoning on the other hand establishes the likely case based on a premiss and a performance. Abduction requires no complete observations, can be creative, intuitive, and even revolutionary in finding the most likely case (Magnani 2001; Lipton 2004; Locke et al. 2008). One of the key differences between induction and abduction is that whilst induction needs no background theory *per*

se, abduction relies on a background theory to construct an explanation: in this thesis, it is Baudrillard's and Latour's work.

It needs to be noted that a difference is often made between abduction as an explanatory reasoning in *generating hypotheses or context of discovery* and as an explanatory reasoning in *justifying hypotheses or context justification* (Hanson 1958; Simon 1977; Eriksson and Lindström 1997; Haig 2005; Campos 2011). In other words, the hypothesis of this thesis should derive from abduction as it is "the only logical operation which introduces any new idea" (Peirce 1958 p173) which rightly or not has attracted various debates (Frankfurt 1958; Fraassen 1983; Harre 1988). Abduction is not about establishing a true or verified hypothesis but exploring one that is worthy of further investigation. In other words, scientific inquires use a mix of abduction (formulating hypotheses, methodologies or investigating hypothesis), inductive reasoning (comparing data to draw likely conclusions or examine hypotheses/evidence from literature or formulate theories) and deductive reasoning (use data to falsify a hypothesis necessarily based on inductive evidence to achieve certainty). The everyday usage of the word in the form of "best guess" or "hunch" comes from the process itself, as we can usually construct many hypotheses (likely cases), but only one or a few will be selected as "best explaining" the observed phenomenon to be further examined.

This also means that a solution or explanation offered as a result of abductive reasoning lacks certainty. This is due to the fact that the signs of a performance in ordinary settings, regardless of whether they are material or abstract or discursive, can be ambiguous, illusionary, logical or believable. In fact, in the ordinary, in the everyday performances, we do not experience facts but signs (material, abstract, discursive), and the semiotic associations between them. Hence, Law (2004) and Shank (2016) argue - in line with Baudrillard's (1993) and Latour's (1993) philosophy - that in everyday life we should not

search for truths through inductive and deductive reasoning but for significance and associations. It follows, my methods are based upon semiotics with an abductive focus. Throughout the years, I have encountered various performances and practices of hidden dis/ability that could not be deduced from the existing mainstream and predominantly separated health and social approaches and their notion of hidden disability. Besides, even if the approach used appeared to be inductively derived from the observed practices and performances of the various conditions, they often did not achieve the ideals of apposite care, services and inclusion for people with hidden dis/ability (NMC 2018, HCPC 2016).

I have considered many theories and methodologies for the exploration of the everyday performances of hidden dis/ability to overcome such issues. Yet I found that most approaches treated the natural and the cultural as two independently existing domains and worked with the already separated conditions as apparently justified truth claims, two key concerns underlying this thesis. Examples of phenomenology, hermeneutics or constructionism changed the content of the investigation in how we think about hidden dis/ability, but I argue, not some of the fundamental assumptions. They look at hidden disability differently but in a similar methodological fashion in terms of privileging certain actors over others and establishing relationships between a handful of actors only by induction whilst everyday life is based mostly upon abduction. What else could explain the thrilling advances of computational science where abductive reasoning is crucial in researching and developing artificial intelligent (machines' abilities to think and work like humans) (Dimopoulos and Kakas 1996; Paul 2002; Ignatiev, Narodytska and Marques-Silva 2018).

Therefore, this thesis does not take any existing approaches commonly used in disability studies such as the social model, oppression or minority model, neither contemporary theories like the Deleuzian rhizome or the Foucauldian notion of power to collect further

evidence on a specific topic (for example, the experiences of people with intellectual disability during hospital visits) but, rather, starts with a novel theory and hypothesis to revisit three fundamental issues observed: the binary oppositions of nature and culture, separated conditions and fragmented practices. I turned away from the general frameworks and models dominant in the field and decided to go in a radically new direction looking at semiotics as a foundation for the new approach. I used abduction to explain puzzling observations based on specific theories, characteristic of many situations of practitioners with incomplete observations to set the scene for crafting new practices in understanding the everyday performances of hidden dis/ability in ordinary settings. In the observations of the everyday performances of hidden dis/ability, I see signs: material, abstract and discursive. Therefore, I turned to two influential philosophers' works on semiotics. Baudrillard, who is well-known and respected for his work in the domain of cultural-semiotics, and Latour, a key figure in thinking material-semiotics relations.

Baudrillard and Latour, together with Actor-Network-Theory, offered an alternative ontology and epistemology (set of premisses) applied to various phenomena (performances) but not hidden dis/ability *per se* (case). Therefore, I abductively interfered what might be a novel case and ways of 'seeing' hidden dis/ability in the everyday performances that the hypothesis of the thesis expresses. It is the aim of the rest of the thesis to investigate the everyday performances grounded in abduction. This will require a novel way of collecting and analysing the data to eventually conclude whether the hypothesis can offer further theories and practices. I developed the 6D semiotic-network practice, a novel way of looking and understanding performances (both in research and practice) which is aligned to the ontological and epistemological assumptions of the thesis. The 6D stands for details, dynamics, dimensions, disposition, dislocation and description. It is a non-linear and detail-oriented approach focusing on connectivity, signification and capacity, on alternatives emerging from local interactions.

Whilst some scholars claim the word hypothesis belongs to a specific type of scientific research and methodology (Creswell 2002; Morgan 2014), others argue that working hypotheses can serve as inferential grounds in ethnographic studies and other flexible designs (Fredericks and Miller 1988; Shields and Tajalli 2006; Everett and Johnston 2016), as not only health and social models of care do not exist in separation and binary oppositions, but the putative marked division between qualitative and quantitative research traditions are potentially outmoded too as the various designs lie in a continuum between fixed and flexible rather than in two separated domains (Anastas 1999; Robson 2011). Therefore, this inquiry does not aim to yield apparent factual data and findings claiming a sense of objectivity and universality but to offer detailed descriptions that can be powerful in dealing with complex situations and influencing practices and policies.

The central argument (hypothesis) of the thesis

Hidden mental and cognitive dis/ability is not a stable, fixed and ordered reality, but it is constantly **perFormed, disSolved and reProduced** by diverse actors in complex webs of relations. Connections temporarily stabilise, and the categories of the conditions help create the impression that hidden mental and cognitive dis/ability is a definite and a permanent state.

1.3.2. Generating the central argument (hypothesis) by abduction

Theory (rule, major premise) based on Baudrillard's and Latour's philosophy: nothing exists in isolation and no independent knowing is possible as there is no one independent, external and ordered reality. There are performances that come into existence, change, disappear and reappear as a result of complex webs of connections between signs – materials,

abstracts and discourses. Connections can be stabilised, fixed and made durable. Such connections nevertheless remain temporal, though this can create impressions of an external, ordered and independently existing reality. Such apparently independent and real signs compose binary oppositions leading to a state of fragmentation and separation in order to maintain the notion of external reality. However, signs have always been unstable and increasingly they lose their ability to designate things or they relate only to other signs. This can make it difficult to know what we 'see' in the performances with any certainty, and potentially binary oppositions seem to implode or collapse.

Performances (results): In everyday life, it appears we have separated most of the diverse performances according to the many categories of hidden disability. This created separated and fragmented professions, disciplines, charities, training, research and more. It is not surprising then that autism, intellectual disability and the various mental health conditions appear to be distinct, objective and justified conditions. Yet, what I have also observed is that people with hidden mental and cognitive conditions share many performances. Furthermore, I often could not induce from those performances the apparently objective and universal pattern of signs reflecting the categories. I am often confronted by the complexity of signs (abstract, material, discursive) in composing a performance of shouting, an apparent lack of energy or the misunderstanding of communication.

Case: It appears that the connections of actors composing and maintaining the categories of the conditions became so stable and durable that we take them as objectively and independently existing truths. It seems like the very aim of these categories is to create and maintain not only the reality of hidden disability but of the separated conditions. However, if this is the case, that people with hidden disability share many performances in common, then it is also likely that they might miss out on opportunities. It is further possible that our solutions are not always the most beneficial as instead of allowing a solution to emerge from

the performance, we are already limited and constrained by the boundaries of the categories. So, the question must arise and be investigated: is it possible to compose a novel methodology for the exploration of everyday performances of hidden disability if we start the investigation with an unorthodox theory applied to incomplete observed performances? Could this novel methodology of exploring performances, collecting and analysing data, not only in research but in practice, provide us with fresh ideas concerning some of the pressing and ongoing issues of hidden dis/ability? Would it make a difference if we explored the everyday performances of hidden disability with the tools of everyday life rather than with the methods of distant and sterile research methodologies?

1.3.3. Research aims and questions

To study the hypothesis, I aimed *first*, to compose a novel methodological and theoretical analysis outside of the conventional health and social approaches. *Second*, I wanted it to assist me in the exploration of how people living with the various conditions performed and consumed composed roles of hidden dis/ability. *Third*, to investigate variations in the enactment and performance of hidden dis/ability in everyday situations. *Fourth*, I anticipated this inquiry could lead to alternatives in guiding practitioners as well as other stakeholders in how to provide apposite care, services and inclusion for the myriad conditions that competed for attention and resources. On this basis, I established two aims and sought to address three research questions to enable an examination of my hypothesis, the central argument.

Research aims:

1. To bring into focus issues of ‘seeing’ the everyday performances of hidden dis/ability by shifting practices from fixed states to conditions of possibilities

- to explore hidden dis/ability as effects of various connected actors in order to make visible the materiality and semiosis by which the visibility of hidden dis/ability might be composed

2. To advance discussion about hidden dis/ability in terms of approaches, values and proposed solutions

- to reveal reflexive stories of people with various conditions as the entangled accounts might afford an actor-network-theory grounded understanding of what is negotiable by people in complex everyday performances

Research questions:

1. How do the actors affect, produce and consume everyday performances as hidden dis/ability?
2. How spectators ‘see’ the everyday performances as hidden dis/ability and what are the affects of their judgement?
3. How do spectators come to ‘see’ hidden dis/ability as an essential and universal thing, rather than effects of actors that through their networked connections constantly perForm, disSolve and reProduce hidden dis/ability?

1.3.4. Justification of the study

According to a survey published by the Department for Work and Pensions in 2017, 21% (13.3 million) of adults in the United Kingdom have a disability, out of which 22% has a mental health problem. Approximately, a quarter of the reported disability is working-age adults. We also know that intellectual disability is calculated on the basis of IQ whereby 2% of the population have an IQ under 70. It is also estimated that about 1.1% of the population might have autism spectrum disorder half of which potentially also has an intellectual disability and up to 70% of might have one or more mental health condition (Simonoff et al. 2008; Russell et al. 2016; Griffiths et al. 2019). In a separate study, Public Health England (2019) found that only 31% of people with intellectual disability are known to health and social care services, whilst we still do not have any reliable statistics about the number of people with autism known to services. Historically only people with autism who also have a diagnosed learning disability, or a mental health need were recorded (HM Government 2016; ONS 2017) that the Autism Act 2009 and the two government policies (2010, 2014) have changed by making mandatory the establishment of such database. Yet, it is likely that at least 50% of people with autism have no diagnosis at all, and out of the known cases, 90% will have more severe autism, in most cases with intellectual disability (Brugha et al. 2011; Devon County Council 2015; Wirral Council 2015; Kent Public health Observatory 2017). There is a somewhat better picture for mental health conditions including dementia yet there remains a similar 40-50% gap between prevalence estimates and known cases using services (NHS Digital 2014; NHS Digital 2018; LSE 2019; Public Health England 2019a; Public Health England 2019b; Baker 2020).

It is clear, first, that despite the evidenced overlap between mental and cognitive conditions, intellectual disability, autism and mental health remain mostly separated both in research and practice. Second, more people living with hidden disability are unknown to services

than are registered, indicating that their everyday life is mostly visible to the spectators but hidden from mainstream research. Third, the limited number of research into the everyday life of people with hidden disability still favour neat and polished traditional research methodologies. It is possible that such approaches fail to match the research methodology with the obscured and unpredictable nature of everyday life. Fourth, only a few studies employed ideas from either Baudrillard or Latour to dis/ability and none employed them together. Whilst their theories share some commonalities of lineage with other contemporary theorists such as Deleuze or Foucault, they also offer novel and radically different ideas from them, mostly by moving away from power and politics as a central, grounding issue. In summary, it is far from being conclusive how best to understand and work with the diverse conditions in everyday life. Therefore, I argue there is a continuous need to explore the everyday experiences of people with hidden mental and cognitive difference with the application of novel theories that could offer new ways of seeing these performances.

1.4. Summary

I start the thesis with an assumption about the everyday performances of hidden dis/ability rooted in the works of Baudrillard, Latour and Actor-Network-Theory, that are radically different from the mainstream health and social assumptions. My aim is that Actor-Network-Theory together with Latour's and Baudrillard's ideas can make visible the processes by which the visibility of hidden dis/ability is composed in everyday life and how it is perFormed, disSolved and reProduced. The 6D material-semiotic network practice, a novel approach I have developed, might provide us with fresh ideas on how we can negotiate the complex matters of apposite care, services and inclusion.

CHAPTER 2

Considerations of the philosophy of Baudrillard and Latour

2.1 Positioning the thesis within the major philosophical domains

Locating this study in contemporary academic debates requires that I first address the notion of reality, fundamental metaphysical assumptions about what is real and questions about what kind of things exist. In the traditional health and social education of practitioners, the reality of hidden dis/ability is hardly considered. Mainstream medical and social approaches tend to assume the existence of an external reality where a single truth can be found, verified and our role is to discover, apply and evaluate those facts by various means (Latour 1993 p83, 1999a p12). Likewise, Law (2004 p24) argues, the main problem appears to be not the notion of an out-there reality *per se* but its rather specific formulation. That it is a reality that exists independently from our and other actors' actions. Quantum mechanics have shown, albeit in the physical realm and the world of the smallest particles, how the very act of observation might occasion reality (Buks *et al.* 1998; Weizmann Institute of Science 1998) and as such, impact on what it means to be rendered visible by everyday performances. The cutting-edge complexity, relationality or networked thinking influencing both Baudrillard's and Latour's work further draws our attention to the phenomenon of emergent behaviour where a performance cannot be understood from the exploration of individual actors, or from the preselected interactions between a handful of actors. Rather, they focus on many actors, signification, relationalities and connectivity. There is an element of surprise as actors affect and are affected, adapt to those affects, eventually leading to a performance that cannot be understood as a linear effect and continuation of preceding evidence as there are dynamics of constant change (Baudrillard 2001b).

It could be, Law (2004 p25) and Latour (1993 p21,88) continue, that because such approaches perceive this reality as preceding us, as already there in well-defined and set configurations, that performances seem to drive from stable conditions. This has epistemological and ontological ramifications, in that ideas of multiplicity and complexity rather than unity and universality have implications for displays of hidden dis/ability. Although most people acknowledge various perspectives exist on hidden dis/ability, they still insist that reality itself is singular. My role, as researcher and practitioner, reveals how notions of the absolute, independent and universal have already given us a presentation of hidden dis/ability formed against an invisible backdrop of hidden dis/ability. As such, this thesis is anchored in Latour's and Baudrillard's notion that the objective and external reality of hidden dis/ability does not exist *a priori* and independent of us (Baudrillard 1993 p1). Realities are made, and they are effects of actors and their connections (Latour 1993 p89). Our methods, discourses and very presence are part of reality (Law 2008b p629). The categories and other apparently universal objects represent the composed images and appearances of hidden dis/ability and not an external reality (Baudrillard 1993 p6).

Therefore, the aim of this thesis is not to find the true and objective reality of the everyday performances of hidden dis/ability, but by using a novel methodology and approach, explore how hidden dis/ability might be composed by various actors, the connections they form and the capacities emerging from such relations. How hidden dis/ability in everyday performances might not be a fixed and permanent pre-existing thing, but it is perFormed, disSolved and reProduced providing us with opportunities to reconsider how we negotiate our practices. Therefore, in the everyday performances, based on the metaphysics, ontology and epistemology of Actor-Network-Theory there are only actors, networks and connectivity. The politics, economics, ethics and aesthetics of hidden dis/ability emerge from these associations and the capacities they (trans)form. As such, it follows, there are no

binary oppositions such as observer versus observed, nature versus culture, causes and their effects, researcher and participant but entangled, connected and temporary accounts.

A few points of interest include that the approach of this thesis is neither realist (in that it explores the reality of hidden dis/ability independent of humans), nor relativist *per se* (in the sense of looking for multiple perspectives on one objective hidden dis/ability) and less constructivist (Latour 1993 p104), more ‘relationist’ and ‘compositionist’ (where not only humans but all actors have agency to compose the reality of hidden dis/ability) (Latour 2010b p484) as defined in Table 4 below:

Table 1. Positioning the thesis within major philosophical domains

Main assumptions	Brief description
Agency	Actors can be anything: humans, non-humans, objects, concepts, ideas and places. All actors have agentic properties not only humans, as they have the capacity to affect, mediate and change a performance through their connections.
Relationality	They are the actors and their connections that compose realities (metaphysics). Thus, nothing by itself has inherent existence (ontology), and no independent way of knowing (epistemology) or aesthetics (particular issue) is possible outside of the enactment of actor-networks.
Composition	Hidden dis/ability is composed and rendered real by actors and their networked connections. Therefore, nature and culture, normal and abnormal do not exist in binary opposition and independent of the actors that compose them, and we are always part of it.

Thus, my thesis explores the everyday performances of hidden mental and cognitive dis/ability by moving away from traditional, predominantly essentialist and universalist health and social care approaches. It assumes that everyday performances exist as a flux of opportunities that might perForm, disSolve and reProduce hidden dis/ability. My

aspiration is that this novel approach, including the emergent 6D material-semiotic network practice, can stimulate professionals as well as people living with and without hidden dis/ability.

Various disciplines are involved in my complex understanding of hidden dis/ability. The literature review will explore some theories, mostly rooted in the social model of disability. However, contemporary academics have long argued that most phenomena concerning hidden dis/ability are neither medical nor social, but an interaction between them that is reflected in the growing number of studies within the confines of inter-professionalism, holism and integration. Various methods have been developed to bridge the disciplines and appreciate hidden dis/ability as an integrated whole. However, such inter-disciplinary studies, as well as disability studies generally are rooted in the social model and have already divided hidden dis/ability into separated and purified domains, the binary oppositions of the natural and the cultural, and they try to re-establish the connection between them with more or less success.

2.2. Simultaneous application of Baudrillard and Latour

Baudrillard's and Latour's work provided me with the underpinning theories of how to move away from the grand narratives of hidden dis/ability and artificially separated and tired actors like power, language, nature or culture towards 'signs' and 'things', the details of everyday performances and connectivity. Baudrillard and Latour base their epistemology and ontology on a fundamental challenge to binary oppositions at the heart of realist descriptions, relying instead on deploying the multiplicity of significations and associations. Thus, they aim to question realist epistemologies and related ontologies of truth claims. In their diverse arguments, they both reject metaphysical ideas of privileged vantage points from which an independent reality and an inherent, essential quality for the discovery of

truth is possible. Furthermore, both claim that distinctions between belief and knowledge, appearance and reality, science and mythology no longer hold up.

Baudrillard's orders of simulacra explores the various phases of constructed images, in this thesis, hidden dis/ability in Western culture. He considers the changing roles and abilities of the signs including the categories to build an external reality and the language by which reality can be known and manipulated (Pawlett 2013 p36). Baudrillard focuses on signification, primarily, the play of signifiers that have no link with the signified, or with the actual referent. Latour (1993), on the other hand, displays how the birth, separation and purification of nature (said to exist independently with humans only discovering its laws) and culture (where human beings construct society deciding freely about their actions) suggests an external reality. Latour turns his attention towards associations of the material, how they affect and are affected.

Both Baudrillard and Latour ontologically privilege the structural, the connections, the formation rather than the essential physical matter, as for both of them it makes no difference whether the material associations or the immaterial significations are involved, as these two are inseparable. For both, the key thing is to draw attention in an unorthodox, radical and often disrupting way to their fundamentally similar epistemological and ontological assumptions; the social, the economic, the political, the aesthetic are effects. They depend on systems of exchange for Baudrillard and on complex networks of capacities for Latour, but both ultimately point to signification and association of actors (signs and things). Baudrillard offers the notion of signs and their reversion in symbolic exchange, whilst Latour offers nature, culture and reassembling as a new way of 'seeing'.

In summary, Latour and Baudrillard share an anti-essentialist epistemology and ontology that focus on signification and association, rejecting all forms of foundational discourse.

However, they are also different in translating such positioning into contemporary theory and what it means for society or in this thesis, for the everyday performances of hidden dis/ability. Both reject the Marxist notion of materialism and replace it with more abstract concepts based on semiotics, the nexus of relations, sharing a common lineage with Saussure. What I bring from Baudrillard and Latour then, are the exploration of complex signification and associations that intersect, contradict and entangle. Baudrillard and Latour will be used to inquire how 'signs', 'things' and 'appearances' compose performances, how we 'see' hidden dis/ability in these complex networks and how people living with the conditions perform and consume those composed roles in everyday performances.

2.3. A brief introduction to Actor-Network-Theory

Actor-Network-Theory is a non-modern theoretical and methodological approach to social theory. It breaks down the binary oppositions of the natural and cultural, normal and abnormal. It questions the notion that hidden dis/ability is a permanent and fixed thing that the apparently universal categories of the conditions hint at and the traditional medical and social approaches take as their foundations. Baudrillard's semiotic-idealism and Latour's semiotic-materialism provide the theoretical underpinning and assumption that the everyday performances of hidden dis/ability are relational and composed. Actor-Network-Theory gives the tools of how such performances could be explored, analysed and described that I detail in the methodology chapter.

2.3.1. The main concepts of Actor-Network-Theory

Actor-Network-Theory, also called the sociology of associations, aims to transform how we understand the relationship between actors, and a move away from cause and effect relations (prevalent in scientific research) and the narration of perspectives (dominant in

interpretative research). It uses the words actors or actants as opposed to factors and humans to signal its significant propositions. In Actor-Network-Theory, actors can be people, objects, non-human subjects, ideas, organisations, inequalities and places. Anything that can act or to which activity can be assigned in the composition of hidden dis/ability is seen to have the same potential to play a role (Latour 1987 p84, 2004a p75). Networks do not refer to any immediate and unmediated access to every piece of information such as with the notion of the world-wide-web. Rather, it is the concept of participating actors making other actors do things through their connections (Latour 1996a p2). Law (2007 p7) has summarised the six main characteristics of Actor-Network-Theory that the following Table 6 retells:

Table 2. Six characteristics of Actor-Network-Theory (Law 2007)

Concept	Brief description
Semiotic relationality	Networks and actors define and shape one another.
Heterogeneity	There are various actors, humans, non-humans, objects, ideas.
Materiality	Materials are as significant as any other actors, like humans.
Processes	All actors play a part in reality composition moment by moment.
Power	An effect of stable and durable configurations of connections.
Time, space, scale	Connections extend, stabilise and translate distant actors.

The flat methodology theorised by Actor-Network-Theory has offered me a rethinking of how everyday performances are treated as effects of translations. It starts from the assumption that hidden dis/ability is an effect of connected actors. It focuses on the formation of relations, the processes as opposed to separated elements, and aims to trace how those always unstable connections form, change and disappear. The tools of Actor-Network-Theory reveal how the connectivity of the actors including the medical professionals' social

practices, the social practitioners' scientific methods and human actors' capacity of meaning-making and information extracting perform hidden dis/ability in everyday life. In the everyday performances of hidden dis/ability, when looked through the lens of Actor-Network-Theory, everything plays its part, relationally (Law 2007 p13). This way Actor-Network-Theory enables a methodology to break down binaries, researcher and participant, medical and social, normal and abnormal by observing the actors and their connections that generate networks and form capacities for transformation, as noted by Latour (2013b p562), assisting me to transfer the data of my study in the realms of the 6D practice and categorise the following lexicon of key concepts:

2.3.2. Positioning Actor-Network-Theory within the major philosophical domains

In an Actor-Network-Theory analysis, there is a form of relationality and semiotics between the actors as "realism can be achieved much better by giving up the unification of the concept of nature" (Latour 2005b p232). According to Latour (2013b p561) nature does not explain nor justify anything. However, when we start the investigation with the notion that nature and science exist and produce factual outcomes, then verification or falsification will be the consequences of such *a priori* separation and purification. Actor-Network-Theory is not concerned with human intentionality, the lived experience, or the interpretations of individual minds with humans being at the centre of exploration. Yet, Actor-Network-Theory is not a constructionist approach either, social or otherwise as argued by Latour (2005a p229). There are no fixed and privileged actors with a sole agency (actors' capacity to affect and be affected), social, historical or individual, and there are no hidden forces, or a priori notions of power or oppression, to construct hidden dis/ability.

In the everyday performances, as seen in my data, every actor plays a role through connectivity that composes hidden dis/ability as a political, economic, ethical and aesthetic

matter. Hidden dis/ability is an effect and enactment of the heterogeneous actors, their relations and not a cause of or its result. Therefore, in Actor-Network-Theory the initial distinction between humans, non-humans, objects and abstracts has no relevance because as Law (2007 p8) explains, eventually specific compositions might be called 'human' or 'non-human', but this is a secondary matter. I have taken this to mean that the notion of 'various levels' or 'depth' or 'hierarchy' is also a relational effect. There is no overall social, natural or conceptual framework or scale within which performances of hidden dis/ability take place. Actors connect, such associations extend their scale and size and such metrics are also the effect of translations and the number of participating actors.

Some specifics, such as simplification or 'black-boxing' in Actor-Network-Theory, is the result of actors' agency, which is the capacity to affect and be affected. Simplification hides how such black-boxes were composed. They appear to be universal, fixed and permanent but, according to Latour (2005a p202), it is the configuration of the connections producing the appearance of stability and durability. Stability and durability are composed in various ways and do not refer to materials or human intentions themselves. Instead, in my thinking, there are connections maintained through continuity and discontinuity, or through comparison and difference or because they overlap (Law and Singleton 2005 p337). How actors and their connections are noticed, selected and ordered will define conditions of possibility, making some connections easier and others difficult or impossible. And sometimes more or less enduring (Law 2007 p10).

2.3.3. Narrating multiple realities

The implications of Actor-Network-Theory centres on the recognition of multiplicity. Law noted (1999, 2008b) every performance is a possibility for a different reality, a political, economic, moral or aesthetic composition of hidden dis/ability (in the sciences, the social

realm and the lived experience). However, those realities not shown, heard or narrated can still exist, and this idea formed a theoretical basis for my work. Both Latour (Latour *et al.* 2012 p600) and Law (2007 p17) highlight that for Actor-Network-Theory to describe the reality of hidden dis/ability is always a politically, economically, ethically and aesthetically charged act, as they are our methods that make the noticing, selecting and ordering of actors and their connections.

However, what is democratic, what is effective, what is good, what is beautiful and what is real are only partially connected: freedoms, productivities, virtues, sublimes and reals cannot be reduced to each other. This was certainly the case in the emergent data collection whereby observants had to take responsibility for the real, but also for the democratic, the effective, the good and the beautiful. So, this is the challenge I am facing in exploring the everyday performances of hidden dis/ability. To explore novel ways of working in and on the real, the democratic, the efficient, the good, the beautiful as giving prominence to my project. Serres writes beautifully about the price and reality of such goodness (Serres and Latour 1995 p10): “in dominating the planet, we become accountable for it. In manipulating death, life, reproduction, the normal and the pathological, we become responsible for them”. As such Actor-Network-Theory gives me theoretical direction on one hand, and the responsibilities of multiplicity on the other. Applying this to data led to an emergent force of its own which, as Serres (*ibid.*) might say, “the objects that we produce give birth to us too”.

2.4. Summary

The application of Baudrillard’s and Latour’s philosophy, and Actor-Network-Theory is the simultaneous rejection of naturalisation, socialisation and interpretation of hidden dis/ability (Latour 1993 p6, 1996a p16). It can be said that the approach of this thesis is a post-humanist, anti-anthropocentric and anti-foundational that is radically different from the

mainstream health and social assumptions and thus often controversial. I hope that it is this drastic shift from universals and essentials to connectivity and capacity that has the potential to offer alternatives to some of the burning issues present in hidden dis/ability that so far have not been adequately addressed through the dominant discourses. For example, all the contradictory tensions that I have observed in my practice, such as materiality and immateriality, connectedness and disconnectedness, dependence and independence, are re-thought. My aim is that Actor-Network-Theory together with Latour's and Baudrillard's ideas can make visible the processes by which the visibility of hidden dis/ability is composed and how in everyday life is perFormed, disSolved and reProduced. The 6D material-semiotic network practice that I developed in this thesis, a novel approach, might provide us with fresh ideas on how we can negotiate the complex matters of apposite care, services and inclusion.

CHAPTER 3

Literature review of disability studies

In this chapter, I offer a concise description of over 30 years of research in disability studies. I summarise themes of past and current directions with some detail included that this thesis builds upon. I also indicate the most notable limitations of the available evidence within disability studies. Finally, I suggest how some new theoretical and methodological tools might help us transform those limitations in exploring the everyday performances of hidden dis/ability to broaden our discussions in terms of approaches, values and practices.

3.1. A brief history of disability studies

The thesis is not located in the dis/ability literature *per se*, the extensive work of various schools of thoughts from diverse disciplines but considers how hidden mental and cognitive dis/ability are positioned in the relatively new academic discipline, disability studies. Before summarising the vast literature into three main streams, it is necessary to acknowledge that living with any form of hidden dis/ability will be shaped by cultural, political and environmental specificities. Therefore, the review is mostly limited to the United Kingdom (UK) and the United States of America (USA) with interest in ideas about everyday living with hidden dis/ability in the United Kingdom. As I have already discussed whether individuals living with a hidden mental and cognitive condition self-identify as disabled people is a different question. However, so long as people have an 'official' diagnosis, they nonetheless qualify for disability rights as defined by the Equality Act 2010 that this thesis follows in its definition of dis/ability.

Disability studies is an emergent field with roots in the social sciences, humanities, and rehabilitation sciences. Although its origin goes back to the end of the 19th Century, disability studies became a distinguishable field in the UK and USA in the late 20th Century. It has a direct link with disability civil rights movements during the 1960s and 1970s, where disabled activists reconceptualised disability to reflect their political experience (Albrecht et al. 2001; Finkelstein 1990, 2001). The Union of the Physically Impaired Against Segregation (UPIAS), formed in 1972 by Paul Hunt (a person with a physical disability who used to live in institutions) was instrumental in politicising disability in the United Kingdom and abroad. In the United States, inspired by the UPIAS, the Section for the Study of Chronic Illness, Impairment, and Disability (renamed as Society for Disability Studies) was started in 1982 by a group of academics led by activist and writer Irving Kenneth Zola (who also lived with physical disabilities). Michael Oliver, a sociologist with a physical disability, published his book *Politics of Disablement: A Sociological Approach* (1990), in which he analysed how disability is a social issue as opposed to an individual and medicalised phenomenon. Detailed accounts on the history of disability studies can be found in numerous publications (DIG 1972, 1987; Pfeiffer 1993; Campbell and Oliver 1996; Burchard 1999; Goodley 2011; Shah and Priestley 2011; Hampton 2016).

At its broadest, disability studies encourage scholars to value dis/ability as a form of cultural difference by the merging of research with civil rights and social justice. In this literature review, I examine hidden mental and cognitive differences as dis/ability. I explore some of the theoretical and methodological concepts that scholars and researchers in the field have developed. Then, I inquire into how well those positionings apply to hidden mental and cognitive dis/ability in the context of everyday living. Finally, I discuss some of the strengths of disability studies and some of its weaknesses related to hidden dis/ability and what I believe are the challenges lying ahead in researching, theorising and working with hidden

dis/ability. I include representative works within each stream and theme discussed, but I do not intend this as an exhaustive review.

3.1.1. The method of the literature review

There are three main types of literature review, the traditional or narrative review, the integrative review and the systematic review with over a dozen of subtypes (Broome 1993; Grant and Booth 2009; Whitemore and Knafelz 2005; Jesson et al. 2011; Bryman, 2012). A narrative review provides an overview of the literature on a subject or issue. In contrast, a systematic review is applied when the aim is to get answers to a specific and succinct question on a well-defined topic, thus reviewing all the available information from every identifiable source. Whilst an integrative review summarises past research and draws overall conclusions from the body of literature on a particular matter of interest. I argue in this thesis that people living with a so-called hidden mental and cognitive dis/ability are not a homogeneous group with similar everyday experiences within a group of disorder. Therefore, an integrative review appeared to be the most appropriate to establish to what extent the relevant studies enabled heterogeneity to be explored.

The presentation of the review follows a loose chronological sequence, starting with the most distant years and ending with the most recent years. The three identified streams are not separated by rigid boundaries but rather illustrate how disability studies have emerged and evolved. The integrative review synthesises findings from a diverse range of research and scholarly works in order to provide a breadth of perspectives and a more comprehensive understanding of the topic. Data and information from the selected papers extracted covered the conceptualisation of dis/ability such as positioning, the alignment with the methodology and the main arguments.

In order to perform this literature review, I conducted a systematic search using three different Universities' search engines and examining multiple databases (EBSCO, ProQuest, Web of Science, JSTOR). I covered the period from January 1980 to July 2020 using search terms (and their alternatives) related to disability (specifically to the various mental and cognitive conditions) in combination with keywords (and their alternatives) emerging from the themes. The main search terms were based on the MIP approach specifying the methodology, issue and participants (Appendix 1). Research on hidden mental and cognitive dis/ability includes a variety of approaches and topics, often using different terminology (intellectual disability, learning disability, learning difficulty). Therefore, I used a wide range of terms (equality, oppression, ableism, social model, stigma, discrimination, everyday lives, lived experience, inclusive research) to attempt to capture all relevant studies (Appendix 2). I utilised Boolean operators, truncation and a wild card approach to ensure inclusion of all variations (Appendix 3). The use of the search engine's thesaurus had at least two benefits. First, they enabled me to find articles about mental and cognitive dis/ability beyond the words that papers used to describe it. Second, because the thesaurus uses a tree data structure, it is possible to search for specific alternatives under the main heading of a keyword. I repeated the search strategy to explore additional terms to find the most relevant articles. The terms minority and value-based research were added, for example, to the search strategy. Electronic searches went along with the ancestry method and the hand-searching of the included studies' references to identify any further relevant studies.

I considered all studies addressing either or both mental and cognitive conditions primarily from the geographic location of the UK and the USA including those in the 'grey' literature such as unpublished theses, conference presentations, and reports. The main subject of the articles had to be relevant to adults (18+ years) and cognitive and or mental dis/ability. Primary research but not scholarly articles were excluded if they primarily addressed

physical disabilities, children, research from specialist services such as the military, and crisis intervention and which only included people who could not consent to research. Only studies written in English were included. Study designs or methodologies were not specified because various designs could provide relevant information regarding the research questions. The selection process for the studies consisted of three actions. First, studies were located in four different databases from three Universities' online library. Second, I reviewed the titles and abstracts of the works located, in which duplicates and irrelevant studies were excluded. Third, I scanned the full text, and I included potentially relevant theoretical or empirical studies based on the inclusion and exclusion criteria. Because of the diversity of the matters, design and setting of the included articles, the findings of the review will be presented as a narrative synthesis.

3.1.2. The three streams of the literature review

Disability studies incorporate a vast array of research and scholarly works. Many of the early studies (first stream) were produced by relatively distinctive approaches to disability studies, with specific ideas about what dis/ability is, how we should understand and study it. The early works can be summarised in terms of dis/ability caused by institutional discrimination and by social exclusion, rejecting any medical understanding of dis/ability. Rather than as being a physical difference between individuals, and of disabled people, it is viewed as a historically oppressed but politically recognised group under civil rights. Dis/ability tends to appear as a concept, set of practices, and a material phenomenon. Much of the works in the first stream reflected the intentional political turn to uncover the violence of representation, oppression and discrimination, whilst appraise resistance, anti-normativity and anti-ableism.

These early works of the 1980s and 1990s were followed by an extremely productive decade of work that further defined and expanded the interdisciplinary field. Disability studies in the 2000s (second stream) elaborated on the earlier ground-breaking works that called attention to dis/ability as a cultural phenomenon. With the critical idea of dis/ability being a universal and constructive existence in the world and with growing academic support, the field generated elaborate interdisciplinary work that covered most areas such as education, law, art, technology, and design. Goodley (2011) also draws attention to the expanding research on intersectionality considering the relationship of dis/ability to other identity signifiers such as gender, sexuality, age, race, ethnicity and social class.

Work on the founding issues has continued to the present by integrating or reinterpreting themes. Disability studies' research has not stopped influencing politics, fighting against oppression, discrimination and ableism, and giving a voice to dis/abled people in research. In the third section, I summarise contemporary works (third stream), some of which are less easily identified as extensions to prior streams. Others exploring the vast literature might arrive at different conclusions about which works comprise 'extensions' and what 'new themes', and I am convinced I have left out some that others would include. I have selected papers as contemporary works that were significantly different from the early schools for one or more reasons. Some works in the third theme are carried out by researchers in disability fields other than disability studies. Others might be practising within disability studies, yet they either integrate multiple themes from different schools or mingle with new or eclectic ways of thinking about dis/ability.

The re-conceptualisation of dis/ability as diversity and minority identity, a civil and human rights issue, a cultural formation, and an independent group of analysis represents the hallmark of disability studies. At the same time, each of those works has some limitations, some common to all of them, some shared by most. Many of those limitations stem from

the conceptual positioning of disability studies that enable these scholars to produce so many fruitful works. These constraints suggest that disability research needs to transform some established assumptions and practices if it is to continue to explore new ways of looking and understanding of hidden dis/ability and of how to 'see' it in everyday performances that the contemporary works seem to justify.

My positioning in this thesis is that disability research is now established and, in truth, has been exploring more eclectic approaches through ideas imported from other fields. Theoretical ideas and empirical findings learnt from these streams form the substantive underpinnings of my approach. The next sections cover all three streams grouped into twelve themes of past and current research. I then discuss some limitations of the existing literature and summarise the theoretical ideas and practices I think are needed if the following decades of research on hidden dis/ability are to perform the next dramatic shift I feel is necessary and possible.

3.2. Early disability studies - questioning previous and developing models of disability (First Stream)

3.2.1. A socio-political and materialist approach to the causation of disability

A large body of works in the early years of disability studies questioned the models used to understand disability and the causation of disability. For Centuries, the notion of impairment has not received the visibility and critical inquiry that has been directed to race, class or gender. With the expanding influence of scientific rationalism and the notion of curing diseases, Darwin's idea of the survival of the fittest, and the changing economy with its growing emphasis on productivity gave ground to medical interventions, segregation and discrimination by the 20th Century. The medical profession diagnosed impairments as

mental deficiencies and defective bodies. People with disabilities have continued to be sent to large hospitals, institutions and remedial therapies. The biomedical model separated people into medical conditions through the use of diagnostic categories. Such medicalisation of disability viewed human variation as a deviance from the norm, a pathological condition, and significantly, as an individual burden and personal tragedy. This biomedical view pushed people with dis/abilities to the margins of society, ignoring them as individuals who are capable of independent living and meaningful participation in society as discussed in many articles of this era including Finkelstein (1980, 1988), Oliver (1981, 1983), Abberley (1987, 1992), Barnes (1991, 1998) and Linton (1998).

Advocates and academics started becoming more potent in resisting and reframing such understandings of disability, eventually developing a new theoretical framework. The sociological and linguistic turn in the 1970s, together with growing political activism represents a significant departure from the traditional disability discourses. The period from the mid-1970s to the late 1990s proved to be an important transition for the disability rights movement and disability studies. Many of the early contributors were either practitioners (mostly social workers), advocates or academics with physical disabilities (mostly white and male) like Abberley, Barnes, Finkelstein, Hunt, Oliver, Zola and many others (Gleeson 1997; Shakespeare 1998; Rembis 2010) focusing almost exclusively on physical impairments. They believed that impairment could be overcome by changing the way we think about the social-political-cultural environment we live in.

The Fundamental Principles of Disability published by the UPIAS (Union of Physically Impaired Against Segregation) is considered to be the first, which formulated that disability is not a biologically rooted condition. It is the discriminatory society that disables physically impaired people: “disability is a situation, caused by social conditions, which requires for its elimination” (UPIAS and Disability Alliance 1975/1997 p3). Early disability studies began

formulating a socio-political model of disability, making a critical distinction between impairment and disability and placing the experiences of disabled people at the centre of any analysis of their lives. It identifies the root causes of disabled people's oppression in social, cultural, and environmental barriers that disable them, not in any individual deficit or impairment (Oliver 1984, 1986, 1990; Barnes 1991, 1998, 2000; Barnes and Oliver 1993). Oliver (1996 p38) explained that "the social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability" making a distinction and a binary opposition between body and society, between the natural and the cultural.

This distinction between impairment and disability formed a fundamental characteristic of the construction of the social model in early disability studies. Such a redefinition of disability also brought an epistemological and ontological shift from the body to the environment, from the individual to society, and from illness to culture. The primary aim for scholars became achieving changes in and by society. Disability is understood as a social construct, external and imposed upon the physically impaired, leading to exclusion and discrimination declaring people with disabilities as an oppressed group, as "those we meet cannot fail to notice our disablement...an impaired and deformed body is a difference" (Hunt 1998 p12). In summary, the social model has four main assumptions. First, disability is a form of social oppression, and disabled persons are a minority group that is discriminated against and excluded from mainstream society. Second, impairment and disability need to be separated and do not exist in a causal relation. Third, it is society's responsibility to remove the barriers that persons with dis/abilities are facing. Fourth, the voice of disabled people needs to be at the centre of discussions and policymaking.

The social model of disability is considered as a ground-breaking concept that provided the political drive to disability activism for civil rights in many countries, particularly in the UK and the USA, generating a clear agenda for social change. It offered a fundamental critique

of capitalist society and a new way of thinking influenced by Marxist political economy. This shift from the medical model to the social model (and from the individual to society) emphasises oppression incorporating the idea that people with dis/abilities are a minority group. Various professionals took on this view and indeed such definitions of disability (people with disability, carers, politicians) to the point that many scholars argue unless a study is located in the social model, it cannot be considered a work belonging to the academic field of disability studies (Barnes et al. 1999; Ferguson and Nusbaum 2012).

The social model openly intervenes with politics, economics and moral as it proposes that people are made dis/abled by a lack of resources to meet their needs, and various inequalities of participation in society. The social model played a crucial role in attempting to develop a collective disability identity and strengthening the dis/abled peoples' movement. It had an impact on nearly every area of life from how media portrays people with disability through policies and accessible transportation to education. It was incorporated into national and international policies, such as the UN Convention on the Rights of Persons with Disabilities, the World Health Organisation classifications (1980, 2001) or the Valuing People white papers (2001, 2009). The movement also started disability studies' curriculums, seminars and research that have been flourishing since the early 1990s. The discourses of people living with dis/abilities developed a powerful narrative of what it means to live differently in the world, discarding notions of disability being a negative, a biological and an individual problem. What remains central to the social model is improving and defending the lifestyles of dis/abled people.

Criticism of the social model had started as early as its formulation (Crow 1996; Shakespeare and Watson 1997). However, the social model of disability continues to be fundamental in disability studies (Finkelstein 2007; Oliver 2009). Whilst this debate has not ended, most contemporary scholars moved on notions of binary oppositions between the

medical and the social, impairment and disability. As Oliver and Barnes commented (2012) if the social model is still useful, utilise it and share it, otherwise do not tell us but rather create something else.

The features of these works that have informed my approach to hidden cognitive and mental dis/ability are its substantive emphasis on how social and material barriers affect individuals, its conceptual questions on the external-internal and external-external relations and the methodological approach of studying hidden dis/ability from a historical-materialist viewpoint.

3.2.2. Disability rights agenda: oppression, ableism and a minority identity

Another central theme in early disability studies rooted in the social model and causation of disability is concerned with oppression, ableism and people with disability being a minority group (Campbell and Oliver 1996; Charlton 1998). If impairment is perceived as a threat to social progress, then people with impairments will be subject to marginalisation. In other words, by the last two decades of the 20th Century, disability issues acquired a political, social and disability identity in stark contrast to earlier years. There was a growing recognition that dis/abled people were an oppressed and disadvantaged minority group, naming discrimination as the primary barrier faced by people with dis/abilities (Barnes 1992; Northway 1997; Oliver and Barnes 1998; Grove 1999). The notion of 'normal individuals' and 'abled bodies' arise from the modernist assumptions of the 19th and 20th Century, creating ideals. Early scholars have started to challenge 'disablism' (Wendell 1989; Morris 1991; Davis 1995; Mitchell and Synder 1997; Thomson 1997; Linton 1998; Perlin 2000) drawing attention to how it is 'ableism' that constructs normalcy, 'typical' citizens and the fear of others.

Disablism and ableism (or mentalism and sanism in the field of mental and cognitive health) then closely related to the oppression of disabled people to discriminate, normalise and segregate those impaired bodies and minds that do not fit the privileged narrative, act as a powerful ideology for the disability movement and studies. Moreover, it is in some ways aligned with the medical model that puts all the responsibility onto the individual as opposed to society. Barnes and Oliver (1993) offer evidence of discrimination, “both qualitative and quantitative, of the extent of institutional discrimination against disabled people” covering many aspects of life from education through leisure and media to the workplace. Abberley (1987) provides a detailed account of disability oppression and being a minority group that, for him, requires at least two things. First, the difference of disability oppression from other minority groups’ experiences, which he sees in the notion of impairment. Second, establishing a common feature of oppression within the disability minority group, which he sees mainly in the form of material and economic disadvantages.

Other scholars also aim to establish, first a commonality between disability as a group as well as a difference from other minority groups to develop a firm theory of disability as oppression, marginalisation and minority (Oliver 1986; Finkelstein 1990, 1993; Stuart 1992; Barnes 1996) with some scholar putting more and more emphasis on cultural representation and a phenomenological and existential stance (Shakespeare 1994) to counterbalance the predominantly historical-materialist positioning. Hahn (1982, 1985, 1986, 1988), for example, argued that the minority group analysis must be applied to people with dis/abilities, linking oppression to a political strategy in seeking civil rights assurances. Whilst most early scholars seem to agree with Hahn in terms of disabled people being denied their civil rights and full participation by systematic discrimination, they differ regarding how much faith they have in the legal system to change this (Oliver 1990; Shakespeare 1993; Young and Quibell 2000). Zola (1988, 1993) has already hinted that this approach could only be a short-term strategy with moving towards universalisation, “demystifying the specialness of disability”

so they would not be measured “against the needs, wants and rights of the rest of the population”.

The notion of oppression, ableism and discrimination of disabled people, being the largest minority group becomes a central research theme in early works and continue to be explored in the next streams in every area of life including health and social care professions (Goodall 1992; Lillesto 1997; Scullion 1999; Reeve 2000; Ross), employment (Barnes 1991; Hum and Simpson 1996; Barnes 2000), education (Barton 1988; Corbett and Barton 1992; Troyna 1994; Corbett 1997) and community care and independent living (McCluskey 1988; Morris 1993; Kessler et al. 1999). In summary, the oppression and minority model have four main assumptions. First, impairment has a social origin, and it is a society that forces upon disabled people all sorts of political, environmental, financial and attitudinal disadvantages separating them from the ‘normal’ as other. Second, these oppressions are historical products and as such, are linear. Third, the voice and experiences of people with disabilities can fight against discrimination. Fourth, it has to be a politically driven change at government and policy level, involving both material and ideological issues.

These works had, and continue to have, an enormous influence on disability studies. Focusing on oppression and marginalisation acting upon people with dis/abilities serve most studies starting positioning. Whilst these scholars tend to acknowledge differences amongst disabled people as a heterogeneous group, they argue from an oppression and discrimination point of view that they need to be brought together as a minority group encouraging a common identity to unite against the medical and administrative dominance and to redefine disability in positive terms and construction of new services. Most scholars within the field appear to agree that it is the notion of impairment, particularly its materiality and visibility that makes a critical difference from other minority groups, whilst it is also the

visibility and the materiality of these bodies as others that connect them with other minority groups.

This approach has also evoked criticism from the beginning of the argument, mainly as it favoured a single-identity politics and a form of essentialism by focusing on disabled bodies as opposed to intersectionality, context and diversity including the less material and visible minds (Young 1990; Begum 1994; Morris 1996; Wendell 1996; Vernon 1999).

This body of work is vital to my theory development because of its emphasis on discrimination and its early concerns with the patterning of processes over time leading to emergent affects of oppression. It draws attention to the dynamics of discrimination that are linked to the construction of society, rather than any personal deficiencies, empowering people with disabilities.

3.2.3. The survivors' movement and deinstitutionalisation

Scholars working in the field of mental and cognitive disability share many of the theories, assumptions and issues with academics predominantly focusing on physical dis/abilities. These commonalities include the move towards the social model, the notion of oppression, the hidden nature of disability history or the importance of the voice of people with hidden mental and cognitive disability (Ryan and Thomas 1987; Williams 1989; Atkinson and Williams 1990; Goodley 1996; Read and Reynolds 1996; Atkinson et al. 1997; Fitzgerald 1998; Holmes et al. 1999; Simpson 1999). This section will draw attention to a few significant differences in the early days of disability studies as other theories, directions and movements have been developing in the field of mental and cognitive disability.

One such concept is normalisation, developed by Nirje (1969, 1982, 1985) and social role valorisation from Wolfensberger (1972, 1983, 1999) that remain highly influential, initially fighting for the deinstitutionalisation of people with intellectual disability. Normalisation has an overarching aim to help people with intellectual disability live as normal life as possible covering every aspect of their life, including health, education, and welfare. Whilst social role valorisation is based on the idea that groups of vulnerable people in society such as people with intellectual disability are likely to experience systematic devaluation and once in roles that are negatively valued it is more likely that corresponding behaviours and actions will follow (Bronston 1971; Bank-Mikkelsen 1976; Lemay 1995; O'Brian 1987). Oliver challenged such theories arguing that they do not offer real change to people with dis/abilities, whilst Wolfensberger called Oliver's materialist and Marxist economic approach a quasi-religious dogma (Oliver 1998; Wolfensberger 1999).

Walmsley (1997) and Aspis (1999) argued that disability studies failed to position people with intellectual disability in their theorisation, including both Oliver's seminal paper (1990) or the UPIAS statement (1976). Conversely, both normalisation and social role valorisation attracted numerous criticisms, manipulation and misinterpretation. Although both are relatively well-known in the intellectual disability field, they have never become an integral part of the wider disability studies nor mental health (Briton 1979; Gresham 1982; Chappell 1997; Flynn and Lemay 1999; O'Brien 1999; Culham and Nind 2003). Whilst the social barriers are as real for people with intellectual disability as with physical disability, the so-called 'psycho-emotional disablism' seems to reflect better their experiences as argued by Thomas (1999) stemming from a rather immaterial and invisible disability related more to communication and information barriers.

Another key difference presented early in disability studies is how well the notion of disability and its separation from impairment (Bogdan and Taylor 1982; Taylor 1996) applicable to

people with intellectual disability. Moreover, whilst a sense of unification and preference for grand narratives can be observed in intellectual disability research, it is life story and personal narrative research that have become of the primary importance from the 80s and 90s (Crawley 1988; People First 1993; Sutcliffe and Simons 1993; Atkinson). Although it was not that straightforward in the first stream due to perceived and real communication differences (Both and Booth 1994, 1996; Goodley 1996; Able and Cooper 2000).

In the mental health field, the anti-psychiatry movement has been growing parallel to other disability's movements (Szasz 1961, 1973, 1994, 1998; Chamberlin 1990). This was followed by the establishment of 'Mad studies', with 'Mad pride' groups and 'survival movement' led mostly by ex-patients. The relations between survivors and disability and between the survivors' and disabled people's movements are complex, and there is little agreement about them. There are significant differences as well as overlaps which is the case between mental health and intellectual disability. All forms of disability have their experience subjected to medical interpretation and treatment, face social oppression and discrimination. As a result, all people regardless of their disability, encounter disproportionate problems of poverty, unemployment, social and economic insecurity.

Many mental health survivors are included as 'disabled people' in the medical definitions upon which eligibility to disability benefits and services are based. Some people involved in the survivors' movement are also involved in the disabled people's campaign for civil rights legislation. Nevertheless, some disabled people do not see survivors as disabled, because they do not have an impairment, or their conditions may not be permanent. Some survivors do not see themselves as disabled because they associate disability with the medicalisation of their distress. There are also anxieties among survivors and disabled people about being associated with the negatives linked with the other group (Marcus 1990; Beresford et al. 1996).

It is not only other groups of disabled people who think differently about cognitive and mental health, but the public and professional perceptions seem to mirror those voices (Read and Baker 1996; Campbell and Raja 1999; Cook 2000). It is the case with both intellectual disability and mental health that their hidden dis/ability is materially and visibly considerably different from physical disabilities. They experience moments of disability in different magnitudes and varying durations. Whilst both the mental health and intellectual disability movement found the social model useful in understanding concepts of oppression. However, both groups also reject it for similar reasons: they have no visible and material impairments. It follows, intellectual disability and mental health research lack a coherent philosophy, both an advantage and disadvantage, as argued by Beresford (1997) and Frese and Davis (1997). Members, for example, do not have to conform to a particular belief system as the main agenda, "Speaking Out" becomes the fundamental positioning.

It is also argued that mental illness is a social construction, including the medical, the social and other models sometimes with no clear preference in this era. Neither cognitive nor mental health approaches reject the use of medication, therapy and 'cure' entirely. Lindow (1994, 1996), McCabe and Unzicker (1995) and Barnes and Shardlow (1996) also draw attention to rights and citizenship arguing the mental health movement is less politically driven and more interested in looking at people as customers promoting individual choices. Services are dominated by the presence of the private sector and business-like thinking, and there is a much closer relationship and reliance upon service providers.

In summary, both the mental and cognitive disability movements have distinguished their conditions from physical illnesses early on. However, they also merged politics and the study of disability, sharing some sentiments with the disability activism of people with physical disabilities. Despite the many seeming similarities between the experiences of people with a physical, mental and cognitive disability, disability activists from different

groups have had difficulty forming a sustained coalition. Part of this difficulty involves the simple fact that the three groups are composed of different subcultures with different histories, cultural artefacts, and networks of associations. Conversely, the early scholars of the mental and cognitive health fields will experience the same shift into a more contemporary argument in the second stream whilst retaining many of the original ideologies.

It is evident that disability studies in the first stream were in the dominant position with the social model and its focus on bodies and theories of oppression, whilst the theorising of mental and cognitive dis/ability has been very limited. Second stream scholars have paid more attention to these issues, yet a group of scholars representing hidden mental and cognitive dis/ability have taken a different road. One might consider them working outside of disability studies. This includes many practitioners such as nurses and social workers but also artists and philosophers. The result is that by 2020 not only intellectual disability and mental health have become a contested area full of paradoxes and contradictions but generally disability studies too.

This body of work is significant to my positioning as it highlights some early concerns with the notion of the materiality and visibility of disability leading to more dynamic understandings of some fundamental values and principles characteristic of the field. It draws attention to diverse experiences and collaboration that are linked to more fluid approaches in how to support and empower people with hidden dis/abilities.

3.2.4. The voice of people with disabilities and the search for a new identity

The previous themes have shown that in the first stream, people with dis/abilities become the centre of inquiries. Albeit there are differences, all three groups agree – physical

disability, mental health and intellectual disability – that the voice of people, their carers and their families is paramount in research, politics and service provision. They challenge their histories, representation and experiences written and researched by medical experts' as well as non-disabled people (Oliver 1983, 1990; Goodley 1997; Worrel 1998). As a minority group living in a disabling society, people with dis/abilities have been denied basic human rights of self-expression, independence and participation. Therefore, at a very minimum people with dis/abilities should have the right to speak out, express their wishes and choices, and make decisions for themselves as highlighted by Simons (1992). Self-advocacy has become essential since the early '80s as people with dis/abilities who have been silenced for Centuries, found their 'voices' and started to make them heard.

People started to campaign for their rights, established self-advocacy groups, and there were a growing number of written publications featuring their voices in life histories, autobiographies, testaments, research and publications (Barron 1989; People First 1993; Williams 1998). Self-advocacy has the potential to revisit and challenge the political processes that ultimately oppress, prejudice and position people with dis/abilities as different, lesser, and other. People with dis/abilities have become recognised in their right as activists and full citizens changing the negative stereotypes to a culture of positive disability identity. Nevertheless, the lines were blurred between campaigning and self-advocacy as both had elements of speaking out, challenging oppressive practices and empowering people with dis/abilities marginalised by others and society at large. In short, early scholars were focusing on notions of power, powerful individuals and organisations, and how to challenge the distribution of power and relocate power to the people themselves.

The increasing political mobilisation of people with dis/abilities has been an evolving but distinct ideology to explain and challenge their marginal societal status (Finkelstein 1981; Scotch 1988; Campbell and Oliver 1996; Charlton 1998; Linton 1998). The emphasis on

identity, which has been hidden, is a key feature of this era. What had been a source of exclusion and marginalisation is transformed into a source of energy and pride. However, this positive identity is far more contentious, and far less accepted as a unifying theme for many dis/abled people as the logic of the social model suggests. The underlying concept is that if disability is a social category rather than medical one, the common interest might be capable of bringing people together to form a collective identity.

Disability activism of early scholars pushed the idea that disability is an identity, moreover a political identity. This notion of identity has significantly divided and continues to sharply split the disability community (Brown 1995; Davis 2001). Consequently, in the next stream, intersectionality becomes a prominent theme expanding the notion of identity. Nevertheless, by highlighting difference, multiple and fluid identities, there are fears too that it will result in the loss of clear goals and cohesion. Despite this apparent fragmentation, one thing remains common, most disabled people's wish to have the same and full rights as citizens. The movement of identity politics has led to many positive outcomes for people with dis/abilities, for example, the establishment of diverse self-advocacy groups, service user-led organisations and services, people with dis/abilities becoming advisors and consultants, and other innovative ways of including people with disability in community living, thus becoming active citizens from passive recipients (Clare 1990; Barnes & Wistow, 1992; Oliver 1996; Walmsley 1997).

Many features of these works have informed my approach to hidden cognitive and mental disability in this thesis, as they cemented the importance of putting people with hidden dis/abilities at the centre of the works. They highlight the significance of methodological approaches where researchers can learn from the people with hidden dis/ability themselves rather than educating them.

3.2.5. Searching for positioning in disability studies

Early scholarship in disability studies was dominated by understanding physical disabilities not as impairments in individual bodies, but as disablement caused by social barriers. Such a strong focus on the causation of disability and the drive for the politicisation of the field naturally meant neglecting some other important factors such as individuals' diverse experiences concerning impairment, gender, race or sexuality (Gresham 1982; Morris 1991; Chappell 1992; Begum et al. 1994; Crow 1992; Nuyen 1994; Shakespeare 1994; Bickenbach et al. 1999). The second stream will expand to represent individuals with a wide range of disabilities and experiences. However, the debate over the commonality of disability continues.

The relationship with race, sexuality or gender, the connection between bodily experiences, politics and the built environment has been another core issue and remain so even today (Abberley 1987; Finkelstein, 1993; Morris 1993; Stuart 1993; Goodley, 1996). Higgins (1980) goes as far as to suggest that disabled people main concerns are about everyday living and not identity and other politicly influenced questions. Whilst other studies like Hacking (1998), Burch (2001) and Longmore (2003) have shown how groups of various disabilities have been actively defending their differences. It is not only the question of disability identity, unification and the nature of impairment that were raised in the first stream already as an issue but the lack of coherent theories, the epistemological and ontological positioning and the history of disability as highlighted by Gleeson (1997).

Hogan (1997) and Barnes (1997) continued to emphasise the importance of one history in the development and maintenance of disablism. Other scholars have called for more scrutiny and empirical evidence in the field. It was highlighted how such works predominantly represented disability history as the narrative of institutional practices, often

presenting mistakes and opinions rather than facts as they rely on secondary sources (Woodill 1989; Bredberg 1999; Shakespeare 2002). Linton (1998) and other publications edited by Rioux and Bach (1994) argued how there was a need to define the direction of theory and research of disability study and formulate the epistemological foundation for viewing disability as a critical category of analysis grounded in the humanities and social sciences, reflecting the interdisciplinary nature of the field.

Goodley (2011) summarised the issue of positioning of disability studies as being a matrix of theories, pedagogies and practices that should not be confused with perspectives or disguised as grand truths. The various standpoints are knowledge positions. However, they should all share the same aim of questioning disablism. Scholars should not argue whether such diverse positionings are oppositions or complementary strategies but rather place them into context from which they have emerged (Davis 1997; Linton 1998; Barnes 1999). These contemporary approaches assert that “the complexity of human existence calls for multiple and complex methods and approaches” (Hedlund 2000; Gustavsson 2004 p19) and should be less driven by debates of binaries “to grasp the nuances of disability” (Roulstone 2013 p2). These voices resulted in more critical studies emerging that will dominate the second and third stream whilst retaining many of the achievements of early scholars.

This body of work influenced my study as it highlights some early concerns about positioning, the epistemology and ontology of hidden dis/ability and the methodologies used to explore various topics. These works draw attention to the growing opinion that it is unlikely that a single overarching model or meta-narrative could resolve the complexity of hidden dis/ability. It is from these sentiments that this thesis takes its foundation that the performances of hidden dis/ability are composed in the details, dimensions and dynamics of things and signs.

3.3. Expansion of disability studies - understanding disability as positioned within diversity and identity (Second Stream)

3.3.1. Intersectionality

The concept of intersectionality has its roots in feminist philosophy to theorise the synthesis of 'race' and 'gender'. It is situated in Black feminist thought becoming the symbol of victory over previous modernist, thus essentialist methodologies. By the late 1990s, early 2000s, intersectionality has cross pollinated various disciplines including disability studies. This widespread application of feminist positioning is often criticised for its inattention to the lineage, as argued by Carastathis (2016). Goodley (2011 p33) summarised intersectionality in disability studies as "body or mind that is disabled is also one that is raced, gendered, trans/nationally sited, aged, sexualised and classed". These and other social identity markers bring a sense of difference, marginalisation and oppression as well as a commonality to disability studies.

It has been argued by many scholars that disabled people were not only discriminated based on their disability but potentially experienced multiple disadvantages (Shakespeare et al. 1996; Morris 1996; Both and Booth 1998; Crocker 1999; Thomas 2001; Sherry 2007; Beyer and Robinson 2009; Campbell 2009; Durkin et al. 2010; Kaye 2010; Enea-Drapeau, Carlier and Huguet 2012; Theodore et al. 2018). It is the interaction of these identities, not their addition that results in a qualitatively unique experience of oppression (Crenshaw, 1989, 1991). Conversely, Davis (2005) argues that disability is one of the newest political and cultural identity categories when compared to race, class, gender, sexual preference, and religion that makes a difference.

Initially, in the first stream, such identity markers acted as a coming together to fight all forms of oppression and discrimination. In the second stream, once a strong disability identity and political presence have been established, this initial collaboration starts to change. We can witness how separated groups and disability identities grow in confidence, more and more focusing on their differences rather than similarities (Lane 1993; Camm-Crosbie et al. 2012; Ali et al. 2013; Best 2016). This is also reflected in post-colonial disability studies that have challenged the western (Global North) subject dominance of disability studies itself (Connell 2011; Meekosha 2011; Chataika, 2012). Moreover, studies have also shown the varied and often contradictory narratives of people with similar identity markers on the same question and events (Landsman 2005; Jones and Kroese 2007; Harmer and Orrell 2008; Willis *et al.* 2015; McKenzie *et al.* 2018) highlighting how the influencing factors must go beyond single identity markers for example, disability.

Nevertheless, scholars argue that “identities are culturally mediated constructs implicated in relations of power, privilege and oppression” (Liasidou, 2013, p.300) making a strong link between intersectionality, the social model of disability and oppression theory. For scholars like Moore (2001), Erevelles (2002, 2011) and Bumiller (2008) intersectionality is everything but the ideal Western citizen: white, male, heterosexual and able-bodied. Intersectionality in disability studies cover a huge amount of work then under various subcategories, most often identified as feminist (gendered), queer, race, and class. Intersectionality brought more in-depth theoretical frameworks for understanding disability and, in turn, it enriches feminist, race, class and queer theories.

An intersectional understanding of disability can be a distinct advantage when trying to understand how particular inequities are made in times and places. Scholars argue that the experiences of disability require the appreciation of the intersecting dimensions of race, class, sexuality and gender (Blum 2007; Gillies and Robinson 2012; Annamma, Connor,

Ferri, 2013; Fannon 2016). They share a fundamental aim of critiquing the ableism-disablism binary and the normative social policies giving a voice to narratives that have been silenced. Using various means, they are motivated to end hegemonic conceptions of health, culture and representation. Disabled bodies and minds share a history with the poor, female, black, queer histories of being marginalised. Countless empirical studies (covering most areas of life) support how intersectionality is relevant, affective and help interrogate fundamental questions about us, humans and our relationships with the world and each other (Marshall et al. 2012; Richmond 2012; Balderstone 2014; Abbott 2015; van Schalkwyk et al. 2015; Mitra et al. 2017; Brown and Moloney 2018; Kerrison 2018; Richardson and Stoneman 2019).

This vast amount of work is important for this thesis as it highlights how intersectionality discourse can be used to comprehend better the interaction of oppressed identities, including ethnicity, gender, class, and sexuality. The importance of including disability in an intersectional framework lies in its ability to challenge every day composed inequalities.

3.3.2. Narratives and discourses of dis/ability

Discourses and narratives are another dominant way to replace truth and facts with the lived experience, a primary epistemological and ontological positioning of disability studies. Language is an abstract system that finds its articulation in a discourse, and it is the discourse, this temporal event that creates meaning constructed by the world and the individual together. It is founded on binary opposites, a comparison with the other. Hermeneutics interpret an individual's discourse as to how one understands his/her hidden dis/ability and how then objectifies her subjectivity through discourse whilst phenomenology focuses on the universal elements, structures and dynamics (Lavery 2003; Leonardo 2003) taking into consideration both the experience-near (subjective) and experience-distant

(objective) analysis. The work of Foucault is significant here that many papers and scholars use as its positioning in disability studies with the focus on exploring how discourses of disability and the self within are produced and reproduced in institutions in the broader sense (Foucault, 1973, 1983).

For Foucault (1977) and scholars working with his positioning oppression and disability itself are the product of power relations rooted in discourses of professionals, politicians and people in positions to make us act in ways that fit with the norms (Jingree, Finlay and Antaki 2006; Tremain 2015). Oppression and discrimination arise when discourses constituting hegemony, become the dominant knowledge construct (Foucault, 1989). Foucault's ideas on power, knowledge, archaeology, genealogy, problematisation, surveillance, the technology of the self, heterotopia and discursive practices have been applied to various topics and empirical works combined with various methodologies including grounded theory, discourse and conversation analysis (McCabe and Holmes 2009; Aston et al. 2014; Feely 2016; Beckett, Bagguley and Campbell 2017; Johnson and bagatelle 2018; Ringwald 2019; Shakes and Cashin 2020) illustrating the wide-ranging relevance of Foucault's work for disability studies.

These works make us recognise how hidden dis/ability itself is socially constructed and explore the power that produces it. In this paradigm, there is no outside reality to the historical effects and socio-political operations of power on the body and mind that produces hidden dis/ability as a socially and politically marginalised identity. The approach is also used to investigate naturally occurring interactions and conversational practices to understand how common knowledge of culture and disability in it are produced and reproduced arguably promoting or hindering service-users' personal agency in carrying out everyday activities. It aims to analyse the details of the discourses and the patterns between informants as they happen in real-time (Antaki et al. 2007; Antaki, Young and Finley 2010;

Antaki and Crompton 2015; Bottema-Beutel, Louick, White 2015; Maynard, McDonald and Stickle 2016; Elraz 2017).

Williams (2011) asserts that focusing on communication in everyday life is significant as it does not only connect the private with the public but intimately linked with the construction of identity and disability. Moreover, Goodley (2011) highlights how the details of narratives let us 'see' and deconstruct the dominant disablist discourses and that there is no such thing as 'impairment' outside these discourses as hidden dis/ability is discursively constituted in a disablist society. Networked relations rather than fixed identities and hidden dis/abilities are central here as it is not a physical reality but a discursive society that constructs the reality of disability. The discourse of agency and its effect of power, capacity and will can be made visible through these networked interactions.

These works remain influential in the thesis as they draw attention to how language affects and is affected in everyday life. It breaks down binaries as the action of communication consumes, brackets off both nature and culture. Language is not a medium any longer, but the one that produces and reproduces hidden dis/ability.

3.3.3. Inclusive and participatory research

All the previous themes have already implied how contemporary research places the people living with a disability at the centre of inquiries (Franklin and Sloper 2009; Esan *et al.* 2012; RCGP 2014). The growing interest in research with people with hidden dis/ability where participants could have a voice and act more as a mere subject of the investigation became prominent from the 1980s as "research has usually treated disabled people as subjects of research, rather than partners in research" (Disability Rights UK 2016). Whilst inclusive research with people with hidden dis/ability has increased, and numerous studies highlight

the benefits (Williams 1999; McClimens and Allmark 2011; Williams *et al.* 2015; Woelders *et al.* 2015) significant issues still exist due to ethical considerations, the phenomena of over-protection and the question of capacity (Walmsley 2001; Abell *et al.* 2007; McClimens 2011; Staddon 2013; Frankena *et al.* 2015; Crook *et al.* 2016). Nind and Vinha (2014), Walmsley and Johnson (2003) and Atkinson and Walmsley (2010) highlighted that this field remains fraught with difficulties and that there were many marginalised groups whose voice has been silenced in research not only people with hidden dis/ability.

Brown (2003) and Brewster and Ramcharan (2005) highlight that including people with dis/abilities as experts lead to overall better outcomes, and how they should be present when decisions are made about them (McLaughlin 2009; Disability Rights UK 2012; Noorani 2013). The literature has shown how higher education institutions have established service user groups to be partners in the selection, learning and research (Simpson 2006; Bollard *et al.* 2011; O'Boyle-Duggan *et al.* 2012; Naylor *et al.* 2015). Public bodies such as the NHS, CQC, Local Governments set up networks to involve their expertise in policy development, audits, commissioning or the planning of their strategies, service delivery and feedback mechanism (Evans *et al.* 2003; Moore 2008; Sexton 2010; Martin 2011; Omeni *et al.* 2014). Conversely, Horrocks and colleagues (2010) and Cowan and others (2011) highlight how people with disabilities are often well-articulated and hand-picked, thus the benefit of involvement often does not translate to the wider hidden dis/ability population.

Involving people with hidden dis/abilities as experts are wide-ranging from partnership working and collaboration to a form of symbolic and rewarded consultation. Scott-Hill (2003), Terzi (2004), Shakespeare (2004, 2005, 2014), Taylor (2005), Shakespeare and Watson (2010) and Schalock and colleagues (2018) draw attention to the difficulties of exploring and describing the interconnected nature of the experiences. Besides, conflicting

realities and an imbalance between the partners are an inevitable part of such connectivity that is challenging to overcome (Carr 2007; McCutcheon and Gormley 2014). Nevertheless, these studies draw attention to the importance of putting people with disability at the centre of works. People with hidden dis/ability are experts in their own lives. Participation in research gives people a voice in identifying what matters in their lives. Participation is an important way to achieve choice, control and confidence through taking action about some of the difficulties people with hidden dis/ability face (Docherty et al. 2005; Beckett 2006; Tilly 2015; Williams, Pronting and Ford 2015).

Participation and inclusion raise as many questions as it answers. What this study takes from it that as long as people with hidden dis/ability remain underrepresented in most areas of life including research, then the issue of participation and inclusion must remain central to the field.

3.3.4. The mundane and everyday lives in disability studies

Since the de-institutionalisation process, a central aim for realising the social inclusion and rights for people with a disability was through community living (Davidson et al. 1996; Morris 2004; Mansell 2005). Most research relating to community living predominantly have explored issues of participation such as employment, parenting and leisure, forms of support or living conditions with a critical aspect on accessibility and equal rights. A smaller body of research has inquired particularly about everyday life. Everyday life in this thesis refers to the mundane, ordinary and the specifics from an interdisciplinary perspective as it presents in social relations and practices. The study of hidden dis/ability should be explored within the context of everyday life as it is this arena in which the production and consumption of social roles manifest as people with hidden dis/ability come into contact with others (signs and things) through their participation in the mundane, ordinary and specific aspects of life.

The processes of marginalisation, oppression or inequality, the fundamental focus of disability studies, are created in these varied daily activities. The study of everyday life with a particular focus on the mundane that brings an inherent focus on the details has become an essential part of understanding cultures including dis/ability (Lefebvre and Levich 1987; Felski 2000; Herzfeld 2001; Scott 2009; Simplican et al. 2015; Brekhus 2016). On the one hand, the broad conceptualisation of everyday life presents us with the fragmentation of themes as it is difficult to define it, and it lacks clear boundaries. On the other hand, it is this fluidity and flexibility that help us explore multiple dimensions of the complexity of everyday life of people with hidden dis/ability. The included studies, therefore, varied in terms of the settings, designs and theoretical underpinning whilst keeping at the centre the service users' perspectives on everyday life. I offer three characteristics of such studies.

First, a significant amount of papers on the everyday life of people with hidden dis/ability consists of methodologies that solely rely on retrospective accounts such as interviews and focus group discussions (Parr, Philo and Burns 2004; Donna 2008; van Alphen et al. 2010; Bond and Hurst 2010; Nonnemacher and Bambara 2011; Go 2012; Milbourn, McNamara, and Buchanan 2015; Gjermestad et al. 2017; McDowell, Bonner-Thompson and Harris 2020). These papers draw attention to a wealth of knowledge on almost all the important aspects of everyday living (barriers, best practice examples, meaningful activities, belonging, skills, autonomy, vulnerability, attitudes). However, even if the underpinning theories acknowledge the complexity and connected nature of everyday living, they are limited by their methodological constraints (limitation of data from interviews and focus groups and participants' ability to verbalise experiences).

The second group of research involves fewer studies using methodologies of real-time, naturally occurring, prospective data collection (Antaki, Young and Finlay 2002,

2007; Sirota 2006; Williams, Ponting and Ford 2009; Williams et al. 2010; Williams 2011; Antaki 2013; Antaki and Crompton 2015; Dowling et al. 2019). The wealth of knowledge created by these scholars is significant and impressive to show how actual interactions take place for people with hidden dis/ability in various context. Such studies highlight how hidden dis/ability is relational and the possibility of focusing on different strategies. However, studies in this group remain limited by their data analysis method used (even if their theoretical underpinning would not warrant this). They tend to focus on aspects of interactions, predominantly language (mostly verbal and non-verbal discourses) and humans' relationships bracketing off all the other factors that potentially could have influenced the interactions.

The third group consists of an even more limited number of research that used ethnography, life story research and other creative ways to the collection and analysis of prospective data, including geographic and social practice approaches. Whilst language (meaning-making) remains central, these studies have widened the circle of potential influences on everyday activities considering the material and abstract world in their methods (albeit often analysed separately). The works tend to acknowledge that everyday activities do not happen in isolation (Bagatell 2007; McClimens, Partridge and Sexton 2014; Abbott and Mcconkey 2016; Williams et al. 2018; Wilton, Fudge and Marquis 2018; Stajduhar et al. 2019; Voronka 2019). Therefore, these research approaches are potentially one of the closest to the thesis. These studies draw attention to the complexity of activities, including the role of signs and things. They show in more detail how everyday activities are composed and also how they change and evolve.

The vast amount of work on everyday life is essential for this thesis as it highlights how social roles are composed in interactions. It draws attention to the details of the frequent, small areas of everyday life in which a person can experience power imbalances and how

such practices create inequalities and oppressions. It also highlights that it is important to focus on small and banal opportunities.

3.4. More recent works of disability studies - refiguring representation and restructuring universal concepts (Third Stream)

3.4.1. Critical disability studies

Critical disability studies remain grounded in the social model and views disability as a form of institutional discrimination, oppression and social exclusion. It is, in fact, a cross-cutting theme, the continuation and synopsis of all the works explored and many more that would not easily fit into the simplified themes of this literature review. In other words, critical disability studies connect the aspirations of disabled people with transformative agendas of class, gender, queer, race, postcolonial and post-conventional studies. Moreover, it is the view and commitment of scholars to include a wealth of approaches, share ideas and practices, whilst responding with political activism and critical analyses of ableism and disablism. The studies aim is to identify, describe, and evaluate the origins of the social and political culture, discourses, and institutions that underpin oppression. The significance of this body of work lies in its eclectic and wide-ranging empirical and theoretical investigations acknowledging the complexity of disability matters (Goodley, Hughes and Davis 2012; Goodley 2014).

Contemporary works revisit key issues of disability studies such as binary oppositions (impairment and disability, nature and culture), identity and the cartesian dualism of the body and mind. Whilst this body of work is founded on the first and second streams, scholars seek to extend and elaborate on its theoretical and empirical investigations by drawing on ideas outside of the traditional disability studies. Continuing previous theory formations, a

biological view of disability is rejected. Instead, it investigates the discursive, cultural and political construction and the relation of the natural and the social (Shildrick, 2012; Goodley 2013; Nguyen et al. 2019). Critical disability studies openly create spaces for rethinking normative bodies and minds, self and other, institutions, identities, powers and agencies. Performativity, deconstruction and becoming, the work of Lyotard, Derrida, Deleuze, Guattari, Haraway, Butler and Braidotti amongst others are significant in exploring an active and embodied disability.

Deleuze (1992, 1995) shares many of Foucault's standpoint on power, control and society. He develops it further as he argues how the massive, closed institutions, characterising the first half of the 20th Century, have begun to fragment into many smaller open organisations and community care where social control and power work in different ways. Deleuze and Guattari, like Foucault, have been privileged in disability studies as their philosophies deal with questions like how to achieve recognition of minority groups and formulate the politics of difference as multiplicity. Moreover, philosophy is a political act for Foucault, Deleuze and Guattari to disrupt norms and produce new inquires that fits nicely with critical disability scholar's work of political activism. Meekosha and Shuttleworth (2009) and Goodley, Liddiard and Runswick Cole (2018) emphasised how critical disability studies is an emancipatory and emerging discourse where disabled people and the lived experience remain at the centre of the approach. Critical disability studies explore and discuss differently the impaired and disabled body and mind as postmodern thoughts become significant.

Haraway's (1991) and Braidotti's (2002) works on the hybrids of technology and humans remain hugely influential as they revisit fundamental issues of normalisation and cure penetrating further the case of binary oppositions (able and disable). Deleuze and Guattari (1988) have also deconstructed binaries moving away from statements of disability to the

processes of becoming. Such contemporary views have been applied to various topics in disability studies (although predominantly relating to physical disabilities) to overcome apparently competing binaries and find new ways of understanding and transforming the complex questions of self, culture and society (Garland-Thomson 2002; Griet et al. 2008; Beckett 2013; Henderson et al. 2014; Vandekinderen and Roets 2016). The works also show how scholars remain faithful to the origin of disability studies and the belief that change can only be achieved through the politicisation of disablism. Shildrick (2020) highlights that the move towards postmodernism in critical disability studies has been creating one of the most exciting new theoretical works.

The concepts of Identity and identification in critical disability studies has received a renewed interest as more eclectic and contemporary understandings and voices have emerge. An exciting development has been the affirmation model and it's non-tragic view of disability and impairment aiming to encompass positive social identities. This is markedly different from the previous two streams and closely aligned to this thesis's approach. Swain and French (2000) and McCormack and Collins (2012) who argue how the experiences of disabled people demonstrate that being disabled can have benefits, and identification as disabled can be positive. Contemporary research in disability studies shows a range of orientations to disability and identity as disabled people do not share a common perspective on ableism, oppression, the social model or the personal tragedy view (Darling 2003, Darling and Heckert 2010).

It is also worth noting how Stamaou, Aleviradou and Soiufla (2006) show in agreement with a number of studies (Solis and Andreou 2007, Ytterhus, Wendelborg, and Lundeby 2008, Welsby and Horsfall 2011, Bosteels et al. 2012, Cardona 2013) that people living with dis/ability seem to be less stereotypical and rigid in conceptualising different types of disability. Disabled people tend to find it more complex and challenging to negotiate their

identities in everyday life between the social and the medical model and the mainstream assumptions about disability than earlier works on disability identity have argued. Some authors go as far as to suggest that many disabled people are not even aware of the central debates present in disability studies, including notions of identity and identification as disabled (Dunn and Hammer 2014; Dorfman 2018). Therefore, there is a growing voice in contemporary disability studies challenging some of the relatively rigid positions on disability identity. For example, they argue that disability cannot be understood as a simple and fixed thing, and it should be viewed as complex, shifting and emerging from everyday situations. Colin and David (2012) explain, for example, how most disabled people do not want to hide the complex and often confrontational part of disability identity. However, they are often forced to do so by our practices. Besides, it is people living with hidden disability and especially autistic people who presented new ways of understanding disability and one's identity in relation to disability.

This emerging body of research focuses on the nuances, complexity, and individualised experiences. There is a move away from the very word disability to more positive and inclusive terms like neurodiversity. Neurodiversity does not distinguish between disabled and disabled or disabled and non-disabled but facilitates a variety of experiences and a more contemporary concept acknowledging that hidden disability is complex (Antze 2010, Armstrong 2010, Sarrett 2016, Beck 2018, Anderson-Chavarria 2020). This thesis takes this contemporary understanding of identity as its starting point. It aims to add to this body of knowledge by focusing, not only on how identities are formed in complex and shifting context but, on how they dissolve and then are reproduced again. This novel understanding of disability identity, especially autism and hidden disability, blurs boundaries between the social, the medical and the personal and reassembles concepts of disability and difference. Works from critical disability studies are essential sources in this thesis as they keep on interrogating the socio-political constructions of disability and the impacts they have on

people's identity. These works destabilise grand narratives and render problematic universalism, unification and foundations whilst they keep on displaying disability in immediate reference to power. Although disability remains a unique identity, nevertheless it is flux and constructed.

3.4.2. Assemblage thinking and new materialist approaches

Critical disability studies were influenced by the environmental turn, constructionist turn, linguistic turn and an emancipatory agenda (Corker and Shakespeare 2002; Gustavsson 2010; Shakespeare 2014, 2016; Owens 2015; Power and Bartlett 2018) focusing more on interactions and relations rather than individual factors or the dominant role of language characterising the second stream. Söder (1999) formulates the underlying principles as “not to lock oneself into the idea that certain individuals have certain problems ... or that one beforehand has decided that the context has certain characteristics”. The relative-interactionist approaches aim to bridge if not break down the separation between the various factors causing hidden dis/ability by focusing on relations at a theoretical and practical level. These approaches assert that the complexity of disability requires multiple and complex methods and should be less driven by debates of binaries to grasp the mundane and specific aspects of living with hidden dis/ability.

I will explore New Materialist (affect, rhizome and assemblage) theories (often associated with the work of Braidotti, Deleuze and Guattari) separately, as these studies have moved on from the exploration of complex interactions to connectivity and assemblages. Thus, these studies are one of the closest to the approach of this thesis. The underpinning positioning can be said to be anti-anthropocentric (other terms include new humanist, post-humanist and dis-humanist), anti-essentialist and anti-foundationalist. Humanity and generally humans being at the centre of all investigations have become an issue for many

contemporary disability scholars for various reasons, for example, questions of rationalism, embodiment, autonomy, normalcy and agency. New materialist studies decentre humans and explore everyday activities and the concept of hidden dis/ability as assembled and connected (Goodley 2007; Braidotti 2010; Holligan 2015; Fox 2016; Fox and Alldred 2016; Brownlie and Spandler 2018; Fox and Bale 2018; Goldschmied 2018b).

The studies are predominantly positioned in Deleuze's and Guattari's philosophies where the social world is constructed by non-hierarchical and complex interconnections, which they refer to as assemblages. In other words, no human or material phenomenon exist in isolation, and nothing has existence and meaning without an analysis of the processes, the becoming by complex arrangements of interrelated entities (Deleuze and Guattari 1987). Assemblages and beings are in constant flux and multiplicities. The impaired body and mind are social, embodied and non-dualistic. Hence these studies have a focus on the processes of social production, the becoming of things, like the sexuality of people with hidden dis/ability as explored by Feely (2015, 2016b), where impaired bodies and minds are always in process. The word rhizome is used to describe the interconnections that occur between humans, objects, times and places.

Within this ontology, material and semiotic entities are on the same flat plane mutually affecting each other. Deleuze and Guattari's philosophy, as already interrogated, agree with disability studies' aims of activism, challenging inequalities and deconstructing deficit thinking within dynamic and reflexive networks of social activities (Goodley and Roets 2008; Roets, Reinaart and Van Hove 2008; Mercieca and Mercieca 2010; Skott-Myhre and Taylor 2011; Braidotti and Roets 2012; Shildrick 2015; Feely 2016a, 2019; Dalgleish, Everett and Duff 2019; Fox and Klein 2020). Whilst there are a few empirical studies involving people with physical disabilities and children in this theme, studies with adults with hidden dis/ability and specifically concerning the mundane, everyday life are embryonic at best. In summary,

such works argue that our society is built on norms, and people are ordered depending on their positioning concerning the norm. Furthermore, the use of binaries (as well as the in-betweens) remains important to show how normative assemblages are organised and how people with hidden dis/ability are controlled in it. There are multiple, complex and layered identities, not one fixed disability identity. Moreover, the transformation of power and oppression is possible through ongoing movements and disruptions of the dominant assemblages by becoming minorities.

Assemblage thinking and its ontological and epistemological positioning also pose significant difficulties in disability studies as it understands oppression, power and disability as effects like any other phenomena. However, as Goodley and colleagues (2020 p3) work summarise, scholars must remain faithful to the founders of disability studies (mainly Hunt's and Oliver's ideology) and how "race, ethnicity and disability merge together in moments of power and oppression". Nevertheless, these works are highly influential in the thesis as New Materialism and assemblage thinking share the most with the positioning of Actor-Network-Theory regarding the notion of reality, knowledge and being.

3.4.3. Actor-Network-Theory, Latour and Baudrillard in disability studies

The literature review has explored how we need to work with many conditions that have attracted numerous ideals, theories and practices composing multiple realities of hidden dis/ability in the 21st Century. Law (2016) used the term 'suffocating alternatives' to refer to the existence of myriad theories and their practical consequences on how to decide which reality is preferred, by whom, to whom and how to draw lines of divisions. This proliferation and fragmentation seem to direct our attention away from the actual everyday performances: the mundane, the specific and the ordinary. Both Baudrillard (1993) and Latour (1993) argue where a causal process can be established, it means it can be

replicated. What we need to see is that “noncausal event can never be duplicated” (Baudrillard 2002 p191) and we need to reverse and re-assemble hidden dis/ability (Latour 1999a).

Some scholars argue that there are minuscule and easily reconcilable differences between the ontological and epistemological positioning of Actor-Network-Theory and New Materialism and the Deleuze-Guattarian assemblage thinking (Whatmore 2002; Bennett 2010; Farias and Bender 2010). However, this thesis asserts that whilst there are similarities, there are also some significant distinctions (Latour 1993, 2005; Mol and Law 2005; Law 2007). One of the key differences lies in the notion of agency and the emphasis that any entities can be granted the force to act. These entities are called actors as they are produced and reproduced as effects through their associations with other actors. The main characteristics of Actor-Network-Theory are introduced in other chapters. Here, I provide a summary of works that applied Baudrillard or Latour and Actor-Network-Theory to hidden dis/ability.

I could not locate any studies that used Baudrillard’s and Latour’s works or Actor-Network-Theory together and applied some of their main philosophies to hidden mental and cognitive dis/ability. No studies were found in the broader area of disability either, except two theoretical papers that considered the two cotemporary thinkers simultaneously (Ward 1994; Gali 2017). A limited number of studies were found that did not use Baudrillard in detail, but instead mostly offered a brief reference to his well-known concepts of hyperreality and simulation (Todd 2002; Shuker 2004; Pendergast 2008; Todd, Bernal and Forrester-Jones 2013; Stone-Mediatore 2014; Pinchevski and Peters 2016; Żółkowska 2014, 2016; MacLeod 2019). I could not locate any empirical or theoretical studies that specifically applied a Baudrillardian analysis to the everyday life of people with hidden dis/ability, or more generally to disability.

The literature search yielded a similar result when Actor-Network-Theory, Latour and the various terms for hidden dis/ability and the mundane were explored. Only a handful of studies have been found within the broad definition of disability (Prout 1996; Moser and Law 1999; Manning 2002; Mol and Law 2004; Moser 2000, 2006; Mol 2008; Struhkamp, Mol and Swierstra 2009; Tummons 2010; Galis 2011; Larsson 2011; Mol et al. 2011; Moser 2011a, 2011b; Ahmedshareef *et al.* 2014; Heeks and Stanforth 2015; Venturini *et al.* 2015; Wróblewski 2015; McDougall *et al.* 2016; Abrams and Gibson 2017; Goldschmied 2020). These studies expand on the previous post-conventional approaches, specifically, the heterogeneity of actors and the capacity to act. However, most works remained short on how they employed an Actor-Network-Theory-informed data analysis, eventually using well-established methods, more or less successfully aligned with the epistemological and ontological positioning of Actor-Network-Theory. I could not locate any studies that explicitly applied both theoretically and practically the tenets of Actor-Network-Theory in an empirical study to the everyday lives of people with hidden dis/ability.

These studies are significant in this thesis as they have provided valuable ideas of how Actor-Network-Theory, Latour's and Baudrillard's works can be theorised and applied to hidden dis/ability in an ethnographic study.

3.5. Key ideas and strengths learnt from disability studies

The studies summarised in three streams stand for an enormous number of published works in disability studies. I have provided a brief review of how these approaches have made a significant contribution by working with the conceptual and methodological tools that have dominated the field during this era. I have learnt something from all of these streams, and they have provided my research with critical ideas on the everyday life of hidden dis/ability. I will summarise here a set of characteristics based on the existing research and theories

in disability studies that I took as their strengths and influenced my work on hidden dis/ability.

First, hidden dis/ability can be approached more than one way. All the works in the three streams are valid ideas about what hidden dis/ability is, and how we should understand it. Hidden dis/ability is complex and influenced by social, cultural, political, moral, but also biological actors. There are connections and affects between the actors that can be studied. Some of these are how people with hidden dis/ability become to be oppressed, discriminated, marginalised, or protected. People with hidden dis/ability have a voice. The exploration of such connectivity, composition and effects can be significant in our understanding and development of theories and practices.

Second, although people with hidden dis/ability can be considered as members of the various categories (made up of individuals as well as many other connected actors), each category is more than just a collection of actors. What a category represents, its signification, its associations with other actors, and its capacity to affect and be affected have significant consequences for how it performs in everyday life, and how the people with hidden dis/ability as well as others (professionals, carers, policymakers) 'see' the performances. The various conditions of hidden dis/ability can be grouped with boundaries, but they are never permanent, isolated or closed. The boundaries are composed and culturally situated. Thus, it is symbolic, temporal and permeable. Therefore, the vast amount of research showed that there could be other, more beneficial boundaries and groupings in everyday life as people with hidden dis/ability connect with many other networks (and identities) in which they are embedded – organisations, communities, physical and cultural environments. They also have the potentiality to affect other people placed within their categories, as well as others or those placed differently.

Third, people with hidden dis/ability, the categories representing the so-called mental and cognitive conditions as well as all the other actors composing them (including the medical and social models) form, perform and change over time, even dissolve and transform. Hidden dis/ability does not only form and affect via multiple connectivity, but they are also affected by those connections. People with and without hidden dis/ability, all the actors present in an event, have the capacity to affect as they form relations with people, objects and abstracts in their various embedding networks.

3.6. Some limitations of disability studies

Despite its many strengths in contributing to our understanding of hidden dis/ability, much work done within disability studies shares some conceptual and methodological features that also limit what they can offer, especially in exploring everyday life. Certain limitations, I believe, are determined by the dominant ideology of social oppression and social model of disability to which the underlying methodologies are linked and within which most works are positioned.

3.6.1. A moral-political-identity research paradigm

Much of North American and British disability studies, within which hidden dis/ability research has recently flourished, have been heavily committed to the standpoint of disability being an identity. It is rooted in two main concerns: disablism and the resulting political struggles against all forms of power, discrimination and oppression. Within that positioning, the lived experience, human intentionality, and a moral-political approach is the ideal underpinning of the methodological strategy. In the second and third stream, a poststructuralist and a postmodern influence aimed to counteract some of these limitations by deconstructing notions of binary oppositions, normativity and single identities. However,

in my reading of the literature, most of these studies were unable to be fully committed to the epistemology and ontology of their acclaimed paradigm. I argue that even contemporary scholars were unable to overcome their moral-political-identity standpoint: the foundational commitment to disability being not an effect but an oppressed and marginalised minority group. It appears that oppression, discrimination, and vulnerability and notions of power that compose them somewhat remain 'real' and beyond analysis.

The first stream differs from the second and third streams regarding the source of the issue. The first stream tends to highlight the way capitalist economies have no use for people with hidden dis/ability because of their impairments (materialist, Marxist, neo-Marxist, critical realist). Works from the second and third stream rather emphasise how cultural meanings are constructed by those perceived 'normal' in centres of institutional power (poststructuralist, postmodernist, post-conventionalist, new materialist). The former was heavily influenced by Marx's labour theory, linking values to the economy. People with hidden dis/ability are left out of fundamental social interactions and community activities because of their inability to make economic contributions. The latter was heavily influenced by Foucault's ideas and scholars like Deleuze's and Guattari's works where certain people or groups hold privileged discursive and other forms of power, linking values to normal bodies and minds. They argue that people with hidden dis/ability are excluded, controlled and oppressed because they are disruptive and undesirable.

Economically driven exclusions mean people with hidden dis/ability are a drain on resources that has to be managed by the authorities. Whilst cultural representation driven exclusions can be traced back to powerful discourses of individuals and organisations with authority that also influence others. The first stream promotes that changes must begin at a political and economic level, whilst the second and third streams put change in the cultural realm, the world of ideas and knowledge. Besides these differences, I believe, most works share

a similar ideological and methodological positioning: people who live with hidden mental and cognitive dis/ability are deemed 'abnormal', 'vulnerable, and 'discriminated' by some actors but not all, mostly humans with agency keeping the notion of power and oppression at the centre.

Besides, whilst the social model of disability is a powerful political tool to identify external social barriers as the cause of disability, their coming into existence (formation, dissolution, reproduction) is not interrogated. It has been made static and somewhat already existing. Works in disability studies must be located in the social model and this is problematic. Contemporary scholars argue, the 'updated' social model is an all-encompassing one, yet they are unable to consider an 'updated' medical model that acknowledges that there are social barriers. It is troublesome, as it does not overcome the binary oppositions of nature and culture, impairment and disability, but by mirroring the medical model (and the attached methodological principles), it becomes what it aimed to dismantle: a hegemonic and particular reality of hidden dis/ability. Disability studies then somewhat replicates and reproduces some fundamental (predominantly essentialist and universalist) scientific research principles, for example, the preference of methodologies grounded in existing 'evidence' and the existence of the categories. I argue that even if scholars locate their work in a post-conventional and dis-human paradigm, power, oppression, and the social model remain beyond, or are placed beyond construction. These actors are not seen as becoming but a 'real thing' derived in linear fashion from the past.

These features allow scholars, except for some works from the third stream, to treat hidden dis/ability as existing and constructed by many but not all actors. For the most part, both early and expanding research have embedding networks that construct disability (the academic environment, political arena, interview in isolated places, a single observation in a setting, the researcher who structures the study). However, studies preference to examine

a handful of actors only relevant to their perspective and previous evidence. This is an almost inevitable consequence of the preferred moral-political-identity paradigm and of the analytic forms of theory that are its method. Moreover, most scholars still separate the various categories of disability as a unit of study.

It follows, for both methodological and practical reasons, works done within the moral-political-identity paradigm have to give up other considerations. First, most research and theory pay little attention to the complex associations of actors and their significations composing hidden dis/ability with their embedding network of signs and things. They treat some if not all actors as if they were isolated and whose only significant connections to their embedding network involved the researcher-imposed signs generally based on existing evidence. Second, these works seem to assume that some connections act upon people with hidden dis/ability as the starting position remains static: people with hidden dis/ability are oppressed, discriminated and victims caused by society. Third, it tends to examine hidden dis/ability from a distance limiting its composition to a handful of actors. They study a limited number of actors, ignoring, holding constant, or selectively identifying other aspects of hidden dis/ability and its embedding network. Finally, fourth, studies in that paradigm typically work with designs that assume and accept the differences between people with and without a disability and between the different conditions whilst they reject the medical model that created those categories.

The huge volume of research and scholarly works from this perspective has been significant, and it has brought tremendous results with major influence on policy and practice. Nevertheless, at the same time, those achievements inevitably give us a particular conceptual and methodological picture of hidden dis/ability. I believe, most of these works do not 'see' the potential of hidden dis/ability being an active performance continually engaging in complex associations and significations with other actors of their embedding

network of connections (some of which are travelling from faraway places: people, objects, memories, places, non-human subjects, ideals) from and to which capacity may flow to compose but also dissolve hidden dis/ability. It prevents us from fully appreciating three of the major features of hidden dis/ability: namely that hidden dis/ability is complex, connected and transient. I strongly believe that attempts to ignore that hidden dis/ability in everyday life is performed by non-linear, dynamic, and connected signs and things are both limiting and destined to fail. Although apparently permanent signs and things such as social barriers, power, oppression, and identity can make hidden dis/ability look like as a distinct entity, all hidden dis/ability has multiple existences.

I believe that what is overlooked in these works is the scholars' commitment to the details, dimensions and dynamics of their moral-political-identity positioning. I believe we need to study hidden dis/ability as a complex phenomenon. This may be inconvenient for methodological reasons. However, insisting that hidden dis/ability exists rather than being composed by many actors and their complex connectivity, I believe will systematically mislead us potentially disadvantaging people with hidden dis/ability in everyday life. I firmly believe that hidden dis/ability performs, dissolves and reproduces with their embedding network of significations and associations, as both hidden dis/ability and the embedding networks shape one another.

3.6.2. Methodological and practical challenges

Another notable limitation is, partly as a consequence of the underlying moral-political-identity paradigm, that most research study hidden dis/ability: short-term or one-off, in a well-defined context, linked to existing 'evidence', to inductively collect further evidence about already established issues, positioned in the social model, where one disorder is mostly separated from others, or the same disability distinguished from each other by their

degree. In short, they aim to establish a scientific system of disability research. Hidden dis/ability is treated in context but resembling the scientific laboratory be it a school or a shop, where the brief observations or interviews encompass the entire history of hidden dis/ability. Such a research methodology has no experiences of composition and becoming: the formation of a particular issue might be important but hidden dis/ability itself is there already. Therefore, its dissolution is not very interesting because it is entirely pre-determined: hidden dis/ability is there, in its reality, separated from the rest, constructed and oppressed by society.

Naturally, for both practical and methodological reasons, such rather short and isolated studies done with separated conditions have been far more prevalent within disability studies than longer ones, including a mixture of conditions and many contexts. More extended studies, involving more than one condition, context and repeated data collection (mainly traditional longitudinal research and ethnographies) are incredibly costly in time and resources. Nevertheless, individuals living with hidden mental and cognitive dis/ability carry a rich combination of culturally meaningful identity signifiers that distinguish one person from another within and between groups. We do not only fail to 'see' the fluidity and relativity of the traditional identities like gender, sexuality, ethnicity, religion, age but the less frequently considered ones too such as taste, hobbies, memories or profession.

The transient nature of identity signifiers (like any signs) reminds us not to unite people into apparent permanent categories such as 'the disabled', 'the woman', 'the old', 'the musician', 'the autistic' or 'the oppressed'. It also signals that people with disability comprise of diverse lives with many shared as well as different performances beyond their assigned categories and role in society. Nonetheless, balancing 'sameness' (the collective) and 'difference' (individuality) is not straightforward. Moreover, even if disability may be viewed and analysed in light of intersectional theories, the implications for methodology and research

design are not self-explanatory. Therefore, and because of the moral-political-identity positioning, it is inevitable that disability studies have chosen the importance of campaigning for rights as a community of disabled people on the one hand, whilst keeping the mental and cognitive conditions separated on the other, to maximise their potential political and social impact.

I believe this approach is not satisfactory any longer as it presents us with theoretical and methodological challenges. I argue that such transient matters are worthy of study, and we need to experiment with and invent novel designs and methodologies. Even if such research is complex to realise, a body of work made up almost entirely of one-off and short studies, with participants habitually separated by the medical categories, mostly using neat designs to collect and analyse predominantly retrospective data or prospective ones in well-defined contexts leaves the field with something missing from its knowledge base, especially when everyday life is concerned. My practice experience has shown me that people with hidden dis/ability live a far more exciting, obscure, and unpredictable life for far longer than the typical studies showcase it, usually highlighting their oppression, inequality and difficulties.

Hidden dis/ability performs and dissolves, adapts and changes continuously. It generates a history. However, this history may not be linear or additive as it can be quite different from the histories of other comparable hidden dis/ability's histories yet can be very similar to the ones usually considered to be quite different (because they do not have a disability or not the same category). Aspects of that history, like any other actors, has the capacity to affect a performance. Moreover, the processes by which the performance of hidden dis/ability is composed, form connections with other actors in the embedding network, and the significations of such often random and unpredictable associations, are rewarding to study if we aim to 'see' hidden dis/ability in everyday life as a possibility for transformation.

I appreciate that such expectations and complexity generate several methodological problems. First, to learn about the processes by which hidden dis/ability made visible (perForm, disSolve, reProduce), we need different approaches. I believe such a methodology should use as many components as possible of varied observations (collect various data) of diverse processes at differing settings (many contexts and activities) with multiple conditions (maximum variations sample) and observe the consequences too (repeated and longer time intervals). Even if for practical reasons, we use short term designs or retrospective data, we should do research with many conditions (and people without) to see the shared as well as distinct performances. Second, we need approaches that move away from starting the inquiry from already established 'evidence' positioned in a moral-political-identity paradigm to remain open and adaptable to the challenges of everyday life that if anything is complex, obscure, and abductive but rarely factual, inductive or deductive. I alluded earlier how such designs generate a different history of hidden dis/ability that is significant but also methodologically challenging. First, we can notice and record the naturally occurring dissolution of hidden dis/ability. Second, any later performances selected for observations are inevitably affected by earlier events. In short, hidden dis/ability at any given time, for the most part, is affected by its networked past, including the history of all connected actors - legislation, medical categories, benefits. Therefore, whilst this will not provide us with linear and additive 'causations', it can show us how opportunities operate to explore alternative possibilities and future potentials that most present studies fail to acknowledge. Complex multi-directional affects then compose hidden dis/ability.

The connectivity of actors composing hidden dis/ability are continuing, dynamic and transient. Data based on one-off inquiries or the explorations of effects before and after a connection with specific actors or a specific setting and issue, do not give us much opportunity to explore the composition, production and consumption of alternative possibilities. The choices, driven by our dominant methodological paradigm, prevent other

ways of 'seeing' the performances. When we study hidden dis/ability by methodologies that has no past and future beyond a single session and the already existing associations (at a particular place, time and context), we are imposing methodological limitations as well as practical ones. We fail to notice how signification operates, shared performances are composed, and the ordinary, specific and mundane activities perform people into existence.

3.6.3. The legacy of the founding physical disabilities

Disability studies were established by people living with physical disabilities, hardly paying any attention to people with hidden mental and cognitive disability initially. Traces of a general hesitancy among scholars to link disability and the various mental and cognitive conditions (partly explained by the convoluted history of disability politics over the past 50 years) are still observable today. Studies in the first stream were based predominantly on physical disabilities, and scholars have been slow to include people with hidden dis/ability in their works. We know that activists of hidden dis/ability established BILD, NAS, Alzheimer Society, MIND and MENCAP with a UK-wide network at the same time as people with a physical disability were lobbying for recognition. Such organisations were also committed to similar rights such as empowering people, giving them a voice and fighting against stigma, oppression and discrimination in line with the disability rights movement' slogan: "Nothing About Us Without Us". In academia, examples include works from researchers in the intellectual disability and mental health field (traditionally they were not part of disability studies) who have explored comparable topics (examples are given in the literature review).

Beresford (2002), Beresford and colleagues (2011), Goodley and others (2012) and Shakespeare (2013) explain the delay and controversies, many remaining today, with the disability movement's long-standing struggles to becoming an all-inclusive approach to all identity groups within disability (all possible conditions) and beyond (people who primarily

identify as 'LGBT', 'Black', 'Deaf', or 'Female'). All these moral-political-identity difficulties of diversity connect to and are affected by the ongoing theoretical and methodological arguments within disability studies about the nature of the impairment, the body, the mind, the environment and embodiment. It was the works in the second stream that started to deliver some significant outcome for people with hidden dis/ability and engaged with 'mad studies' and 'intellectual disability studies' (the renaming of research centres, like the Norah Fry Centre around 2015 for disability studies, symbolises this move).

It is not surprising that scholars, who were among the first to include mental and cognitive conditions in disability studies, found inspiration in the moral-political-identity positioning, the social model of disability and the founding works of Paul Hunt (1966), the UPIAS (1976), Vic Finkelstein (1980), Erving Zola (1988), and Michael Oliver (1990) on care provision, political-social-cultural barriers, the social activities and collective practices of professionals. From the beginning, disability studies focused on the social barriers to represent the best interests of oppressed people. This also had two further inevitable consequences. First, the notion of overprotection and control of people with hidden dis/ability became a concern. Second, over the last decade or so, we have also witnessed a growing willingness to disclose a hidden mental and cognitive dis/ability. Public campaigns, non-profit organisations, scholars and high-profile figures have joined on behalf of people living with hidden dis/ability. In short, the unique voices and perspectives of people living with hidden mental and cognitive dis/ability now have a presence in everyday life.

3.7. Needs for future research

Research concerning intellectual disability, autism or mental health problems is now well established in disability studies and beyond. However, I believe work remains to theorise the individual and social consequences of linking dis/ability and mental and cognitive

differences. In my view, disability studies have reached its limits of what can be learnt about the everyday performances of hidden dis/ability using the currently dominant moral-political-identity paradigm, the related methodologies, and the attached data-gathering and analysis methods that are its main tools, and the theoretical conceptions that arise from it. I believe it is possible to make the next transformation in our understanding of hidden dis/ability and people's everyday lives. I argue we need to keep on borrowing and mingling with tools to invent new ways of 'seeing' hidden dis/ability and doing research that allow us to conceptualise and study hidden dis/ability as complex, transient, and connected.

At least three fields of study have been concerned with such challenges as complex, transient and connected. I argue some of their concepts may be useful in hidden dis/ability:

1. Contemporary philosophy, particularly the work of Baudrillard and Latour whose key concepts using semiotics are already partly integrated within sociology, cultural studies and arts.
2. Complexity and network theory, which is beginning to be prominent within sciences but with only traces seen in sociology, cultural studies and arts drawing attention to notions of adaptation, self-organisation, heterogeneous agents, connectivity, and dynamics where order emerges from local interactions.
3. Focus on surprise and alternative possibilities, which draws attention to temporality, non-linearity, adequate determinism, and emergent effects revealing potentials for transformations.

In short, the routes to mundane, specific and ordinary performances of hidden dis/ability are many, complex and even if it is mostly (but not always) determined by the actors' actions embedded in the networks, it does not mean it is predictable or causal but neither chaotic. We can find the traces of all three areas in social sciences, cultural studies and arts

including disability studies, but their implications have hardly penetrated the thinking of the field, and neglectable attempts have been made to translate them together into empirical work and practice, especially concerning hidden dis/ability. I believe that all three of those areas offer a great promise as the underpinnings of a theoretical conceptualisation and practical application of hidden dis/ability being complex, transient and connected awaiting transformation. To use such concepts in our theory and practice of hidden dis/ability requires, at the same time, that we shift both the logic of our study designs and the tools we use for collecting and analysing data. In the following chapters, I introduce the core of the theory from these considerations applied to hidden dis/ability, and the 6D material-semiotic network practice I have developed to collect and analyse data. I also discuss how shifting our way of 'seeing' hidden dis/ability leads to a new line of inquiry.

Summary

The literature review explored over thirty years of scholarly activities and research in disability studies. I highlighted many significant works and achievements and how they underpinned this thesis. I also noted some constraints and how this thesis aimed to overcome those limitations offering an original contribution to hidden dis/ability. I argue no single theory, approach or model of dis/ability can deliver universal solutions, and we must see what else is possible. I propose, one of these novel ways of seeing could be the application of Baudrillard's and Latour's work, including Actor-Network-Theory to the everyday performances of hidden dis/ability. This thesis starts with the position that hidden dis/ability is complex, transient and connected. Such positioning has the promise to offer some distinctive features to the dominant discourses that I believe can enrich our understanding and practice of hidden dis/ability in everyday life. Where so far, we have failed to fulfil our aspirations of giving dynamic responses to the often complex and unexpected challenges.

CHAPTER 4

Actor-Network-Ethnography methodology

At the beginning of this thesis, I proposed that the various categories of hidden mental and cognitive disability that are the foundation of most health and social approaches might be limited in exploring how hidden dis/ability is performed in everyday situations. I argued in the consequent chapters based on both research evidence and practice experience that traditional approaches to research were often based on the separated conditions and the binaries of the health and the social domains. The literature review showed how there was an opportunity for novel approaches and methodologies in working with the everyday performances of hidden disability. Therefore, I chose two contemporary theorists in semiotics, Baudrillard and Latour, to guide my work in developing a novel methodology avoiding the binaries.

4.1 Adopting a novel research methodology

I draw the conclusion from the presented evidence that if I move away from looking at the essentials of what it is to be dis/abled into the realms of connectivity and networks, then the everyday performances of hidden dis/ability become something very different. They are transformed into a jostling set of possibilities that could be viewed variously such as politically, financially, or morally; symbolically, aesthetically or as logical judgements and evaluations of what it is, we 'see' and 'value' rather than simply 'use' in the everyday performances of hidden dis/ability. I conclude from the literature and related practices that there is an emphasis on the politics, ideology and ethics of hidden dis/ability investigated with apparent scientific approaches and inductive methodologies. The exploration of hidden

dis/ability with the tools of semiotics and art is often neglected. Hence, my interest in exploring hidden disability in everyday living as 'performance art' concerned with aspects of experience which are hard to define with rigid scientific methodologies because they penetrate boundaries of the performer, the spectator and the scene due to the multiplicity of material, discursive and immaterial signs, their associations and significations. There has been a growing interest to extend art to non-art experiences including the everyday (Sartwell 2003; Shusterman 2003). Performance art, in this broader sense, examines an event as performance (made up of the performer, the spectator, and the scene) in the here and now, thus, often confrontational beyond traditional artworks. In this thesis and hypothesis (central argument) development, this expansive understanding of performance art helped me move towards an evaluation of the everyday performances of hidden dis/ability.

The literature review demonstrates how hidden dis/ability as performance provides me a solid basis for my study. Semiotics offer me a way to re-evaluate the political, moral, financial, aesthetic and the symbolic, as they are culturally situated and as such assembled. Yet, the signs, significations and associations of actors composing the everyday performances of hidden dis/ability are often hidden and silenced. Therefore, I made the conscious decision, I would explore how the everyday performances of hidden dis/ability looked not necessarily in terms of political, moral or identity matters investigated with scientific approaches but rather as performance art through semiotics to offer a novel lens to the everyday experiences life of hidden dis/ability. Consequently, when deciding on a suitable design and methodology, I considered which approach firstly, has the ability to surmount binaries and boundaries in this research between health and social, disabled and non-disabled, objects and humans, and the various categories of hidden dis/ability. Secondly, that could assist me in shifting the focus away from the assumed essentials and the universal towards particular significations and complex associations. This is a moving

away from the general epistemological concern of what methodology is best to represent the 'true and objective reality' of hidden dis/ability in every case towards situated ontological descriptions of the way different actors through their connections enact various realities of hidden dis/ability in everyday performances (Law 2007 p16; Latour 2013b p562).

The somewhat traditional view in research is that methodologies present a position or system in schematic form that is the combination of ideology, theory and practice. Methodologies provide the tools to achieve the intended outcome and, as well as, the world views denoting research (May 2011; Robson and McCartan 2016; Field 2018). These include immutable mobiles like standards related to statistical significance and less evident norms, the quasi-objects, the role of the categories or literature review in research, which serve a purpose and, as Latour (1993) explains, condense complex relations and their effects into manageable compartments to attempt to ensure we measure, narrate and promote the same aims.

In addition, the traditional research approach to 'ability' and hence 'disability' is dominant in separating apparently fixed hidden dis/ability performances into 'factual natural' and 'fabricated social' components. Law (2004) in agreement with Latour (1993) highlights that such approaches might give us reductionist answers about apparently isolated and stable phenomena but also conversely, such approaches have not yet delivered aspirations in understanding the palette of everyday performances that remain vague, unpredictable, constantly transforming and obscure. Serres (Serres and Latour 1995 p180) warns us that such binaries in hard sciences run the risk of becoming inhumane, just as the social sciences is seen as irresponsible. The desire for standardising and universalising on the one hand and separating and purifying the contributing actors and the categories themselves on the other is evident in most research and practices (health and social) exploring hidden mental and cognitive dis/ability that the literature review also noted.

The DSM (APA 2013) and the ICD (WHO 2015) provide the foundation for such essentialist and universalising objectives as well as for the political, economic and moral judgements. This is clearly present in the hidden dis/ability related literature as most research, professions and organisations explicitly or sometimes implicitly base their project on the categories and accept many of the assumptions as established facts. From the literature I have tended to disagree with, or at least challenge the terminologies and approaches used in hidden dis/ability that attempt to consider a handful of participating actors only and neglect how hidden dis/ability might perform differently in various everyday situations. This also means that the concept of hidden dis/ability remains problematic with no adequate answers on how we should, if at all, connect the diverse approaches and theories into one workable model. Latour (2005a) goes on to discuss how we should not fight against the categorisation, the frameworks and the many approaches but to consider what kind of capacities and effects the relations of actors compose and how they might transform connections.

I argue in this thesis that the categories of hidden mental and cognitive dis/ability aim to condense complex connections into a few words and the social model mirrors those practices that are not the only or the most pertinent way to understand and work with hidden dis/ability in the everyday performances. The need for pluralist approaches in hidden dis/ability show the complexity of the matter recognised by many contemporary professionals and academics (Moser 2000, 2006; Rogers and Swadener 2001; Davis *et al.* 2003; Gustavsson 2004; Shakespeare 2006; Francis and Silvers 2010; Baglieri *et al.* 2011; Gallis 2011; Venturini *et al.* 2015; Abrams and Gibson 2017). In other words, acknowledging that hidden dis/ability is heterogeneous, that there are competing affairs, and that we need multiple methods to explore and describe the diverse performances. However, Actor-Network-Theory and Latour's and Baudrillard's philosophy are more specific than such pluralists' arguments as their theoretical underpinning asserts that hidden dis/ability is not

a social construction, a fact of nature or a question of perspective but that hidden dis/ability itself is multiple. It is composed and performed differently every time depending on the actors and their connections. In this sense hidden dis/ability is not merely an 'ability' from one view and a 'disability' from another but emerges from the actor-networks and is performed differently in various connections. Multiplicity is an attribute of hidden dis/ability as well as the actors composing it, it is not a question of interpretation or causation. Interpretation (meaning-making) itself is relational, composed out of vast numbers of possibilities, and semiotics study the movement between signs and meaning, signs and things, and how order is composed (Akrich and Latour 1992).

Actor-Network-Theory might be seen then to be operating as language through connectivity. The network can be observed to replicate, or even be constituted by the structure of language, where there is relationality between the actors that compose ambiguous and multiple capacities and affects, as opposed to one true representation and interpretation. Separation and fragmentation in our medical and social approaches as opposed to connectivity lead to unconnected answers for some of the most pressing questions of hidden dis/ability: How best to represent hidden dis/ability? How do we decide who is 'disabled' and who is not? What makes someone 'disabled'? Who is eligible and for what services? What training should we design? I argue in light of the literature review that the complexity of hidden dis/ability cannot be resolved by traditional approaches or even by the prominent contemporary approaches and there is an opportunity to extend the approaches offered.

Medical and social existing as two independent domains (as the basis of the specialised categories of the conditions) continue to dominate most approaches and research methodologies in disability studies (both traditional and contemporary) and as such remain the most influential view. My position was at the outset of this research to employ an

alternative methodology beyond the usual rhetoric of hidden dis/ability being merely a political, economic, identity or moral question of an independently and thus objectively existing fact. I argue, such positions offer one way of understanding the complex everyday performances of hidden dis/ability whilst the approach of this thesis another in terms of dissolvment: hidden dis/ability is not a thing-in-itself but it is rather a shifting set of capacities to be perFormed, disSolved and reProduced. Instead of separating a performance into moral, political, social or economic parts in advance, my aim is to explore, appreciate and deploy the complex relations temporarily composing hidden dis/ability (if they compose it at all) that I believe is mostly missing from the literature.

My research, therefore, based on the aforementioned epistemological and ontological considerations has integrated Actor-Network-Theory and Ethnography to offer an unconventional approach to the exploration of the everyday performances of hidden dis/ability. Actor-Network-Ethnography, a novel methodology and toolkit, might not offer straightforward answers (for apparently universal and objective problems of hidden dis/ability and the use of the categories), but presents opportunities for transformations through the exploration of how the relationality of the actors (signification and association) enact the performances of hidden dis/ability in everyday situations.

4.2. Actor-Network-Ethnography offers a novel methodology to hidden dis/ability

I have developed and adapted Actor-Network-Ethnography as a novel methodology determining assumptions of this thesis and consider it to be a robust approach to explore the research questions for the following seven reasons.

1. Actor-Network-Ethnography is relationist.

Actor-Network-Ethnography accepts the non-modern notion that there are no clear boundaries as well-defined domains including our health and social practices are material (material is always natural and cultural). The notion of connectivity enables us to explore the complexity of the everyday performances (in the form of material, semiotic, discursive actors). No methodology independent position can be established as there are only actors and their relations that compose an event.

2. Actor-Network-Ethnography focuses on connectivity and capacity.

Actor-Network-Ethnography offers this new vision of connectivity and capacity in the everyday performances of hidden dis/ability. It focuses on the details of the act, the associations between the heterogeneous actors, and the capacities they form leading or not to transformation. Agency (the capacity to affect and be affected) is a key feature of the actors. Actor-Network-Ethnography has the potential to bring the dynamic associations that connect the actors and perform the actions to the fore to show how emerging capacities might form and perform, solve and dissolve, produce and reproduce hidden dis/ability by those shifting relations.

3. Actor-Network-Ethnography blurs boundaries.

Actor-Network-Ethnography blurs boundaries constituting domains (humans and objects, researcher and participant, objective and subjective) and brings connectivity, capacity and a sense of heterogeneity into prominence. Once suspended, notions of distinction are rendered complex, composite and connected. The everyday performances of hidden dis/ability as material-semiotic relations of heterogeneous actors and the capacities they compose become the theoretic and research focus.

4. Actor-Network-Ethnography is non-anthropocentric.

Actor-Network-Ethnography considers humans, objects and concepts as actors. Each are at the same level of analysis, even the complex connections are raised into the complex web of what appears to belong to the natural and to the social. I am too, as the researcher, part of the relations with the capacity to affect and be affected. Therefore, there is a shift in focus as Actor-Network-Ethnography aims to explore how actors are connected with capacity to act, perform and maintain existence. The actor-network can be more or less complex, as the number of actors is never limited and require description.

5. Actor-Network-Ethnography is anti-essentialist and anti-foundationalist.

Actor-Network-Ethnography assumes hidden dis/ability has no set universal forms necessary to their function and no universal truths. Actor-Network-Ethnography challenges and disrupts narratives where hidden dis/ability is foundational, objective and essentialist. As such the approach does not 'see' the duality of things as how language operates through binary oppositions but in a constant movement between the perFormed and the reProduced, as hidden and disSolved.

6. Actor-Network-Ethnography explores overlapping narratives.

As an Actor-Network Ethnographer, I question methodological approaches in research and practice, where the medical classifications mirrored in social approaches have assigned apparently universal and objective signs to each condition. Whilst the categories and the related actors permit the existence of set differences between people and events, Actor-Network-Ethnography can explore how the shared as well as distinct performances might be formed by the dimensions and dynamics of all the heterogeneous actors and the capacities they compose.

7. Actor-Network-Ethnography promotes negotiation and collaboration.

Actor-Network-Ethnography focuses on complex associations composing multiple realities of hidden dis/ability in the everyday performances to inquire whether there are any novel ways to reconsider connectivity, capacity and composition. Actor-Network-Ethnography challenges and opens up possibilities to negotiate our often contradictory and competing realities as it does not decide *a priori* which future is the best for all, but as lines blur, it illuminates which futures are preferred over others and how we decide about such complex questions.

4.2.1. The key assumptions of Actor-Network-Ethnography

Actor-Network-Ethnography then, is particularly suitable for exploring the significance of the material world including human objects and the connective semiotic relations between them that compose capacities to en-able, re-able but also dis-able someone in everyday performances (Goldschmied Z 2016). Such suitability casts new ways of considering the objects used, the communication encountered, the relationships formed, and the composition, maintenance or dissolution of hidden dis/ability. As such Actor-Network-Ethnography has three key assumptions regarding the everyday performances of hidden dis/ability:

1. Hidden disability is composed.

There exists no fixed processes or forces, social or biological that compose hidden dis/ability. Hidden dis/ability is not already out there waiting for the researcher to be discovered. This novel design also permits a broader exploration than most interpretative approaches that assume the researcher's role is to explain the perspectives and experiences of the participants. Actor-Network-Ethnography focuses on the processes, the formation of hidden dis/ability, and what keeps such

actor-networks together that compose the multiplicity of hidden dis/ability (where perspectives and experiences are potential actors.)

2. Hidden dis/ability is a result of capacity.

The actor-network ethnographer does not apply ready-made explanations or place an event into the broader social context to explain phenomenon. The researcher does not focus solely on human actors either because humans are never alone in the event, so their actions are not under full control, but they are the result of numerous connected actors. Even if short cuts (called black-boxes) are used to explain complex actor-networks, it always assumes everything is composed and has the capacity to affect and be affected.

3. Material-semiotic relationality.

Actor-Network-Ethnography is an object-oriented approach as it critically observes how humans themselves are objects and object-oriented. Social phenomenon cannot be understood without exploring all participating actors including non-humans. Therefore, such design treats humans and non-humans with the same level of significance to affect and be affected within these complex connections that include the researcher, the participants and all the other actors performing.

4.2.2. The act of noticing, selecting and ordering data in Actor-Network-Ethnography

Every methodology is a particular arrangement of specific processes, methods and tools for the exploration of set events. The way the researcher selects, and orders actors will set the conditions of possibility for noticing the data. In other words, methodologies make some associations of actors easier and others difficult or impossible to perform, their connections

more or less fixed or even resistant to change. It is the configuration of the actor-networks of the particular methodology that produces relative stability, durability and eventually, a particular outcome (Law 2007 p9). Actor-Network-Ethnography focuses on the actors, their actions, and the connections that influence what capacities might emerge to affect and be affected. As such, Actor-Network-Ethnography explores events as relations of actors with capacities to compose various effects (Fox and Alldred 2015, 2017).

Actor-Network-Ethnography does not work with pre-selected limiters of what constitutes data (such as discourses only). It does not aim to reduce complexity in advance into a manageable structure either. Structure is eventually data, such as the number and type of actors (research participants, place and time), the associations between the actors (set interventions and interactions such as conversations) and the potential effects (set measurement or outcome for example an unusual behaviour or counting occurrences). Whilst all researchers will select, order and notice specific actions considered as data whilst let others slip, in an Actor-Network-Ethnography design, what we mean by data are guided by the actors themselves, the connections, the observable effects and the transformations they compose. My main task is on the field and beyond, at the various stages of research, then to notice the possible associations the actors form, the capacities that emerged, and the effects that were composed.

As an Actor-Network-Ethnographer, I still have to make certain decisions about what actors to follow and which particular associations to observe in the research and use as data, as each of these decisions potentially can lead to a different outcome. However, as an Actor-Network-Ethnographer, I also acknowledge that I have no overall control over how actors might affect other actors, as the potential is always there for an actor to influence the research and what I notice and use as data and as such, the knowledge this thesis aims to bring to light. Actor-Network-Ethnography fits well into the research aims, as it assumes

nothing is permanent and fixed, that both research as a process and hidden dis/ability as a concept are temporary states and always depend on the particular actor-network within which they perform, which includes the researcher herself.

When hidden dis/ability is not considered as a temporary performance in the various everyday situations, it can appear more straightforward and uncomplicated than it actually is as I addressed in the literature review. As such, it may attract a well-defined, fixed and structured methodology in which the sterility of distance, as researchers attempt to remain objectively removed from their data collection, ironically distances itself from my Actor-Network-Ethnography approach. Sometimes the predictability of the actors converted into data, so often anticipated by traditional approaches and encouraged by distance, pushes its way into the frame as actors do any number of unexpected things worthy of capturing and witnessing as data.

Therefore, the danger of traditional research methodologies is that perceived stability, predictability and the pre-arranged limiters of the design reducing our dataset risk exchanging a movement and composition for immobile structures in advance. In other words, we stabilise the ever-shifting nature of hidden dis/ability with apparently fixed, independent and permanent attributes hence collecting a handful of data only before the performance can be appreciated. When using Actor-Network-Ethnography, I am aware how it is that the researcher selects, orders and notices actors and connections (actors that allow the researcher to be observed). How I make some part of a complex process visible but I also hide, anchor and stabilise, whilst subsequently destabilising and highlighting every time I select data what Law and Urry (2004) suggest are opportunities in an Actor-Network-Ethnography to make visible different connections and capacities, leading to a particular way of composing knowledge of hidden dis/ability.

Actor-Network-Ethnography aims to consider movements, actions and connectivity. Therefore, it is particularly well suited for the exploration of the everyday performances of hidden dis/ability where we experience constant change and formations of connections as opposed to fixed actors and standards that also influences what we consider data. Actor-Network-Ethnography further supports this, as it blurs the artificial lines between research and researcher, researcher and participant, theory and practice, medical and social providing a material, a semiotic and a discursive continuum between the various performances within which hidden dis/ability is enacted. It is not that there are no differences and distinctions between actors, connections and performances, but rather such divisions are effects of the capacities emerging from the networked connections. Data (and as such distinctions) are not given in the order of things and in advance but, like any other actors, take their form and acquire their function as a result of their connectivity with other actors.

As such, hidden dis/ability is not a fixed condition, and the role of the methodology is not to achieve neutrality or stability. Actor-Network-Ethnography is not concerned about which account reflect the notion of hidden dis/ability best. Hidden dis/ability is multiple, enacts and performs differently in various situations. These performances might evoke unity or resistance, rejection or support but most definitely affect other enacted actors. It becomes indispensable and constituting of actors in the performance, their opportunities to negotiate values, ideals and expectations.

4.3. The tools of the Actor-Network-Ethnography

Actor-Network-Ethnography, as a novel methodology, provides me with set tools for the collection of data that I developed from the above detailed considerations and summarise below.

1. Everything is a kind of actor (potential data) in the performance of hidden dis/ability.

I aim to explore the everyday performances of hidden dis/ability by observing all the actors, their connectivity, how associations initiate change and establish a performance of difference. In this sense, I am noticing how actors are always a network of elements defined by its actors (Law 2007; Latour *et al.* 2012). Such performances are so complex and messy, as noted by Latour (1993) and Law (2004), that we can never be certain of who and what acts when hidden dis/ability enacts. However, with the tools of Actor-Network-Ethnography, I can describe a list of aspects about the actors that are present in the contradictory arguments about what has happened and use them as data. It is the uncertainty and controversy about who and what is acting when hidden dis/ability performs that I can explore with such methodology.

Actor-Network-Ethnography asks questions about the nature of data like when we act, who and what else is acting? When hidden dis/ability performs how many actors, humans and non-humans, are present (thus can be recorded as data)? How do they look like? What are their characteristics? How have they been composed?

2. Agency is an attribute of all the actors.

Actor-Network-Ethnography explores connective networks through the notion of agency, that is the actors' capacity to affect and be affected by other actors (Deleuze and Guattari 1988 p284; Latour 2013b p561). Actor-Network-Ethnography focuses on the 'processes' and the 'formations' of hidden dis/ability through actors' capacity and try to capture them as data. Such capacity is composed through connectivity and the signification of those associations (Fox and Alldred 2018). This emphasis on agency shows how networks rely on the materiality of actors, but also benefits from a semantic appreciation of how networks operate symbolically thus turning anything into potential data.

Actor-Network-Ethnography asks questions like what connections are there between the actors? How do they relate? What capacities do they produce? What kind of material and semiotic relations are composed that can be witnessed as data? What are the characteristics of connections? What holds such connections together?

3. Connectivity is a result of agency.

Actor-Network-Ethnography as a methodology takes into account that actor-networks are more or less enduring temporal formations, as it focuses not only on the connectivity of actors but the extent of such connections (time, place, order are data). Actor-Network-Ethnography views such connectivity not as an inherent attribute of materials or human intentions but data, semiotic-relational effects. Connectivity forms, lasts and changes as a result of the agency of actors, and the material-semiotic connections between them (Law 2007; Latour 1993). Actor-Network-Ethnography aims to trace how actors travel into the performances as the actors' journey, their connectivity with other actors, and the affects they compose are all potential data.

Actor-Network-Ethnography asks questions like what is the extent, scale and size of the connections between the actors? How do they perform as to become data? How do they extend their connections? From where and how do they travel to the performance? How does the extent of connections affect the performance of hidden dis/ability?

4. Stability is a part of connectivity.

Actor-Network-Ethnography directs the researcher's attention towards not only the individual actors and their connections in the formation of hidden dis/ability but the apparently stable actor-networks. It does this by exploring first, how the durability has been composed, second, what maintains them, third, how they enact the performances by limiting or ordering capacities to emerge and four, how they lead to effects and performances of

control and predictability. All aspects of actor-networks are potential data in any one performance. When actors remain apparently stable and timeless or when the associations between them are kept definite (thus hinting the appearance of objectivity and universality), the aim is to explore how such connections were made enduring and use as potential data. Apparently stand-alone data (like a category or an IQ), no matter how permanent and real they seem to be, are actor-networks themselves. These actor-networks, Latour argues (2005a) are rather rare in the everyday performances and as noted earlier, the results of other actors' actions and their associations.

Actor-Network-Ethnography asks questions like what makes an actor-network stable and enduring? What are their connections? How solid are the connections and what makes them last? What affect can make them change? How does the stability of connections affect the performances of hidden dis/ability? How all these considerations constitute as data?

5. Capacity is a reason for noticing effects and transformations.

According to Latour (2005a), in an Actor-Network-Ethnography, connections do not transport causality but compose capacities for transformation. Hidden dis/ability becomes the effect of capacity emerged from the temporally formed connections. Researcher and participant, 'dis' and 'ability', expert discourse and personal narratives become entangled providing opportunities to reveal processes that compose or not hidden dis/ability and how, according to Latour (1987, 1998), such data should be discussed, evaluated and negotiated. Thus, the researcher pays attention to moving actants (human and non-human actors) that transforms those which do the moving because they transform the moving object, as what circulates and makes the circulation are co-determined and show as data in my research (Latour 1996a p16; Akrich et al. 2002a p191).

Actor-Network-Ethnography asks questions like what affects leave observable effects thus becoming data? How do such data change and transform performances? What new associations, and as such data, have they composed? What other affects are present that can be viewed as data? What are the effects of transformation that we can record as data?

6. Effects are data that are used to describe an apparent reality of hidden dis/ability.

Apparent causalities make hidden dis/ability appear more ordered and thus predictable. However, apparent causalities are effects showing how actors have been mobilised, connected and assembled, hence becoming potentially significant data in my research. As such, Actor-Network-Ethnography denies the existence of isolated causative actors and is sceptical of medical categories and their social application implying such data and their effects. The primary assumption is that the composing of hidden dis/ability's realities, the composing of statements about hidden dis/ability, the practices, ideals and materials (in short the various data) that compose both the statements and the realities cannot, in the repeated sentiments of Latour (1999a, 2005a), be separated.

Actor-Network-Ethnography asks questions like how do effects appear to compose the performances of hidden dis/ability? What kind of descriptions do the effects compose that we can record as data? What effects do we see in the descriptions? How do the data affect and negotiate the diverse descriptions of hidden dis/ability?

4.4. Actor-Network-Ethnography design

Actor-Network-Ethnography is a novel approach that has been scarcely applied outside of its origins in science and technology studies as the literature review has shown. It is a flexible design, primarily narrative and akin to exploratory research (Lincoln and Guba 1985; Hammersley and Atkinson 2007; Denzin and Lincoln 2011). It is particularly well-suited for

this study because as opposed to more traditional anthropological and ethnographic approaches, it does not demand the researcher's involvement for year-long investigations, yet still promises the detailed descriptions of the particular performances being studied (Roper and Shapira 1999; Mol and Law 2004; Latour 2013b; Jackson 2015). The choice of Actor-Network-Ethnography is well-supported by the researcher's professional expertise of hidden dis/ability and personal experience of autism. It is a dynamic methodology, whereby the researcher is immersed in the day-to-day activities of the participants with the aim of describing rather than interpreting in an effort to narrate the actors' world-making activities. It involves short-term relationships between the researcher and participants to explore how actors connect. Learning from them is about composing domains and semantics related to this connectivity, transforming activities as well as the actors that might maintain the status quo (Knoblauch 2005; Wall 2015).

Actor-Network-Ethnography assumes that the social world and hidden dis/ability in it cannot be understood as a result of linear, additive or causal relationship, meaning fixed laws governing events do not exist. The design, based on Law's formulation (2004 p7), works with uncertainties and controversies about the actors and their connections composing performances, and as such it does not pre-determine what actors constitute as data (Latour 1996a, 2005a). This approach suits the aim of the study well in exploring how connections form, temporarily stabilise, are maintained or disappear. Furthermore, the design assumes participants with various conditions have shared experiences and overlapping narratives that other interpretative approaches often overlook or at least do not explore. It has potential to investigate the performances of hidden dis/ability focusing on connectivity, signification and associations, and the capacity of actors to affect and be affected. By exploring how actors have common as well as unconnected performances, it can inquire what makes similarity or difference semantically operate in the everyday performances. As such, it emphasises how signifying connections are just as much actors and not universal standards

alone, essential forms or functions that compose, discuss and even settle potential controversies in the data. Actor-Network-Ethnography attends to the many actors that play a role in the composition of a particular performance of hidden dis/ability treating them as data. In other words, when faced with a performance, the researcher attends first to the actors and associations out of which the performance was composed and only later considers how the associations and significations in the data might have recomposed hidden dis/ability.

Actor-Network-Ethnography, like most methodologies, aims to create pragmatic outcomes through meaningful order of data noticed, collected and analysed. It attempts to do this by taking into account how the many actors, multiple frames of references, connectivity and emerging capacities compose the performances whilst avoiding hierarchy, predefined rules and domains of knowledge when considering the nature of data. That is to say, the participants, as well as other actors and events are all data in composing the world through their connections. As such data as a result of capacity and effect of connectivity have no specific, universal, and homogeneous forms and functions.

It asks questions such as what data are doing the composition and action? What data are composed and moved? What is the significance of such action? What has been transformed by the actions? What actions do the connections transport? How flexible are the connections?

4.4.1. Actor-Network-Ethnography ethical considerations

The research project has received full ethical approval from both the University of Wolverhampton Faculty of Arts (renamed as Faculty of Arts, Business and Social Sciences) and the Faculty of Education, Health and Well-being (Appendix 4). The main ethical issues

will be summarised here. The project planned to work with individuals age 18 and over who might be considered vulnerable as they have a mental or cognitive condition, therefore particular care was paid to such aspect. In line with the Mental Capacity Act (Department of Health 2005), participants' mental capacity was considered to ensure that their rights were respected and protected. As requested by the ethical committee, a person independent from the researcher was asked to make the initial decision on the participant's capacity to consent and make informed choices regarding participation in the research. Written and verbal informed consent was sought from the participants as well as other informants.

The researcher informed the participants during the recruitment process about the aim and approach of the project. An information sheet was also prepared and shared with the gatekeepers and the participants. The potential risks and benefits were discussed. The researcher ensured that the information was given in a format that was easy to understand by the participants, for example, all written information was produced in an easy-read version for people with intellectual disability and when required (Government Equalities Office 2010). The researcher was aware that a small risk was present such as the researcher's presence and some questions could cause distress that was monitored and managed. The researcher is a registered learning disability nurse and social worker who has years of experience in working with people considered to be vulnerable that ensured the effective perception and management of the risks involved. The researcher is DBS checked (Disclosure and Barring Service) and adhered to her professional codes of conduct with the NMC (Nursing and Midwifery Council) and HCPC (Health and Care Professions Council) as well as the research ethics of the British Sociological Associations and further guidance, such as the Declaration of Helsinki statement on research ethics.

Participants were informed they would receive no direct compensation. However, they could benefit from the participation in the project by sharing their narratives and performances,

and their involvement could also enhance the knowledge of the field. Participants had the right to withdraw at any time of the project without explaining to the researcher. The researcher ensured that all data, record, field notes and transcripts were coded and anonymised, and data were stored securely to maintain confidentiality. The identity of the participants was not and will not be shared with any third-party organisations or persons. Identifiable characteristics of recruitment site and the events were not and will not be disclosed. All records were and will be kept in a password-protected computer and cloud base back-up platform.

4.4.2. Sampling and participants

The researcher recruited a purposive, non-probability sample of individuals with various hidden mental and cognitive dis/ability to be observed in everyday situations. Actors with complex medical conditions requiring continuous professional attention and non-verbal participants who rely solely on any form of sign-language were excluded. People who had no capacity to make informed decisions and consent to the project could not be recruited. Age, gender, religion, ethnicity or sexual orientation were not applied as a selection criterion. The researcher recruited three male and three female white British participants between the ages of 18 and 60.

Table 3. The main characteristics of the participants

	Pseudonym	Age	Gender	Ethnicity	Condition	Living	Data
1	Jane	50-60	Female	White British	Intellectual disability	With other residents, moved to a retirement home	Observation Conversation Interview Artefacts
2	Nick	50-60	Male	White British	Intellectual disability	With others, moved to another place with residents	
3	Anna	20-30	Female	White British	Autism and mental health	Alone independently	
4	Peter	30-40	Male	White British	Autism	Supported living	
5	Monique	20-30	Female	White British	Depression Anxiety	With family	
6	Bob	40-50	Male	White British	Obsessive-Compulsive Disorder	Alone independently	

This research observed and participated in the everyday life of 6 individuals and aimed to maximise case variation by choosing informants with different (apparent) conditions. Two participants have a mild intellectual disability (IQ 55-70). Two participants have autism/Asperger syndrome, and two participants have a mental health condition (depression and anxiety, and obsessive-compulsive disorder). Two participants were living independently, two participants were living with other people receiving minimum support, one participant was living with family, and one participant was living in the form of supported living, all in the community. Two participants who lived semi-independently with other residents moved to a new home during the fieldwork.

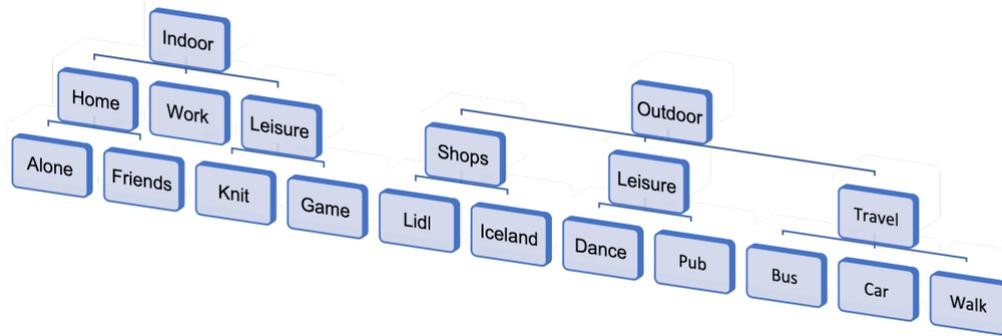
Professional networks were approached at the beginning of the project, and a recruitment schedule was formed. One nurse connected the researcher with voluntary sector organisations who were approached to circulate the letter of recruitment. The same nurse also recruited one person with autism to the project. Another nurse connected the researcher directly with another participant. Once started, all the other participants were recruited through these networks, and the researcher likened the approach to what Latour (1988a p9) describes, as this method does not require a decision in advance about the actors and possible actions. The voluntary organisation recruited another participant for the project and enabled further liaison with a second voluntary sector organisation. These links supported the project to recruit participants with mental health problems. Other participants were recruited and became involved in the project through the two organisations and participants' observation, such as carers, family members, people with hidden mental and cognitive dis/ability and professionals. All participants and the organisations are from the West Midlands. In total, 6 people were closely involved, and another 45 people (5 carers, 11 professionals, 4 family members, 25 people with a mental or cognitive condition) participated through their connections (observed and/or interviewed) at one point or more with the project.

After establishing the initial rapport and expressing an interest in supporting the project, the researcher sent the recruitment pack to the organisation and the participants. It comprised of a letter to the organisation, the carers and the potential participants, an information sheet and the consent form, all in additional easy-read version. The organisation and the nurses established the initial link explaining the study and ensuring participants had the capacity to consent. Once participants expressed an interest in taking part in the project, an initial meeting was set up where the researcher could introduce herself and the project and answer questions. Once the potential informant was satisfied and still wished to participate in the study, all required paperwork was signed. The first date and time of the observation were agreed then further appointments were made as it suited the participants. Participants had full flexibility over when and how to meet with the researcher and what events to observe.

4.4.3. Actor-Network-Ethnography fieldwork and data collection

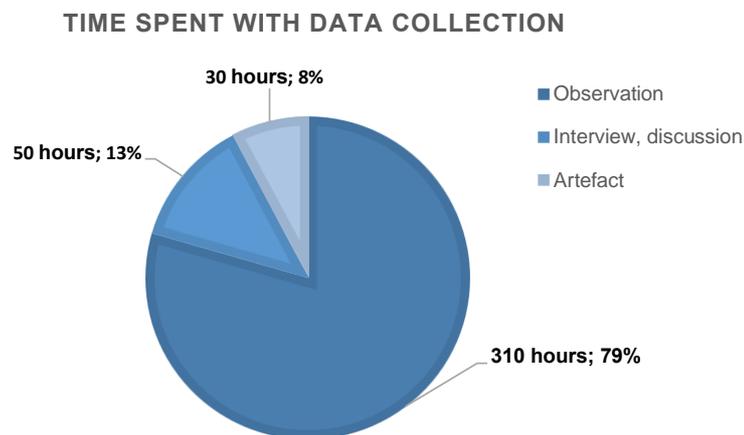
The Actor-Network-Ethnography approach to data collection involved direct observations of the participants and significant others, artefacts, semi-structured interviews, focused discussions, and spontaneously occurring conversations with the informants as well as other community members who were encountered through the network of the participants. The researcher observed participants in their everyday life in different situations for a period of 12 months. The researcher was present at their homes, public places and other settings they visited. They were observed, for example, when they visited friends or at their supported living; attended social events such as pubs, Christmas parties, birthday parties, cafés; participated in support groups and were at work. Activities also included shopping, cooking, moving to a new house and going to a day centre.

Figure 1. The main places of observation



The length of observation varied from one hour to up to a whole day, depending on the activity and the wishes of the participants. The researcher aimed to spend time with the participants at various times such as weekdays and weekends, daytime and evening. The researcher, together with the participants, identified the time, place and events where the researcher could be present as it was not possible to be everywhere. The researcher spent altogether approximately 400 hours on data collection.

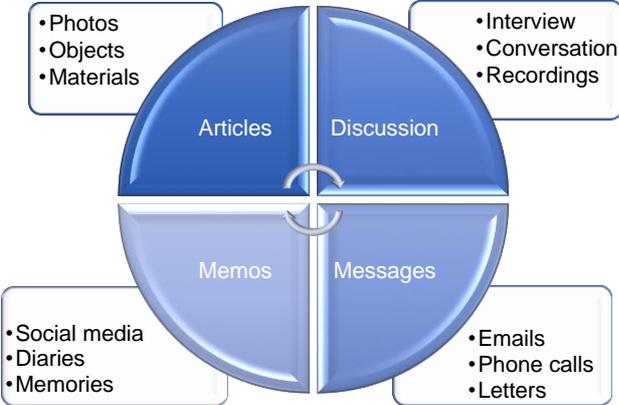
Figure 2. Length and type of data collection



The discussions, informal conversations, semi-structured interviews and observations were recorded manually in field notes and digitally by a Dictaphone or Smartphone when it was appropriate. Digital notes were also recorded on the field and immediately after

observations. Artefacts and other data were also collected in the form of pictures, emails, diaries, letters or scanned documents with the consent of the participants.

Figure 3. The type of data collected



The fieldwork resulted in various data such as conversations, interviews and digital notes; hand-written records, emails and artefacts that formed the source of the data analysis. Audio and digital recordings were transferred into Word documents. The data were catalogued using traditional hand-written cards method as well as by computer programs such as MindMap. All interviews, observations and recordings were typed up and analysed by the researcher. Step one of data collection included the grouping together the data based on the nature of the data, its visibility and materiality. Photographs and other physical artefacts such as paintings and arts were one such group. Data collected through direct observations were a second group, making a difference between recorded conversations and interviews, and the hand-written and digital notes of the researcher. The third group involved all non-directly collected materials, making a difference between written materials such as emails and other formats such as phone calls. Such groupings served data management purposes only and do not represent any hierarchical notion as that would not be aligned to the underlying positioning of the thesis. This was the governing principle too when establishing the main data set that involved several steps that the next chapter will detail.

4.4.4. What data renders hidden dis/ability visible

The main aim of this project is to investigate the central argument (hypothesis) that hidden cognitive and mental dis/ability is not a fixed thing but is formed and performed, solved and dissolved, produced and reproduced in everyday performances as it is an effect of connectivity and signification. It follows, the approach to data collection and analysis is to move away from approaches that prioritise actors, connections and capacities as data. The aim is to offer opportunities for alternative explorations of the everyday performances of hidden dis/ability, for example, revealing similarities as well as differences for other reasons than the categorisation of the conditions.

This has consequences for the data collection and analysis strategy to be applied, specifically, that no initial system was established for what to observe and record and what to look for in the performances as potential data being signs or materiality of hidden dis/ability. The assumption is that missing teeth or dirty clothes, the inability to read, crying, looking away, or going to see the doctor might not be data as they are not necessarily signs of or result in the performance of hidden dis/ability in the everyday. Therefore, the data collection strategy had to be responsive to the many actors (whether material, abstract, discursive or idealistic as potential data) connecting and acting in the performances. My initial aim was to explore how possible it is to select and order what connections compose capacities for transformation (an observable change to record as data), examine how we think we 'see' hidden dis/ability in the everyday performances, and how one affects the other as highlighted in the literature review and the research questions.

In such a flexible analytic design, it is reasonable to query what makes such research trustworthy, credible and valid? What mechanisms can be built in the process of data collection and analysis that provide a level of reliability if not generalisability? I agree with

Wolcott (1994, 2005), Altheide and Johnson (1994) and the growing consensus amongst contemporary academics who argue that fixed evaluative criteria can rarely determine the quality of research in favour of established coherence, alignment and consistency of the study or the steps involved to provide us with the capacity to make judgements about a project. Therefore, there might not be objectivity, validity and credibility in the traditional sense, but there will be ranges of believability that can be achieved by an open and visible demonstration of how the data have been noticed, selected and ordered to reduce complexity and deliver messages (Urkowitz and Laessig 1982; Denzin and Lincoln 2008).

My research has explored the everyday performances of 51 informants (6 through intensive participation and 45 through periodic interaction) that cannot be said to be representative of the population being studied. Yet, it was never my intention to employ generalisation in an attempt to establish a verifiable objective and universal truth of hidden dis/ability. Instead, I wished to draw attention to the various and often contradictory performances of hidden dis/ability. In addition, I aimed to assess the effect the methodology, the researcher and other actors have on knowledge emergence in the hope that more performances, more visibility and more transparency can advance our discussions about how we could move closer to the ideals of apoposite care, services and inclusion of people with hidden dis/ability. Furthermore, my hypothesis calls for me to explore the extent to which Actor-Network-Ethnography methodology can collect data to describe values and detail as they occur rather than relying solely on retrospective accounts of the participants that I highlighted as one limitation of existing literature. Such retrospective narratives in the form of interview or focus-group being active data were useful for exploring how an event might appear and thus contribute to alternative ways of considering hidden dis/ability.

This leads to the conditions of 'dissolvment' and defragging of the persistent claims of unity. The researcher is a health and social professional, a registered learning disability

nurse, social worker, lecturer, a person living with autism. This brings to bear ideals of how bias and objectivity in terms of what data to record, what distance to employ and how to analyse the data break down in Actor-Network-Ethnography. The researcher is always part of the research and the knowledge it creates regardless of the design used, as fully controlled, objective and distant exploration of phenomena is not possible (Law 2004; Goldschmied Z in press). The researcher utilised various tools that aim to demonstrate as visibly as possible how the project has been conducted. I summarised three considerations on how the description of culture has been composed:

1. The researcher has maintained a detailed journal throughout the doctoral research project. This has recorded the following activities: 1. supervisions with outcomes, 2. training and development, 3. participation in research-related events, 4. projects and publishing, 5. teaching, 6. fieldwork diary and 7. a timeline. Every discussion the researcher had throughout the project and before, every document encountered, comment received and events observed had the potential to shape, steer and influence the final thesis.
2. Informant and cross-informant checking, more through convenience, was utilised as the researcher shared observations and experiences documented with the participant who encountered them as well as with other participants that is an integral part of Actor-Network-Ethnography design. This reflexive approach attempts to establish the collected data and its interpretations on the one hand. It also produces more data in the form of potential controversies brought to light about the notion of hidden dis/ability on the other.
3. Data extracts and examples of fieldwork notes are included in the thesis as well as a description of the process in developing the outcome to display the steps involved,

materials collected, and analytical thinking applied as plainly as possible. This aims to build a trust in believability, not in terms of being objective in describing one truth but making visible the actors and the connections that affected the outcome, the composition of diverse realities of hidden dis/ability and contribution to knowledge.

4.5. Summary

As discussed previously, Actor-Network-Ethnography treats everything as an uncertain event with the potential of actors to generate controversies about what we mean by hidden dis/ability. Taking a lead from Latour (2005a p39), this uncertainty flows from the capacity of the actors. My main aim was not to arrive at a final truth, but to notice connections, the capacities they form and the effects they compose at the various stages of research. How the many actors performed on the composition of hidden dis/ability, how the researcher affected and was affected leading to alternative understandings of how connectivity leads to particular effects (Latour 2004a; Law and Mol 2011; Holyoake 2013). This could add to our understanding of the enactment of hidden dis/ability, but only if I can notice and thus record the effects as data. As Latour noted (2005a p53), if no observable mark is left behind, no recordable effects have been produced, actors and their connections offer no data for the researcher. Actors either transport or transform, play a role or not, that is what I wished to record and use as data in my inquiry. The next chapter explores the data collected and what performances of hidden dis/ability a Baudrillardian, a Latourian and an Actor-Network-Theory informed analysis might afford.

CHAPTER 5

The 6D material-semiotic network practice

In the previous chapter, I discussed how in an Actor-Network-Ethnography the researcher becomes part of the participants' emerging lives. Whilst this has obvious connotations to participant observation and similar engagement designs, various other methods of data collection occurred as the project unfolded and opportunities arose to explore the performances of hidden dis/ability in everyday situations. Naturally, the data collected were extensive comprising of handwritten and digital notes from observations, discussions, interviews and artefacts such as documents, emails, shared e-media, diaries, letters and pictures. The analysis of the field notes and data continued throughout and influenced the data collections.

Here, I explain the systematic collection and exploration of data. These analytical tasks examined the performances encountered, the actors in the act, the associations of the actors and how the connections related to the whole hidden dis/ability. I developed the 6D material-semiotic network practice and used Baudrillard, Latour and Spradley's works as a guide. I will now discuss the data set and the 6D practice with the aim of providing a comprehensive description of the data analysis process and how the contributions of the thesis have been composed. The word practice is used as opposed to model or framework to align it with the thesis' main assumptions about the nature of reality and the everyday performances of hidden dis/ability.

5.1. The development of the 6D material-semiotic network practice

Law (1992) proposes that Actor-Network-Theory is not a framework meaning there are no predefined axioms or truths serving as the propositions of research strategy (particularly data collection and analysis). Actor-Network-Theory, however, provides a long-standing pedigree that can be described as the practice of material-semiotics (Latour 2005a; Law 2007). As such, data are analysed continuously composed by networks of associations and with Baudrillard's notions of significations between things, humans and abstractions that form the networks.

My aim was and still is to explore processes rendering the everyday performances of hidden dis/ability visible (or not). When I apply Actor-Network-Theory in the spirit of Law (1999, 2004) and Latour (1988a, 1999a) and Baudrillard's work (1993; 2005) to the data, my task is to explore how their fragmented connectivity affect as heterogeneous actors, how they appear to form associations and to explore the enactment of the material, semiotic and discursive relations that compose all kinds of performances that I found neglected in the literature. It starts with the position that my role as a researcher is to learn from the actors and not to impose any *a priori* system of what a sign of hidden dis/ability might appear to be so often anticipated by research methodologies.

Whilst there exists various coding schemes and frameworks used in flexible designs for the collection, organisation and analysis of the data, most of them seemed to be ill-suited because of their claims of objectivity, attempts at universalism and of course essentialist assertions that the literature review has also highlighted. Their use of either predetermined schemes or emergent patterns (based on a more or less rigid application of pre-existing 'evidence') such as collecting of set data only, considering set activities only as potential data, separating data or establishing differences between data, for example, coding for the

presence or absence of specific non-verbal or linguistic units, demonstrate an incompatibility with material-semiotics, signification and associations of signs (Corbin and Strauss 1990; Crabtree and Miller 1999; Stemler 2001; Graneheim and Lundman 2004). Establishing units, hierarchies, or groups based on such systems with clear boundaries would not be aligned to Actor-Network-Ethnography, Latour and Baudrillard's philosophy, because actors are seen to be non-essential and therefore borderless, blurring, and best considered as connective. Therefore, the method of data collection and analysis had to be in line with the assumption that hidden dis/ability based on my hypothesis, has no reality outside the enactment of the connections that compose it. This process led to many arenas and scopes to do with such concepts as the role of the categories, protection versus vulnerability, the models or the language of dis/ability and posed many challenges for my rethinking and hypothetical reasoning. It became the case that my analysis of the unforeseen as opposed to the perceived 'seen' world would come to dismantle my work.

A decision had to be made of narrowing down the analysis, thus the large amount of data collected, to how the various actors, and particularly the medical categories and the social practices produce, perform and consume hidden dis/ability in the everyday performances and what roles the spectators play in the process. Therefore, the initial work with the data had to focus on ideas of significations and associations in the everyday performances of hidden dis/ability in light of the categories and the separated health and social approaches. One specific metaphysical and ontological issue concerning how we see the everyday performances of hidden dis/ability is how, when and why we, the spectators, tend to judge hidden dis/ability as an essential and universal thing rather than the enactment of all the actors and the networks that constantly perForm, disSolve and reProduce hidden dis/ability? What do we think we 'see' in a performance? In other words, what do we think are data composing hidden dis/ability? And what are the affects of spectators' judgement in the everyday performances of hidden dis/ability?

Based on the central argument (hidden dis/ability is perFormed, disSolved, reProduced), the research questions, and the data collection strategy, analysis emerged as more dimensional in the form of 6D material-semiotic network practice which, in the sentiment of Latour (2013a) and Bilodeau and Potvin (2016), reflects the activity amongst signs to reveal the connections that compose it and its role as a connector. The data collection process, the composition of the data set, as well as the development and the application of the 6D practice, was informed by the following theories:

1. Spradley (1979) Developmental Research Sequence Method (DRSM): the problem-solving and systematic approach to discover cultural patterns.
2. Baudrillard (1993) cultural-semiotic idealism: the phases of the constructed images and signs of hidden dis/ability in building an external and objective reality.
3. Latour (1993) material-semiotic empiricism: the capacity of the actors in reality composition and sign production of hidden dis/ability.

The development of the 6D material-semiotic network practice then stems from a hypothesis-oriented Actor-Network-Ethnography. That is to say, we live in a complex society where hidden dis/ability might be performed and consumed by many signs and realities (Spradley 1979, 1980) once we are ready to notice and record all sorts of signs as potential data. Actor-Network-Ethnography makes it possible to study how actors define the world, what are the assumptions about hidden dis/ability and how signs and things compose the performance of hidden dis/ability. The aim of the approach to data collection and analysis was not to study people and impose the researcher's and of others' reality on them but to learn from the actors, as there is no one universal hidden dis/ability. Objects, humans, and

non-humans, in other words, the actors and their connections compose multiplicity of hidden dis/ability that we need to be able to 'see' as data.

The central argument has a focus on exploring how hidden dis/ability gets performed in everyday situations, to explore the instability, frailty and temporality of the performances. As an Actor-Network-Ethnographer, I observed actors and their relations. I participated in the activities, aimed to trace connections and collected artefacts. During the data analysis, I interfere with what the actors do, what they use and make, what they say, how they connect, what capacities those relations compose and how they lead or not to recordable effects and transformation. I eventually developed the 6D practice for the ordering of data, what appears to be solid from what is rarely noticed in the everyday. The 6D practice enables me to show how cultural meaning, and as such the performance of hidden dis/ability, might emerge from these semiotic-phantasmal-material relations between the actors. The collection and analysis of data, including the development of the 6D practice comprised of four distinct tasks: 1. domain, 2. taxonomic, 3. contrast and 4. theme analysis.

5.1.1. Spradley, Baudrillard and Latour - the theoretical base of the 6D practice

Spradley provided me with a structural analytical research sequence, Baudrillard with a vision of cultural-semiotic sign exchange, and Latour with a material-semiotic empiricism. Each aligned to key semiotic principles of Saussure that instead of looking for totality highlight (produce and consume) actors' connectivity and significations of signs. There is reward in focusing on significations and the actors' associations with others and things. Therefore, the three theorists together offered me the main ideas to break down binaries in the data analysis and reveal how the formation and performance of hidden dis/ability might be rethought in terms of the solved and dissolved, produced and reproduced in everyday

performances. From this, first, I developed the 6D practice, and then second, I applied the 6D practice to the data set to reach the findings and form my discussion and conclusions.

Spradley and the developmental research sequence method

Spradley (1979) theorised the Developmental Research Sequence Method (DRSM) (language as a basis for cultural meaning making) from the long semiotic tradition of ethnographic research. Within his method, there is a strong argument for returning to fieldwork as a key feature, as the researcher establishes initial findings and then develops strategies establishing four fundamental analytical tasks to notice, select and order the information gathered in the fieldwork, namely: 1. domain, 2. taxonomy, 3. contrast and 4. theme analysis.

Domain analysis is a process for reviewing the field notes to discover key areas of cultural meaning and the specific details of those categorised within the domains that are called included terms. *Taxonomic analysis* is a comprehensive investigation of selected cultural domains and included terms and a search for means by which members within selected domains may be organised. *Contrast analysis* is a search for ways of distinguishing among the domains and the included terms and understanding what makes performances differ. *Theme analysis* attempts to describe the observed culture, highlighting its general as well as specific features, the matters of concerns, and how they connect with each other and the domains. The included terms within the domains and the taxonomies are connected by a single semantic relationship based on the relational theory of cultural meaning to explore its structure. Throughout my subsequent analysis and theorising, I stayed true to these four fundamental analytical tasks. The following table shows the semantic relationships which order meaning between informants of any given culture. These showed themselves in the culture of hidden dis/ability during the course of my data collection.

Table 4. Spradley's nine general semantic relationships

Type of Relationship	Nature of Relationship	Examples
1. Strict Inclusion	<i>X is a kind of Y</i>	Objects are a kind of actors. A letter is a kind of actor.
2. Spatial	<i>X is a place in Y</i> <i>X is a part of Y</i>	Actors are a place in networks. Having a pint is a part of connecting.
3. Cause-Effect	<i>X is a result of Y</i> <i>X is a cause of Y</i>	Networks are a result of connections. Autism Act is a cause of distinction.
4. Rationale	<i>X is a reason for doing Y</i>	Connections are a reason for agency. Friends are reasons for making tea.
5. Location	<i>X is a place for doing Y</i>	Agency is a place for doing capacity. A comment is a place for offending.
6. Function	<i>X is used for Y</i>	Capacity is used for affecting and being affected. A white stick is used for friendship.
7. Means-End	<i>X is a way to do Y</i>	Affect is a way to produce effects. A lampshade is a way to do empowering.
8. Sequence	<i>X is a step in Y</i> <i>X is a stage in Y</i>	Effect is a step in transformation. A camera is a step in storytelling.
9. Attribution	<i>X is an attribute of Y</i> <i>X is a characteristic of Y</i>	Transformation is an attribute of performances. Carers are characteristics of the group.

Baudrillard and cultural-semiotic idealism

I discussed how Baudrillard (1993) argues that signs were invented to objectify, universalise and confirm an external material and social reality. However, the link between the signifier and the signified constructing a sign has gradually disintegrated meaning. The sign has started to mask, hide then conceal the absence of reality, having no relation to any reality whatsoever in our postmodern age of hyper-reality. This relates to the performances of hidden dis/ability in that appearances seem to be real, but signs are their own pure simulacrum, simulating meaning. This simulacrum of hidden dis/ability can present in five forms: *interdependency, resemblance, equivalence, reproducibility and excrescence.*

Excrescence is prevalent in our postmodern world where the signifiers such as the fidgeting leg, shy smile or slurred speech are positioned in relation to other signifiers only and not to any fixed external reality.

Latour and material-semiotic empiricism

I also noted how Latour (1993) argues that nature and culture have been separated. How the purification of signs and things into two distinct domains (nature and culture) turned into domains themselves, into existing external realities, so the realities of hidden dis/ability do not have to be explained anymore. In my work, such separation is ironically unifying in the social and medical models relying on the structuring of Spradley, excrescence of Baudrillard and dispersion of Latour. I have theorised how processes and connections are deleted from the production, thus nature and culture become the explanations of hidden dis/ability whilst alternatives become prohibitive (or at least hidden). I am arguing that for Latour, the separation of signs and things of hidden dis/ability are present in five forms: *interdependency, separation, purification, replication and dispersion*. Dispersion is characteristic of the postmodern era, where nature and culture as separate domains no longer offer sound theories.

5.1.2. Absence, presence and visibility in the data

Based on Baudrillard's and Latour's work, the initial schema of establishing a method of analysis was my traditional post-structural and non-modern consideration of absence and presence of actors, signs and things in the data.

Absence and presence of material and abstract signs of hidden dis/ability in the data

We **left the flat**, walked down the stairs, and before leaving the house P1 checked the **post** that were placed on the radiator, in the hall, by the entrance. P1 picked up three letters, examined them, then **opened them, remarked** that it was from the housing benefits and gave them to me. **"These are for my sister. She will read them.** Can you take them? You will meet with her sooner than I." I responded, sure, and as nothing happened, she opened the door and continued with her activities. When I next met the sister, I gave her the letters with P1 comments. She commented P1 **could not read, she was disabled** but recognize letters and her name.

P5 was **having a conversation** with me. A carer came to see us and told P5 she loved my trouser and wanted to take off me. P5 responded "Why do you need it? It will not fit you anyway?" Carer responded: "Are you telling me I am fat?" P5 answered: "No, I am just saying you have a different shape, it will not fit you." We eventually laughed after a suspension, a hole, where anything could have happened. The next week I have just entered the room when the carer said: "You have a nice figure." Then we talked about boots, and how she could not wear them as she was in her 40s and anyway her husband would never allow her to wear a short.

Three aspects of absence and presence of material and abstract signs of a potential hidden dis/ability were considered. *First*, when exploring the collected data, there were different as well as similar actors present in the various performances – *"the letter"*, *"the inability to read"*, *"the sister"*. *Second*, when an actor performed an action in one event and had a particular effect, it often failed to repeat it in another event – *a comment "it will not fit you"*, *a reaction "are you telling me I am fat?" and the effect of "laughing"*. *Third*, connections were made and unmade between actors and the effects were narrated by diverse stories – *"she is disabled she could not read it"*, *"she does not need to read it"*, *"my sister will read it"*, *"continued with activities without considering reading as an important act"*.

Nevertheless, any of these events could have been coded as a performance of hidden dis/ability, as one could argue, a difference became visible when compared to set universal descriptions, a perfect performance, evidence from the literature, for example, *"not reading a letter"* or *"questioning the nature of the comment"*. Many approaches based on induction and existing evidence would do this as shown in the literature review and addressed as a potential limitation. Still, there were many actors present in the performances, including the

performer (the person who made the comment), the spectator (who responded to or witnessed the comment), the researcher (who observed and recorded the event) and the scene with all its materiality, immateriality and discourses (tables, chairs, other people chatting around, cup of coffees and biscuits, a safe place for autistic people, the fan on the ceiling, carers and so on) that potentially influenced whether the performance was 'seen' as an act of hidden dis/ability.

The visibility of hidden dis/ability in the performance but to whom in the data

6. P1 told me they all had **care files**. And whether I wanted to see it. Like it was the most natural thing to **have a thick folder with various information** in it. **She asked her friends too,** whether they would be happy to show me theirs too. She knew some of them, she drew my attention to her benefit assessment and some letters from the doctors. She has never commented on them in relation to her disability. **There were instructions for carers too, but she said, they did not do it.** They do not come as they should, and she has a cleaner but apart from it, she receives no care. Some documents detailed large sum of money that was paid to housing or the care company. **Many documents referred to the presence of a disability,** benefits forms, assessments and required support. However, P1 who has a learning disability had a sheet that implied she had no disability and she did not need support. A mistake maybe? Reading the documents, **I felt I was reading about someone else.** I could not see the P1 that was described in those files. Hardly any good thing, what she can do and how, but all the things that are different, or wrong, or dangerous. She had at least 50+ I read and took notes.

That being so, even if a performance is 'seen' as an act of hidden dis/ability, the complexity of visibility, as central to my hypothesis in rethinking of hidden dis/ability, at least being justified. Like the right to 'retell', the 'several-seeing' of hidden dis/ability is always multiple. There are a number of points relating to 'seeing' the performances. *First*, signs of hidden dis/ability 'visible' to the person may only be experiencing it, but not to third parties (spectators or the researcher) that became evident later by the narratives of the performer. *Second*, witnessing subtleties such as I see occasional whispering, turning away or looking into the distance signals and potential multiple meaning. *Third*, the dynamics and dimension of detail are intensified by any two actors present (performer, spectator, researcher) but not all. *Fourth*, 'visibility' is signalled to all of us, including the person experiencing it, the

spectators and the researcher that effects of laughing, arguing or negotiations signalled. *Fifth*, it was probably 'visible' to the researcher only.

There is a potential *sixth*. I have been participated in and observed many activities and events as the data shows where the performance of hidden dis/ability was 'not visible'. This may initially sound odd, but to any one of us, there was not anything that could have been classed as a sign of hidden dis/ability. These performances, the unnoticed and as such 'less visible' started to become important in my analysis, as they have the potential to provide continuums where hidden dis/ability reflects the non-permanency of context. By considering such activities, I believe, we can show how hidden dis/ability form and perform, but as much as dissolve, to be reproduced again in a different composition of meaning making (details, dimensions, dynamics and descriptions).

5.1.3. Heterogeneity and uncertainty of actors, associations and significations

Following on Baudrillard's and Latour's work after establishing the initial schema of visibility, absence and presence of signs and things in the data, the post-structural and non-modern positioning led me to consider the heterogeneity and uncertainty of actors, associations and significations in four steps.

Semiotics: the sign of hidden dis/ability and the signifying practices of performances

I alluded earlier how Spradley, Baudrillard and Latour show a lineage of Saussure (1916/2011), a structuralist linguist and semiotician whose seminal work detailed that to understand a culture is to explore how meaning is produced symbolically through the signifying practices of language. His central semiotic concept was the binary distinction between the two inseparable components of the immaterial sign: the signifier, which can be

a sound, word or object, and the signified, which is the concept or idea behind the sign – *the letter, the reading, the dis/ability*. In a Baudrillardian sense, this phase can be said to denature and fake reality, whilst in Latour's work separate nature and culture, things and signs.

I noticed during the fieldwork, actors were sometimes visible, yet other times less noticeable, playing a more or less prominent role in the performances. Therefore, the notion of signs offered me opportunity to consider how could stability in the forms of fixed or reoccurring actors, actions or connections be a reliable sign of hidden dis/ability? What signs and objects are present and absent in the various performances that make a difference to whether I code something as a performance of hidden dis/ability or not? Is there any specific actor I can always notice? What difference the presence or absence of the categories as actors make? Thus, an obvious starting point was the noticing of the absence and presence of universal and standardising categories and similar actors as data. Yet, what I found at the early stage of the data analysis that attributes as *difficulties with social interaction or communication, or the inability to read a letter* offered no good explanation of what we were looking at in the performances (as there were many other actors present that through their relations composed the effects). In other words, as noted earlier, what presence and absence I need to analyse in the data and consider in developing the 6D material-semiotic network practice was to be more complex than looking out for fixed signs and things such as prescribed attributes, set behaviours or universal expressions of language only. This led me from the foundation of Saussure to the semantics of Spradley.

Semantics: the structure of hidden dis/ability and the referential practices of performances

Spradley (1980) explains, the use of symbols composes cultural meaning. Symbols are every word I encountered throughout the project as well as objects, ideas, facial

expressions, bodily movements, dresses worn, or shops visited. Symbols such as the inability to read connect the referents, *dis/ability* or *the letter*, with a single semantic relationship. In the example from the data, *the inability to read a letter or passing a letter to the sister to be read is a characteristic of hidden dis/ability; a letter is a reason for reading; reading is a part of a letter.*

Various scholars offer different formulations as to the distinction of semantic relationships, yet all agree, they are limited in nature (Bréal and Jules 1964; Cassagrande and Hale 1967; Spradley 1979; Hermann *et al.* 1986; Winston *et al.* 1987; Chaffin and Hermann 1988; Storey 1993). The problem is that semantics, in the form of referential meaning, shortcut meaning making. They are essential, oversimplify performances and do not take into account how signs and symbols carry multiple codes, potential cultural meanings and materials. As a primary issue of post-structuralism, Barthes (1967) argued how meaning involved the association of signs with other cultural codes of meaning. Distinction is made between denotative meaning (involving the things words refer to) and connotative meaning (the many cultural significances related to reading) as the vignettes recorded: *the type of letters, the sister getting the letter or the relationship with the sender.*

The structure of language might be used as data to establish meaning. However, it tends to ignore how connections compose capacities to affect and be affected in associations with other actors that post-structuralism challenges. In my case, the informant has carried on with the activities without enacting the signs of hidden dis/ability as I recorded in the data even if *a letter* and *an inability to read* were present. What is the relationship between the participant, the reading of the letter, the notion of dis/ability, the going to shop, or giving the letter to the sister? What has changed if anything? In a Baudrillardian analysis, this phase masks the absence of reality, whilst in Latour's reading, it purifies further nature and culture,

things and signs into two distinct domains, and led me toward symbolism as an additional analytical frame of reference.

Symbolism: the symbol of hidden dis/ability and the symbolic practices of performances

Post-structuralists, most notably Foucault (1966/2002) and Derrida (1967/2001) highlight that cultural meaning goes beyond the signifier and signified as meaning is always deferred and in process. Symbols are related to other symbols linked to their function or value. Signs do not possess definite and fixed meanings, for example, in the data set *reading* is related to many other actors like *passing it on, being looked after by a sister or getting benefits*. What are the various actors that have been condensed into the symbolic domain of the inability to read? What are the connections between the included terms and how they connect with the performance of hidden dis/ability? When a participant has a sister who can read the letter for her, is a dis/ability still present in the performance?

The impact of symbolism on my explanation of 'domain', such as *the inability to read* will be connected with a single semantic relationship such as *is a reason for* with all the included terms observed in the field like *not opening the letter, not reading the letter, not putting it in the bag, not getting a job, needing help to fill in a form, using pictures, giving the task of reading to someone else, doing the shopping, getting benefits, having a sister, being relaxed* as language is non-representational and meaning is inherently unstable so that it constantly slides away (Holyoake 2009). In composing the structural domains of the 6D material-semiotic network practice based on semiotic and semantic relationships, signs and symbols have no relation with reality in Baudrillard's reading and hide the connections between the actors and the capacities they compose in Latour's work.

Simulation: the signification of hidden dis/ability and the associations of performances

As such, the signs and symbols of hidden dis/ability can be said to be unstable, relational and compositional. What is the signification and association of actors that we will judge as to a performance of hidden dis/ability? And what roles do the spectators play in such judgements? The question of visibility, a visible effect of hidden dis/ability and to whom need to be reconsidered. If a change or difference becomes visible, then what is the effect? Will be there any confusion, disruption of order, in other words, any new formation? How is *the inability of reading the letter* a sign of hidden dis/ability regardless of the connections that compose them and the effects of those connections? What are the values attached to reading? What is the function of reading? So, analytically at least, I was left curiously wondering how the signified becomes more important than the signifier as signs refer to other signs and not to an origin, the actual performance. I noticed how signifiers are positioned in relation to other signifiers and not to any fixed external reality and how signs of hidden dis/ability are increasingly empty of meaning.

Latour's (1993) semiotic position puts emphasis on the material and situational conditions in the production of cultural meaning and as such, the participation of all the actors and their connections in the process of that production. For Baudrillard, these are the fractal signs, pure simulacrum, of how the performances of hidden dis/ability become simulation rather than the real through the connections argued by Latour. The implications of these non-modern semiotic approaches to the data show themselves not only in the 6D practice but in my subsequent consideration of how materials and abstractions play a role in signification (materials construct ideologies and simulated reality just as the instability of signs and signification hold materials together). These analytical considerations bring together Spradley and the relational theory of cultural meaning, Baudrillard and the signification and

association of signs with Latour and the signification and association of materiality in the 6D material-semiotic network practice.

5.2. Composing the 6D material-semiotic network practice

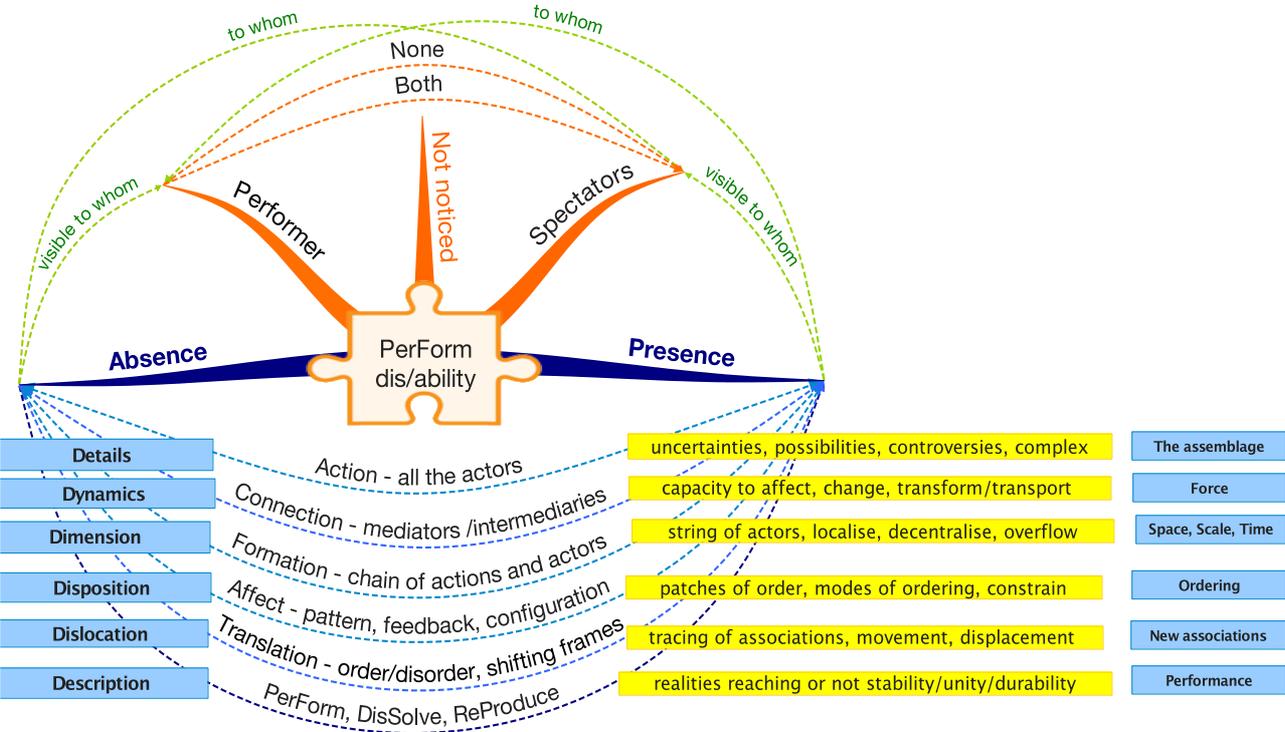
Once I considered what role things and signs might play in the associations and significations of composing and rendering hidden dis/ability visible, a domain and taxonomic analysis of Actor-Network-Theory was performed. Various categories have been composed to organise the main assumptions into manageable domains. Eventually, three domains and five taxonomies of Actor-Network-Theory were composed to guide the development of what would eventually become the 6D material-semiotic network practice together with the aforementioned theoretical considerations and the abductive hypothesis that hidden dis/ability is perFormed, disSolved and reProduced in light of the research questions.

Considerable effort was then spent establishing how many domains the 6D material-semiotic network practice should involve. On the one hand, it was evident, based on the aforementioned analysis, that I needed to show the details when looking at a performance, how connections were formed, what actors might have played a role, and where those actors were coming from. However, it was not just about the type of actors *per se*, but the significations between them, as it was those more or less spontaneously formed associations that initiated other actors' actions, and in our interest, might lead to the performance of hidden dis/ability.

Initially, I established 4 domains of the material-semiotic network practice which proved to be insufficient as they did not provide enough scope for showing the movement within and between performances. The maximum domains considered were 10 which once again proved to be challenging to apply, as it made the analysis too complex for such a project.

Eventually, the constant movement between the fieldwork and the initial analysis extended the initial 4 domains to 6 domains. As a next step, the naming and defining of such domains caused some difficulties as a name needed to be sufficiently relevant by suggesting what it referred to whilst avoiding words with misleading connotations. In the end, the following 6 domains and names emerged: *Details, Dimensions, Dynamics, Dispositions, Dislocations, Descriptions*.

Figure 4. The 6D material-semiotic network analysis



The 6 domains of the material-semiotic network practice denote the symbolising categories of cultural meaning, in this thesis, representing the everyday performance of hidden dis/ability. The following table illustrates the name of the domain, the semantic relationship, and how they compose and render visible the performance of hidden dis/ability. In other words, the relationship between the symbolic domains and how they signify the performance of hidden dis/ability. The domains are analytically composed of the hypothesis

and the ontological and epistemological positioning of the thesis that the following paragraphs will unpack.

I want to emphasise how the 6 domains are not a linear or a step-by-step framework or model with distinct boundaries to analyse the data but symbolic categories for noticing, selecting and ordering the material, abstract and discursive actors, the actions and the connections that might signify and compose the performances of hidden dis/ability.

5.2.1. The domains of the 6D material-semiotic network practice

The following paragraphs explain the domains of the 6D practice and the included terms that are linked together based on similarities and those, as mentioned above, analytical and theoretical considerations connected with a single semantic relationship. It provides details on how the 6D practice can be used not only for analysing and ordering the data, but 'seeing' the everyday performances.

Details domain

I started to theorise how details are about the mundane composition of actors, their uncertainties, controversies and potentials to perform hidden dis/ability.

Details are a referent to composition, variety and analytic rigour. They are significant considerations in reaching a description of everyday performances that includes data in the form of multiple actors. Not an interpretation or material centred approach to the noticing of certain actors or actions only but the researcher's commitment to try to make a note of as many participating actors (data) as possible without deciding *a priori* what might play a role in the significations and associations of a performance. In other words, details pay attention to the performer, the spectator and the scene at the same time.

Dynamics domain

Dynamics are about the forces acting between the actors that make up the actor-networks and the connections.

Dynamics represent the second emerged domain and refer to the associations between the actors, the nature of connections and the capacities they compose. As opposed to the apparently essential and universal categories of the conditions, I cannot assume in advance which actor might be a mediator or an intermediary, initiate change or not. Dynamics bring this connectivity to the front, the possibility to notice how connections affect and be affected as details on their own are not a good predictor of outcomes.

Dimensions domain

Dimensions are about the scope, length, time, extent and scale of the actors and their many connections.

Dimensions refer to how actors have a range in which they make a difference, a distinction so to speak. They require attention, not as individuals or independent factors, but by their effect on other actors. My analysis of 'Dimensions' allowed me to contemplate how actors themselves are composed and become data. How various actors from multiple places and times, as they are more or less connected, travel into the performance composing and sustaining symbolic meaning. Exploring how such actors perform in the various performances, what is their scale, size and place is significant data, as some actors were evidently more connected than others.

Dispositions domain

A disposition is about the arrangements of the actors and their connections, the ordering of associations, and how they compose lasting and enduring ties.

The dispositions domain was added to the initial four (details, dimensions, dynamics, description) as it was evident that actors composing them varied in capacity to affect and be affected. The existence of many actor-networks and the actors' connections composing and sustaining them - even if they remain temporary and do not perform the same way every time - can visibly and notably (or not) steer, intensify and stabilise, form patches of orders, and affect what capacities might be afforded.

Dislocations domains

If dispositions are about the observable arrangements, then dislocation is about exploring what affects capacities compose and how they lead to transformation and new associations.

Dislocations were also added to the initial four domains as there were affects as a result of details, dynamics, dimensions and dispositions but those affects either led or not to effects, to an observable and recordable difference or change. When no such dislocations are visible, it will provide the analyst with as much data about the performance as when such change is visible. As no dislocation might indicate that hidden dis/ability although expected based on the participating actors, the connections and affects formed did not lead to an effect and as such a visible performance of hidden dis/ability.

Descriptions domains

Descriptions are about the performance with all its makings that provide grounds for negotiations, temporary closure and further explorations.

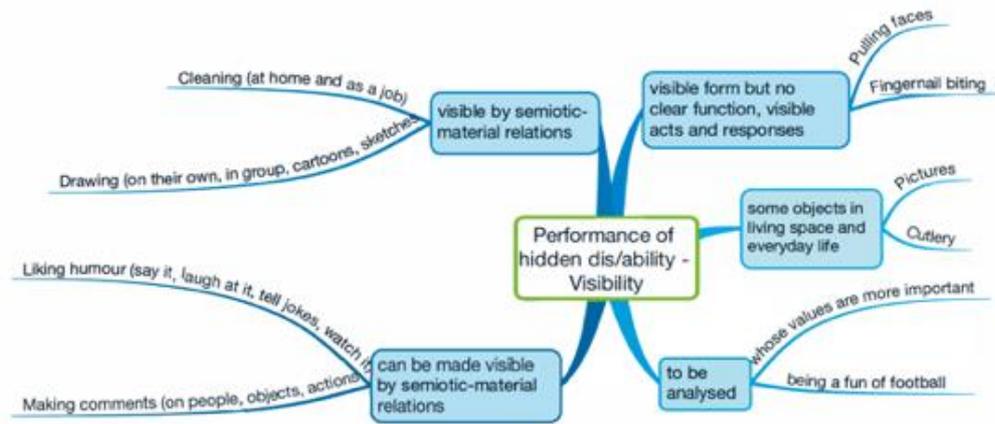
Descriptions are the sixth domain. The literature review together with the theories used helped me reconsider how the descriptions domain is about how hidden dis/ability might be perFormed, disSolved and reProduced by webs of connections to explore whether the performance reached a form of unity implying some sort of consistency or not, whether there were any contradictory realities, and if so, then how they might relate.

5.2.2. Taxonomy of the 6D material-semiotic network practice

The challenge of taxonomic analysis is to establish a set of categories within a domain based on a single semantic relationship. It shows and reveals more of the relationships constituting and structuring the domain and the included terms. The highlighted included terms in the 6D practice (the domains detailed in the previous paragraphs) were explored further in the taxonomic analysis as significant actors, as well as the performances of hidden dis/ability using examples of the collected data.

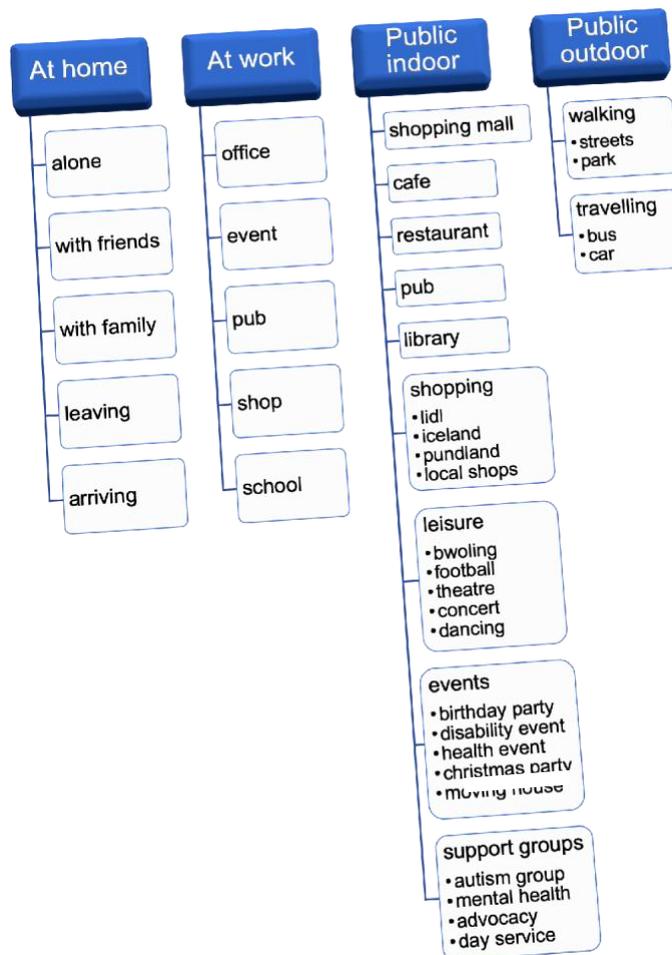
The 6D practice is a map and theory of appearance (visibility), whereby no performance is possible without the details, the involvement of materials, signs and their connectivity.

Figure 5. Taxonomic analysis of visibility (seeing is usually believing) – details domain



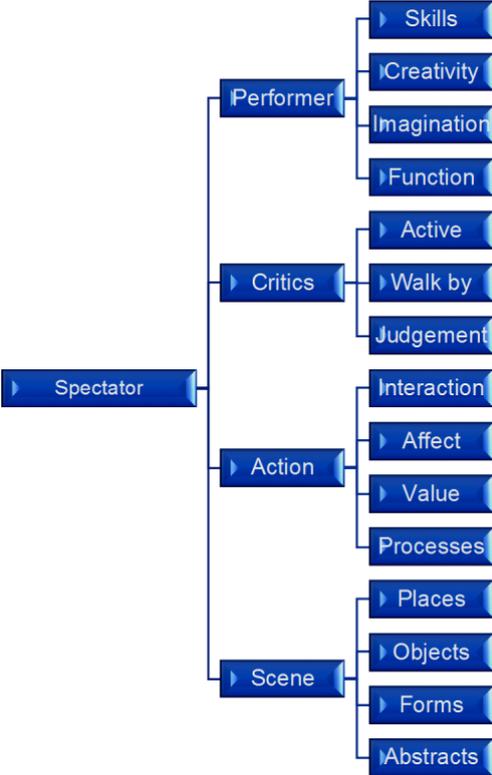
Another taxonomic analysis explored the events, the scenes as data in the dynamics domain within which the performances have taken place with all their materiality, immateriality and discourses.

Figure 6. Taxonomic analysis of events and scenes – dynamics domain



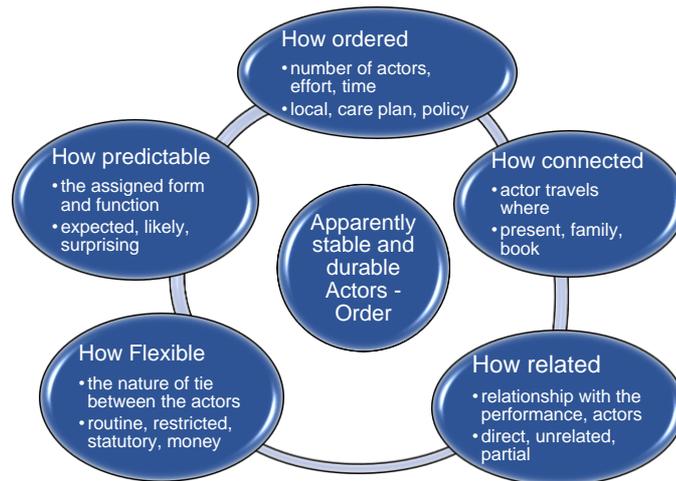
A further taxonomy explored the performance to highlight how hidden dis/ability always depends not only on the performer and his/her apparent hidden dis/ability, the details and the scene with all the actors present, but the spectators who connect the performer and the scene.

Figure 7. Taxonomic analysis of spectators as connectivity – dimensions domains



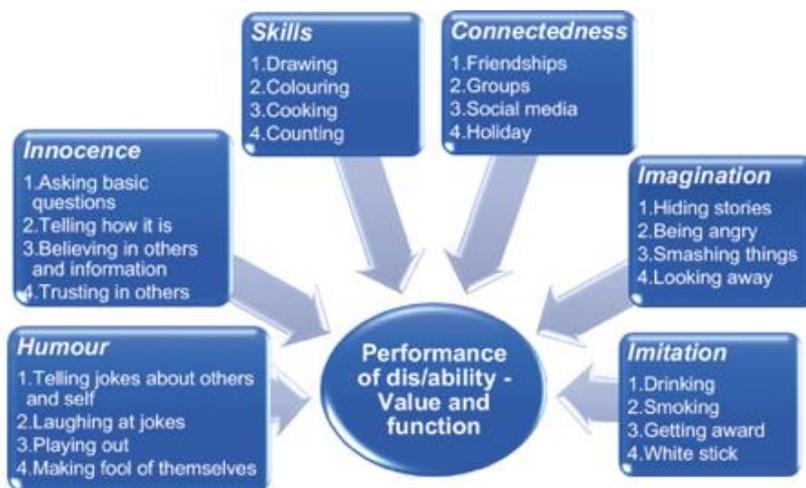
Categories of the conditions as actors have often been part of the performances observed. The role of the classifications and their apparently fixed attributes seemed to be so ordered and connected at times that when travelled into the everyday performances often (dis)positioned the possibilities of capacities to emerge. Furthermore, I recorded many similar events with the involvement of participants with different conditions. Once the diagnosis has been taken away from the analysis, most of the time, it was not possible to establish any longer the person’s condition who performed it. Therefore, a taxonomic analysis explored what makes such actors like the categories ordered, stable and durable.

Figure 8. Taxonomic analysis of connected and ordered actors – dispositions domains



Another taxonomic analysis has been carried out on frequently occurring or otherwise notable included terms. The taxonomies highlight what connects them and what are the actors that present in many taxonomies. For example, activities with a creative element requiring specific skills were grouped into the taxonomy called skills. Whilst various potentially unusual and awkward performances were brought together under the taxonomy humour.

Figure 9. Taxonomic analysis of value, function and significance – dislocations domain



The domain and taxonomic analysis signify the cultural meaning by showing how they emerge again and again in various everyday performances. These categories are significant in guiding further analytical work and the discussions of the everyday performances of hidden dis/ability.

5.2.3. Contrast analysis of domains and taxonomies

The analytic issue I was left with was how do I make sense of the everyday performances? How do I know what to value? How does distinction in the data operate so as to order our knowing and ability to not only notice the hidden, but also trace its genealogy? So far, the analysis has explored similarities, associations between actors and performances (vignettes informing the development of the 6D practice) connected with a semantic relationship. My analysis needed (or at least could do more) to go beyond establishing semiotic and semantic domains and taxonomies. Thus, dimensions of contrast are an analytical examination of how combined and related domains and included terms are based on similarities, but it also shows how they differ (for example, the spectators from the audience).

Seven dimensions of contrasts have been selected from the domain and taxonomic analysis in line with the focus of the analysis: visibility, connectivity, spectators, order, value, function and signification. Whilst these seven included terms show similarities within domains of the 6D practice, they also reveal differences based on the aforementioned signifying practices of signs and things. The next table shows a contrast analysis of the 6D material-semiotic network practice (for example, how details might differ from dynamics).

Table 5. Dimensions of contrast – 6D material-semiotic network practice

Member	Semantic relationship	Member	Domain
Actors	are a place in	performances	Details
Performances	are a reason for doing	details	Details
Details	are part of	doing visibility	Details
Dynamics	are a reason for	connected actors	Dynamics
Connectivity	is a way to do	capacity	Dynamics
Capacity	is a result of	agency	Dynamics
Dimensions	are a cause of	spectatorship	Dimension
Spectatorship	is a step in	emerging affects	Dimension
Affects	are a way to do	effects	Dimension
Dispositions	are a step in	ordering	Disposition
Ordering	is a way to	reduce uncertainty	Disposition
Uncertainty	is a place in	disorder	Disposition
Dislocation	is a result of	unstable signs of dis/ability	Dislocation
Instable signs	are a place for doing	values and functions	Dislocation
Values and functions	are a way to do	dis/ability	Dislocation
Descriptions	are used for	composing realities	Description
Reality	is a kind of	signification	Description
Signification	is a way to	performing into existence	Description

5.3. Data analysis using the 6D material-semiotic network practice

The development of the 6D material-semiotic network practice started at an early stage of the fieldwork with the data collection and linked closely to the composition of the main data sets. The two processes informed each other. Once the 6D has been developed and the data sets have been established, the 6D was used to analyse the data sets. Whilst this process did not follow a linear sequence, for ease of clarity, I explained first in the previous paragraphs the development of the 6D practice. Now, I will describe it with the data set, and the process and findings of the analysis.

5.3.1. Establishing the data set

Domain and taxonomic analysis by its nature points up how semantics render structuring anything but certain. I argue that there is more than one way of organising the data into domains and performing a taxonomic analysis on the included terms. As an underlying feature of my thesis, I recognise how the narrative nature of performances may be awkward and cumbersome in terms of ensuring certainty, but as an analytic method, it has certainly helped generate a new appreciation of hidden dis/ability. This rather fluid and unstructured approach to data proved to be challenging at least on three measures:

1. During the fieldwork, I recognised my reflexive impact on the variety of data collected that needed to be synthesised such as notes, pictures, documents; conversations, letters and interviews. It was required to type out, store and organise the field notes and the recordings.
2. The data had to be arranged into manageable formats without losing the actions, the movement and the potential for making visible the composition of hidden dis/ability, thus avoiding the temptation to reduce it to a few set themes too early. For this purpose, and as I will go on to explain, I employed a structural and semiotic approach to examining how signage can be systematically organised in process of domain, taxonomy, contrast and theme.
3. My elaboration of Actor-Network-Theory to provide a material-semiotic analytic toolkit in itself proved to be a dynamic force resulting in the 6D practice explored in my discussion.

To begin the process of establishing the data sets from the collected data, such as the initial field observations, notes, emails and photos, I composed two lists. The focus of these lists was the performance itself: how hidden dis/ability performs, dissolves and reproduces. And how do we, the spectators and performers see them? Therefore, all type of data (artefacts, text) informed the lists as usually many actors composed the performances. The first list comprised of over 100 data sets of *What I noticed* and the second registered more than 100 data on *What I did not notice* in the field. Here a short example is provided to guide the reader.

Table 6. The two lists of noticed and not noticed performances

What I noticed
Who is disabled here, and who is the carer
What is the difference, how do I know
Control, telling others what to do and how to do things
Constant giving advice what and how they should do
Comparison to other labels and group of people
Humour, one liner, jokes about others and themselves
Independence and dependence, co-dependence

What I did not notice
Discussions about dis/ability, the Equality Act, various academic debates
Awareness of reports and other policies relating to disability issues
Talking about themselves as dis/abled, as different or something being wrong with them
Certain topics such as politics, brexit, other cultures, race and equality issues
Shame of doing things, performing things, embarrassment
Constant complaining about things, people and services
Obsessive planning for future, achieving something, chasing a dream

Whilst the lists were a good starting point, I needed something more substantial to explore the performances than a list that does not show how all the actors have composed those performances. Therefore, at the same time of composing the initial lists, a dozen or so short sections from various type of data were extracted for examination. Here samples are

included. My digital and handwritten notes were turned into short sections. Interviews and other conversations were also reworked from long descriptions to brief descriptions, and the same was performed on artefacts including documents, emails and pictures. They too, like Erika’s paintings or Peter’s chessboard were converted into short written extracts for analysis.

Examples of data extracted from field notes

<p style="text-align: center;">Example 1</p> <p>We left the flat, walked down the stairs, and before leaving the house P1 checked the post that were placed on the radiator, in the hall, by the entrance. P1 picked up three letters, opened them, remarked that it was from the housing benefits and gave them to me.</p> <p>"These are for my sister. She will read them. Can you take them? You will meet with her sooner then I."</p>	<p style="text-align: center;">Example 3</p> <p>P5 was having a conversation with me. A carer came to see us and told P5 she loved my trouser and wanted to take off me. P5 responded "Why do you need it? It will not fit you anyway?" Carer responded: "Are you telling me I am fat?" P5 answered: "No, I am just saying you have a different shape, it will not fit you." Next week when we met again, she added: "You have a nice figure.."</p>
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This exercise informed the next steps, and how the main data set should look like. Data extracts were turned into vignettes that offered more details than the initial lists but were more manageable than the long descriptions. I continued to convert the various collected data into simplified extracts to compose the performances. The various extracts were eventually linked together into vignettes forming the basis of data analysis. I offer an example of the process of creating the data set and the vignettes here.

Even the initial list of 100 performances consisted the following performance:

Making drinks and food, serving drink and food

The making and serving of drink and food performance came from various data collected: for example, my field notes, pictures taken, and conversations held with my participants and other informants from more than one sources. One example is given here:

pictures:



hand-written notes:

did spend most of the time
to where are great stories
to (unlike) friends or god(s)
love to study the mundane...
and the field research
my PhD is on and can be
or around them, using their
world or coming up with funny
concepts about their stories
that will make up the world
academic: language, rules about
culture and cannot say
best: humour, anecdote
about disability too -

Digital notes:

I have just arrived at Jane's apartment. The door was open for me, so I entered the flat and was calling for Jane. "Hello Jane! You alright?" Within a split second came the answer "in the kitchen". I navigated through the narrow hallway, turned right into the living room first to reach the kitchen. I could not go in. Jane's has a rather small kitchen, where Jane and Nick were busy with finishing all the food, she wanted to take to her birthday part. I asked Jane whether I could help. She said they were almost ready, but I could help with carrying all those nice things downstairs. Then Nick left the kitchen, he was looking for another bag with drinks in it. I stepped into the kitchen, and I was amazed with the work Jane and Nick did. There were plates of sausage rolls, bread and butter and a big bowl of salad that Jane had prepared. Jane was getting some more plates for the crisps. Then turned around, opened the fridge and started taking out even more food: sandwiches, quiche, sausages and a few

documents:

Eating and drinking
[redacted] can eat physically independently although as stated above has an inability to plan meals, understand written instructions, use a cooker independently, or understand the complexity of healthy eating. She can chew, swallow and cut food.
[redacted] needs full support in all these areas.

conversations:

P1: yes and when Sunday, when we are down there, I cook for the five of them, we don't get on with the other one so I don't cook for the other one (referring to Ch)

A: okay, interesting

P1: so on the Sunday when we down there I cook for the whole five of them, you usually get chicken or pork or home-made pie, don't we

P2: yes and sometimes when she's working I am cooking I am, I do take on cooking the weekend

P1: he's using me at the moment

P2: nervous laughing

A: I chuckle with him

P1: I don't mind cooking

A: you like cooking?

P2: yeeh, I like cooking

A: Do you like cooking as well?

P1: Me? I love it. He likes it only on a Sunday.

We are all laughing

P1: only on Sunday. What are you going to cook in the microwave tonight?

A: well, that's a sort of cooking as well

We are laughing

P1: yeeh... A: there is a difference, but it is till cooking

5.3.2. Domain and taxonomic analysis of data

As I mentioned earlier, the data collection and analysis has informed each other and was continuous during the fieldwork. Further conversations, notes and interviews were typed out, artefacts (objects, documents and picturised) examined and described. As the data collected were growing, I composed more and more performances and vignettes, and eventually 1054 performances. Here, examples are given for the reader.

Examples of performances noticed and recorded from the collected data

1054 Performances
1. Approachable
2. Asking for consent
3. Being checked upon
4. Carers fighting with each other's
5. Disharmony between facial expression and story
6. Forgiving for others
7. Having a membership
8. Learning languages
9. Missing tooth
10. Not matching clothing
11. Others feeling sorry for person with disability
12. Putting services around them
13. Smashing things
14. Treating them differently
15. Writing a diary

How we 'see' these performances, what we think we 'see' when someone is being checked or what the sign and signification of a missing tooth is not only showed how domains: details, dynamics and description started to emerge new ways of looking, but also the rethinking of how performances, extracted from the data, kept the analytic movement driving towards an appreciation of appearance as well as disappearance (perForm, disSolve, reProduce). The second set of data set with taxonomies (indicating the many ways of 'seeing' the performances thus the type and nature of data) show details of how they were composed. Examples are given below.

Example performances (data) noticed and recorded

1054 Performances with included terms
1. Approachable (respond, hug, move towards)
2. Asking for consent (phone, ask permission, wait for signals, look persistently)
3. Being checked upon (phoned, questioned, ask others)
4. Carers fighting with each other's (argue, betray, post on social media, letter)
5. Disharmony between facial expression and story (smile when say sad things)
6. Forgiving for others (argument, apologetic, phone, cook)
7. Having a membership (football, union, club, bank)
8. Learning languages (German, Hungarian, talk to, text, ask mother, meet)
9. Missing tooth (visibly missing teeth)
10. Not matching clothing (colour, weather, style)
11. Others feeling sorry for person with disability (pity, sorrow, help, repeat, laugh)
12. Putting services around them (documents, carers, managers, living place)
13. Smashing things (seen, heard, stories)
14. Treating them differently (cannot do, only if, not alone)

Figure 10. Taxonomic analysis of places

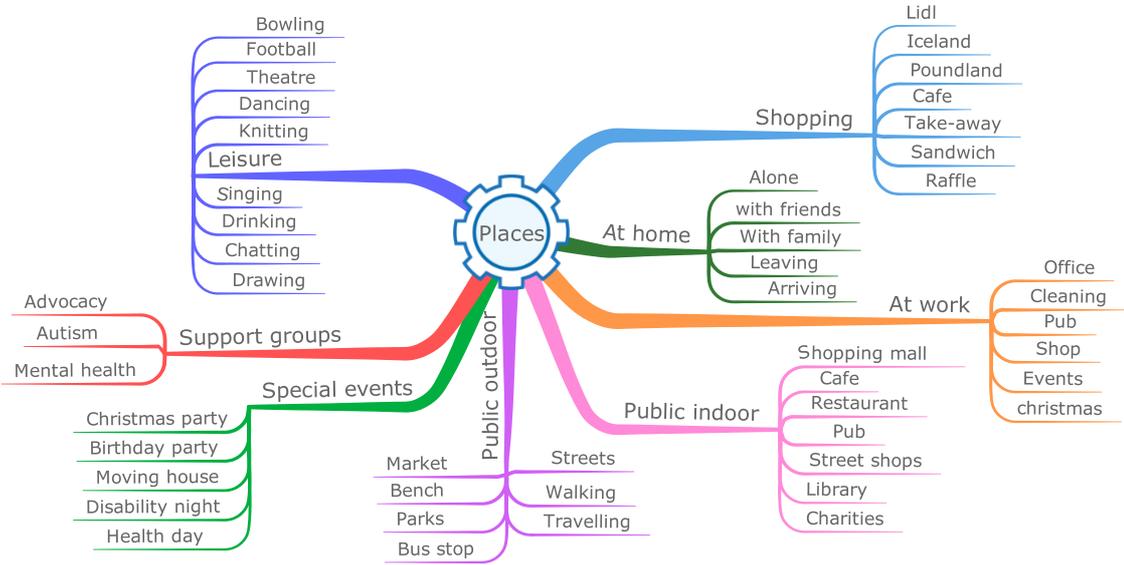


Figure 11. Taxonomic analysis of humour



Figure 12. Taxonomic analysis of objects in the living space



At this stage I already had enough data to suggest that the complexity of what is 'seen' in the performances appears straightforward unless one is purposefully attempting to disrupt. As such, it was noticeable after just a few sessions, and when exploring the above-mentioned initial lists and vignettes, that what we meant by and saw in the performance as hidden dis/ability was not simple. The next step was applying the 6D practice to the data

from the fieldwork that also informed the next steps of the research project. I include a short sample here.

Example data analysis with the 6D material-semiotic network practice

<p>Example 1 We left the flat, walked down the stairs, and before leaving the house P1 checked the post that were placed on the radiator, in the hall, by the entrance. P1 picked up three letters, opened them, remarked that it was from the housing benefits and gave them to me. "These are for my sister. She will read them. Can you take them? You will meet with her sooner than I."</p>	<p>giving the letter to someone instead of taking them or reading them, not reading but identified name and sender; surprise, not usual approach to letters and function</p> <p>postman, letters, reading, support, benefit, council, hallway, message</p> <p>get letters, ask someone to read, the letter made her pass it on, message has not been delivered</p> <p>available support, legislation, use of text, no easy read</p> <p>continued with activity, stabilised by passing on the letters, no expression of feeling or being dis/abled</p> <p>present to both</p>	<p>observation and comments</p>
<p>Example 2 P3 went to play bowling as part of the blind and partially sighted team. He was playing as any others, only a small piece of material on the floor suggested they used extra support to find the middle of the lane. A photographer was taking pictures of the event. I observed the game as any other, nothing different from other players until one of the carer came to me. "P3 complained of the photographer. We had to tell him not use flash in front of them when they roll the ball as it confuse them and can't play.</p>	<p>confusion, inability to perform task as before, recognising difficulty, role of camera, cameraman, charity event</p> <p>playing bowling, recording the event, the values of documenting, chair, players, light, photographer, camera</p> <p>rules of bowling, sensitive eyes, flash, carer, communication, need to record, unawareness of difficulty</p> <p>change in performance, request of act, narrating the event</p> <p>photographer changed practice, continued playing</p> <p>present to the person</p>	<p>observation and conversation with others</p>

The following tables illustrate in more detail the analysis of the collected data and composed vignettes using the 6D practice (in line with the domain and taxonomic analysis detailed in 5.1.1. and 5.2.2.). It shows the actors relationships with the performances constituting and structuring the domains.

Details domains

Semantic relationship	Included term	Domain
Are a way to	Do visibility	Details
<ol style="list-style-type: none"> 1. Foot shuffling (manner, focus on, resistance) 2. Hugging (one side, brief, two arms, symbolic, firm) 3. Hugging, eye contact as opposed to assumptions 4. Impolite reference (to body, actions, and objects) 5. Jewellery (buy, wear, make, few, lot, varied, random) 6. Kissing (partner) 7. Laughing at comments (laughing, saying it was funny) 8. Laughing at jokes (laughing, covering or not mouth, turning away) 9. Lip biting (bottom, top, red, bleeding, often, occasionally) 10. Making noise (mouth, hands, objects) 11. Manner of walking (fast, gait, jump) 12. Marks on the cloth (food, paint, dirt, old) 13. Mimicking (others, movie, picture) 14. Missing tooth (visible, at the back, one or more) 15. No response (when hurt, asked, joked) 		

Dynamics domains

Semantic relationship	Included term	Domain
Are a kind of	Connecting Humans - Actors	Dynamics
<ol style="list-style-type: none"> 1. Bus drivers 2. By passers (street, park, café) 3. Flatmates (permanent, temporary, friends) 4. Friends (club, hobby, school) 5. Guests (club, home, work, event, party) 6. Neighbours 7. Professionals (psychiatrists, social work, charity manager) 8. Carers (paid, voluntary) 9. Family members (mother, father, siblings) 10. Students (placement, nurses) 11. Officials (shop keepers, council, security, bar) 12. Colleagues 13. Volunteers (club, charity, school, doctor) 14. Students 15. Strangers 		

Semantic relationship
Are a kind of
Included term
Connecting non-humans - Actors
Domain
Dynamics
<ol style="list-style-type: none"> 1. Clouds 2. Creativity 3. Gossiping 4. Humour 5. Ideas 6. Jokes 7. Music 8. Performing 9. Playing 10. Policies 11. Skills 12. Smiling 13. Stories 14. Sunshine 15. Talking

Semantic relationship
Are a kind of
Included term
Connecting objects - Actors
Domain
Dynamics
<ol style="list-style-type: none"> 1. Autism Card 2. Bicycle 3. Boardgame 4. Books 5. Dinner 6. Games 7. Headphones 8. Medication box 9. Poster 10. Photo 11. Radio 12. Ramp 13. Tattoos 14. Television 15. X-box

Semantic relationship	Included term	Domain
Are a kind of	Connecting places - Actors	Dynamics
<ol style="list-style-type: none"> 1. Going to the park (walk, air, people) 2. Having local places, pubs and cafes (visiting places) 3. Inviting others (home, party, restaurant, drink) 4. Others whispering (shop, bus, street, café) 5. Partying (going out, at home, birthday, events) 6. Passion for things (animals, family, various hobbies) 7. Playing board games (various games with others) 8. Playing bowling (with others, competition) 9. Playing music (guitar, on computer) 10. Social media (use of facebook, join facebook groups, twitter, messenger) 11. Socialising (shopping, cafes, clubs, concert, library, sitting in group) 12. Special groups for certain conditions (drop in, champions, voluntary groups) 13. Using public transport (alone or with support) 14. Walking a lot (streets, shops, community) 15. Working, having a job (office, shop, café, school, pub) 		

Semantic relationship	Included term	Domain
Are a kind of	Connecting time - Actors	Dynamics
<ol style="list-style-type: none"> 1. Benefit (rely, lose, assessment, not fair, council) 2. Birthday (partying, making and serving food, drink, cards) 3. Collecting things and rearranging them (gifts, pictures) 4. Folders (others control info, assessment) 5. Having Imagination (creative activities, stories, dreams, goals) 6. Having a membership (football, union, club, bank) 7. Having a schedule (start, finish, place, time, activity) 8. Hiding stories (not telling what happened, no sharing) 9. Job searching (having fantasies, having dreams, lifestyle, interview) 10. Learning languages (German, Hungarian, talk to, text) 11. Memories (photos, writings, objects, stories) 12. Photos (nostalgia, remembering others, wall, phone) 13. Remembering things (appointments, holidays, moving, jobs, people) 14. Showing pictures of self and others (phone, book, wall, private, public) 15. Using calendar (paper, digital, record, remember) 		

Semantic relationship	Included term	Domain
Are a kind of	Actions - Actors	Dynamics
<ol style="list-style-type: none"> 1. Cooking for others (Sunday meal, spontaneous, in group) 2. Depending on others (in most things, being observed constantly) 3. Dropping things (keys, paper, food, drink, cloth) 4. Emailing (phone, computer) 5. Horse riding (hobby, watching) 6. Living independently (various support around) 7. Leaving things unattended (in shop, in café, in various places) 8. Not being religious (no signs, images, objects, reference) 9. Playing with their voice (accent, noises, others speech) 10. Rearranging the room (decorating own environment, changing things) 11. Saying out loud (what they think, comments, like, don't like) 12. Singing funny things (on stage, in groups, at home) 13. Telling stories (about self, others, activities, objects) 14. Watching funny things (show, tv, cartoon) 15. Wondering eye contact (restless, look then not, long than not at all) 		

Dimensions domains

Semantic relationship	Included term	Domain
Are a result of	Spectators	Dimensions
<ol style="list-style-type: none"> 1. Adapting to others (in activity, changing according to situation) 2. Annoying others (by actions, use of objects, comments, not doing) 3. Being confused on others reaction (do not respond, withdrawn, ask) 4. Being loved (hugged, presents, help, support) 5. Carers being vocal (talk about rights, injustice, needs) 6. Conformity to please (obedience, adherence to others) 7. Doing things like others (imitate actions, repeat things, drink, smoke) 8. Others being impatient (tapping, looking away, raise voice) 9. Others depending on disability (experts, professionals, business, services) 10. Others making decisions (various things) 11. Others not allowing friendship and relationship (carers) 12. Others talking on their behalf (in public and home) 13. People reacting when they do/ask for things being different (laugh, whisper) 14. Reliance of others (to understand things, legislation, processes) 15. Ticking each other (when together, sitting together) 		

Dispositions domains

Semantic relationship	Included term	Domain
Are a step in	Creating order	Dispositions
<ol style="list-style-type: none"> 1. Assessment of capacity (you don't understand, you can't do it) 2. Benefit (housing, tax, employment, cards, free entry) 3. Buying same thing (food, drink, style of cloth) 4. Comparison to others (with and without labels, tell stories) 5. Counting (with or without knowing the numbers) 6. Do not want to disturb others (quiet, do not do) 7. Filling in forms (benefit, job, cards) 8. Having advocates (family, carers, independent, professionals, organisations) 9. Having professionals in life (various people present) 10. Identifications (care files, labels, groups, needs, autism, organisations) 11. Labels as excuses (you cant do this, no job, i decide you don't understand) 12. Labels as framework (support, living, working, activities) 13. Locking the door (habit, security, leave it open) 14. Never doing it again (suddenly stop activity, not starting again) 15. Regimented (routine, safe, fix rounds, objects, routes, same seat and table) 		

Dislocations domains

Semantic relationship	Included term	Domain
Are a kind of	Value and function	Dislocations
<ol style="list-style-type: none"> 1. Being loved (hugged, presents, help, support) 2. Being proud of achievements (certificates, stories, medals) 3. Being recognised (by others for achievements) 4. Capable of making own decision (most activities) 5. Celebrating (birthday, qualification, 25 years of working, moving in) 6. Cheerful (storying, showing, drawing) 7. Childhood memories (photos, objects, talk) 8. Competent (certificate, judgement, care file) 9. Creative use of language (the box carry me, horse riding) 10. Creative use of objects (open with fork, support with book, own designs) 11. Going to school (learning, skills, not getting what is expected) 12. Having fun on their own (drawing, knitting, watching tv, karaoke) 13. Inventing things (material on the floor for bowling) 14. Liberated (free, stroll the streets, watch tv, no politics) 15. Managing things without understating it (money, benefit, politics, rules) 		

Descriptions domains

Semantic relationship	Included term	Domain
Are an attribute of	Signification	Descriptions
<ol style="list-style-type: none"> 1. Accepting the diagnosis (know and say, disclose as and when needed) 2. Being indifferent of diagnosis (have it but do not use it) 3. Carers know it all (rights, benefits, their diagnosis) 4. Diagnosis (professional, file, paper, stored, shared, labelled) 5. Difficulty of getting a diagnosis (wait, reject, do not want) 6. Eligibility to services (need diagnosis, assessment, expert decision) 7. I do not share the label (reject diagnosis) 8. Mental health is everything (recognise moods, talk about, have diagnosis) 9. Mistakes in care files (no disability when has diagnosis) 10. No link between condition and issues in everyday life (can't tell the diagnosis) 11. Not accepting the diagnosis (i am not autistic, all have routines) 12. Not mixing with people without the same label (carers, money, access) 13. Others labelling them even if no label is visible (you are, you need, you ...) 14. They do not exhibit the labels and assumptions (creative, surprise) 15. Using labels when needed (disclose when suits, need support) 		

5.3.3. Contrast and theme analysis

The performances of hidden dis/ability were contrasted (in line with the contrast analysis described in 5.2.3) by examining how actors and their connections relate and emerge capacities. Contrast analysis investigated, for example, how *reading* or *shopping*, as an actor (data), make an effect differ in connection to the spectators. Various contrast questions were asked at this point (to explore differences between domains and the actual performances as included terms) in support of the data analysis.

Example contrast questions

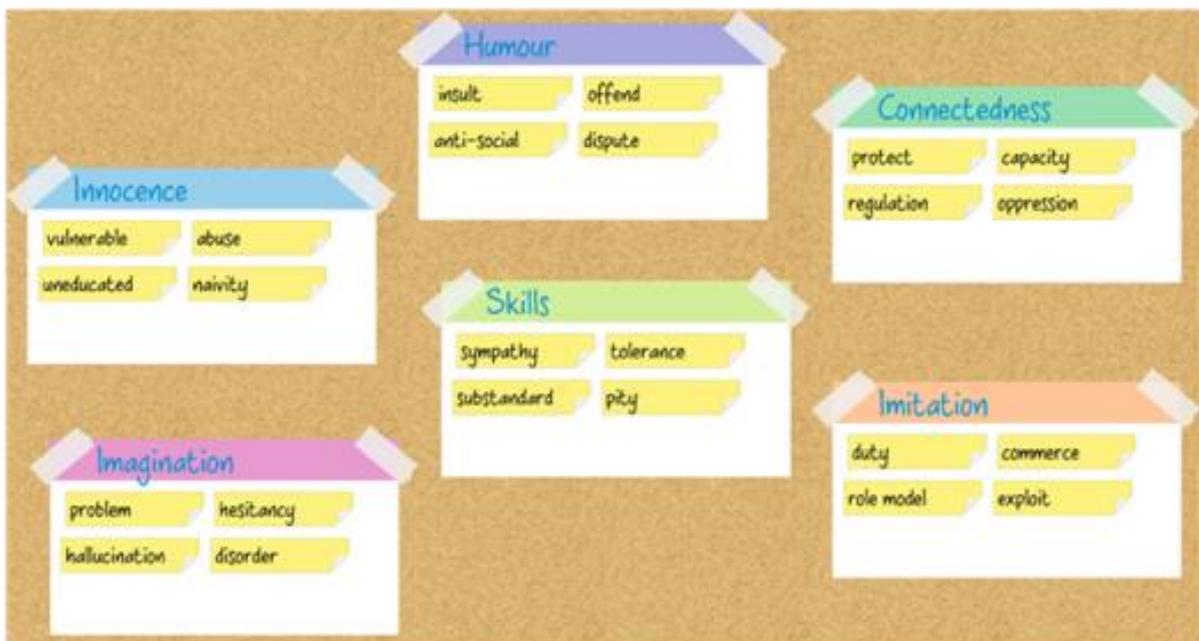
1.	What are all the types of actors? What are all the types of visibilities of hidden dis/ability? What are all the actors the spectators see in the performance of hidden dis/ability? What are all the main places of the performances of hidden dis/ability?	<i>Details</i>
2.	What are all the ways to connect with other actors? What are all the ways to participate in a performance of hidden dis/ability? What are all the ways to be a spectator? What are all the ways the white stick affects connections?	<i>Dynamics</i>
3.	What are all the stages of becoming a spectator? What are all the ways spectators connect with the Autism Act? What are all the types of connections of the Autism Card? What are all the connections that hold together the Autism Group?	<i>Dimensions</i>
4.	What are all the stages of creating order? What are all the results of arranging the room the same way? What are all the ways a diagnosis arranges the spectators' actions? What are all the results of disclosing hidden dis/ability?	<i>Dispositions</i>
5.	What are all the ways spectators value the unexpected? What are all the different types of function of the Autism Card? What are all the results of humour? What are all the results of using objects creatively?	<i>Dislocations</i>
6.	What are all the stages of achieving temporal unity? What are all the uses of negotiation? What are all the ways spectators describe hidden dis/ability? What are all the ways to experience shared performances?	<i>Descriptions</i>

That is to show that on the one hand, I could not compose signs of hidden dis/ability that could be assigned to mutually exclusive categories. It revealed that what made or not a performance a potential representation of hidden dis/ability had no clear boundaries and attributes. Most of the noticed features, behaviours, linguistic aspects, objects, and activities

could be assigned to more than one taxonomy (and domain) as the effect was often different depending on various actors' presence and absence, the significations and associations of actors, the spectators' connections and how they affected or were affected in the performance.

Examples of contrast analysis

The first data set illustrates that every time a performance was considered for humour (a potential taxonomy), for example, the effect of the same act could have been coded other times for offense, innocence or even anti-social behaviour in a different network. It was never the act, the comment or the commenting alone that could determine such effect, and ultimately the performance of hidden dis/ability, but the significance of the material-semiotic connections between the spectator, the performer and the scene.



The second set of contrast analysis is another example to demonstrate that judging an act as a performance of hidden dis/ability was not straightforward either. It was not a question of similarity or difference between a set of actors, but rather, the presence and absence of the significations and associations between various actors.

Which one is a performance of a dis/ability?

Example 1 shows the inability to read. Yet, support system is in place that immediately solves the problem of reading. Is it socially constructed? When only priests could read it was not a disability. When ordinary man started to read it became a disability. Short sightedness is not a disability as it affects a large number of people but also because we have invented reading glasses. So what is the difference between a support worker reading out loud, a computer reading out loud or glasses that help us read or the ability to read without any support geerally objects. The question of dependence and independence is clear. However it is the same with the glasses. If they broke, we depend on someone who repairs it or we need to buy a new one. In this situation the inability to read did not cause change, affect or any concern for her. Can we say that the inability to read causes permanent disability? Or it depends on the actor-network and the objects/humans available? Is this the inability to read to compose disability or the lack of support and solution or the complex interactions of the actors? The inability to read does not necessarily cause concern and issues. Until...

Example 2 involved both an invisible mental disability, autism and a physical disability blindness made visible by the use of white stick, and certain practices such as walking with someone. Yet the moment the white stick was taken away, and they were playing bowliong like anyone else, blindness and what might affect it became invisible. The photographer was not aware or able to perceive the potential consequences of using a camera and the flash. It was the flash, the affect and the ability to make meaning of the effect that made it visible again. I still mainatain the difference between the two group. The blind only needs the white stick and some devices to explain, raise awareness and make the difference visible. The person with autism has no such tools readily available. This rises another question, the formation of actor-network and their effects were not visible for me. How this can then inform practices? If the person cannot make meaning and communicate such experiences. How can I notice it the next time?

Example 3 probably would be a sign of disability, and in this case autism, and these are some of the comments and communication issues listed as concerns. Yet, as an autistic researcher I perceived it as humorous as did the carer who has two sons with autism and understand autistic people often different communication and sense of humour. Would it coded for disability and sign of autism if the researcher was not autistic? If she did not laugh with them? If she received such comments? Inability to communicate, to say the right thing, to make remarks does not necessarily cause disability. It also depends who and what else play a role in the actor-network. And the after effects of the effect of the comment.

Somehow the distinction in hidden dis/ability has been medicalised and socialised and as a result naturalised and hidden. I am now offering 'contrast' and the 6D practice as a new way of 'seeing' the everyday performances of hidden dis/ability that the following chapters will narrate. Contrasts are an important part of the analysis as together with the domain and taxonomy analysis will compose the themes, the matter of concerns of the everyday performances of hidden dis/ability echoing Latour (1993) here. It makes visible how performances of hidden dis/ability are formed and performed, produced and reproduced, but also solved and dissolved in light of the analytical considerations of significations and associations.

The domain, taxonomic and contrast analysis reveal, everyday performances of hidden dis/ability are more complex than semantically connected categories. Actors have been observable and noticeable in most domains and taxonomies (and performances), and the contrast analysis highlighted how it was significations and associations that made a difference. As such, they are present as well as connect different parts of the culture, the performance of hidden dis/ability. The 6D practice made visible various matters of concerns such as objects being more than mere artefacts, the categories being significant stabilising actors and the role of spectatorship in composing the performances of hidden dis/ability in everyday life.

Examples of themes emerged



More examples under the theme objects:

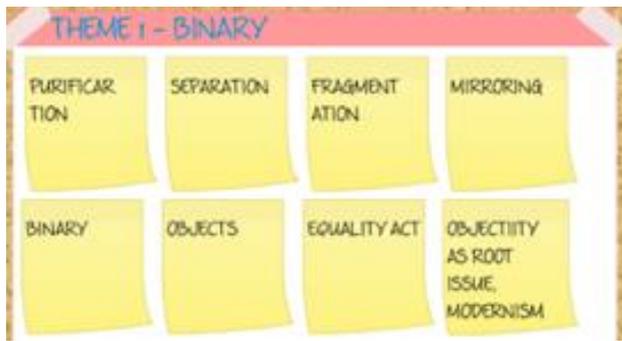
The role of objects in group formation and performance of disability P3

- Use of white stick when with the group of blind and partially sighted
- The use of wheelchair in the library as disabled
- The use of none if the autism group
- The use of computer and other tools at work
- The non use of kitchen tools in the supported living
- The carrying of objects with a weekend hand
- The medication box and its Friday routine

The matters of concerns connect the domains of the 6D material-semiotic network practice (details, dynamics, dimension, disposition, dislocation, description) but also describe the relationship between the included terms within one domain showing how hidden dis/ability is not an essential and universal thing but composed by actors and their connections, the signifying practices of signs and things. The 6D practice led to themes that could show how valued signs of hidden dis/ability are composed, represented and thus consumed in everyday performances. The beautiful hidden. I will introduce here the main themes and discuss them in more details in the subsequent chapters of the thesis.

Example of theme synthesis:





The domain, taxonomic and contrast analysis together emerged the themes that the following chapters will unpack. Eventually 3 themes have been identified. Theme one explores the universalising tendency of health and social care signals and how they position hidden dis/ability in the everyday performances. Theme two concerns how spectators are active and dimensional makers of the performances. Theme three focuses on hidden dis/ability as a dynamic performance, offering capacities for transformation. Once the themes, matter of concerns emerged from the analysis, a final decision had to be made regarding how to order the everyday performances of the informants I observed, analysed and wished to narrate. Various strategies have been considered: *first*, genealogy with moving from the grand narratives of past practices to the small stories of the participants. *Second*, chronology, and how the events were recorded. *Third*, following the domains of the 6D material-semiotic network practice and how performances come into existence and are made visible. *Fourth*, comparing and contrasting the performances of the six informants in light of the 6D practice. *Fifth*, considering the matters of concerns and exploring how the 6D practice reveals performances of hidden dis/ability.

Whilst I believe, any of the approaches could have been applied, I decided to divide the sections according to the three themes, the matter of concerns and narrate how the 6D material-semiotic network practice makes visible (or not) performances of hidden dis/ability which perForm, disSolve and reProduce in everyday situations. This allows me to show details, the many actors present, including the performer, the spectators and the scene. It

considers dynamics and dimensions, how connections form, last and change, and how capacities emerge. It highlights highly ordered actor-networks and how such dispositions limit and steer capacities whilst drawing attention to the affects. It provides further opportunities to narrate how dislocations mean transformations and the forming of new associations. The matter of concerns narrated offer novel ideas of how we might work with the everyday performances of hidden dis/ability, and what alternatives might be possible.

5.4. Summary

The application of Spradley's solution-focused approach (and the relational theory of cultural meaning), Baudrillard's semiotic idealism (and the signification and associations of signs) and Latour's semiotic materialism (and the signification and associations of things) helped me to develop the 6D material-semiotic network practice. The application of the 6D practice to the data led to three main themes that the next chapters will unpack. The themes aim to describe how the associations and significations of signs compose hidden dis/ability and thus consumed by the performers and spectators in everyday performances. The following three findings and discussions chapters follow the same structure. First, it shows the data analysis that is going to be the focus starting with the actual data. Then, I explain how and what I have found interesting, how I have noticed it using the evidence and the vignettes which the reader can refer to and provide a discussion of that analysis.

CHAPTER 6

Theme one – Health and social care signs seek a real hidden dis/ability

I will analyse in this chapter how hidden dis/ability in everyday performances cannot rely on universal and traditional health and social care signs any longer. The separation, purification and proliferation of categories and practices, and the binary oppositions of the medical and social approaches have left us with a gap in working with the everyday performances of hidden dis/ability. If the origin is no longer a precursor of actual performances, then new regimes have emerged to compensate as there can never be a gap in our knowledge. The apparently universalising medical signs of hidden dis/ability are one proliferating model of ideal performances, deleted performers, apathetic spectators and scenes mirrored in social approaches. This state of transition of apparent universal health and social care signs signals and pretends to seek a real hidden dis/ability, an objective and single truth in the complex everyday performances. My data analysis through the 6D practice explores how actors and connection are positioned by such signs and what are the effects on the everyday performances of hidden dis/ability.

6.1. Signs and models of hidden dis/ability have overridden the everyday performances

Data set

I attended the Medical-Sociology Conference in York to present my doctoral poster. Jack, a young man with autism tells his story of how he might struggle at one moment when the noise, the constant chatting and the loud background music make him unable to engage in the conversation with friends. And how the same Jack had walked peacefully in the park the day before or enjoyed the music and jumping with others at a concert the day after. Whilst many visitors commented on how well such a

cartoon on the poster illustrated their story of autism, or their mother's everyday life living with a bipolar disorder, or their sister's panic attacks, some visitors had different and antagonistic attitudes (interacting with my poster and Jack on it). In particular, Darcie, a middle-aged woman, a teacher in a secondary school, claimed with a slightly raised and agitated voice that she needed the categories. She very clearly expressed that she did not like my work and what I was saying. She argued at length how they were the categories that informed her how to look after pupils and without those categories she could not support them.

I met with Tim, an academic, to discuss my thesis. He told me whilst pondering on my hypothesis "you can always tell a 'schizophrenic'; they talk to themselves out loud". He went on explaining, it was the word 'hidden' that struck him as such dis/abilities are always recognisable. I asked Tim to tell me more about his experiences and what made him so visibly flustered about my project. He revealed never meeting a person with an official diagnosis of schizophrenia, but his friend had a neighbour with such condition, and they talked about him occasionally when they met in the pub for a pint.

The application of 6D practice

I started the analysis with the 6D practice to 'see' how Tim could make such a judgment of hidden dis/ability, as if he knew how all the people with schizophrenia would perform and what signs he would 'see' in their performances. The conference and the effects of my poster were another such data that made visible not universal signs of hidden dis/ability but rather, how signs could compose not one but several 'seeing' of hidden dis/ability. At this stage, I had not started my fieldwork, yet I was already noticing from the data how hidden dis/ability can be made visible and constituted by apparent universal signs. How certain actors, particularly the categories of the conditions, have capacity to configure other actors in a performance, based on apparent objective signs of hidden dis/ability. Moreover, how such dispositions then could compose capacities to form a simulated hidden dis/ability neglecting the actual performances happening in the here and now.

When I applied the 6D practice to the data, one actor seemed to be common. What was it that Tim, his friend, the neighbour, the beer and the signs of schizophrenia and Darcie, the

secondary teacher, the poster, the classroom, the task in hand and the pupils with hidden dis/ability, all had in common? The categories of hidden dis/ability as a significant actor. It seems we have not only delegated the potency of objectivity to non-humans but also values, functions, duties, and ethics (Latour 1992 p231). Such judgements (connecting ways of appreciating performances and the object of it) remain noticeable (and thus visible in the data) once I was in the field, talking to informants and observing everyday performances. Listening to Ken, the social worker, for example, in the autism group, it was like all people with autism, and all the performances of autism shared the same universal characteristics. The way Tim knew how people with schizophrenia should perform, Ken was somewhat equipped with apparent universal signs of autism to (dis)position and judge the everyday art of living regardless of the actual performance. I have observed many more similar performances and reflected on the data analysis, how the universal and static categories of health and social approaches simulated, and as such, hid and masked other versions of knowing the performances. How the categories configured the actors, including my participants and their connections. How the models of hidden dis/ability and not the complex actor-networks in everyday life of the participants composed performances of hidden dis/ability.

When I applied the 6D practice to the data, it illuminated not only other actors and connections that might have played a role but how the models (like the categories) were significant actors in the composition of hidden dis/ability. In this section, I am focusing on the latter findings. This dataset and the 6D practice brought into focus on how health and social care signals through the categories affected the actors and their actions positioning the performances. The dimensions and the dynamics of the categories, the connections with the actors, ordered the performance in a way that the spectators like Tim, Ken, and even Julie from the charity sometimes failed to notice how associations might have composed capacities to perform or not a so-called hidden dis/ability. Whether such models

and images focus on apparent universal signs that are inner and biological, or external and social, the details of the performance and the capacities actors formed through their dimensions and dynamics were not part of it. Whilst it is the case that the categories aim to signal universal signs of hidden dis/ability when looking at the performances through the 6D practice, my analysis questions the notion of an objective and universal performance, and a subjective and individual perspective, both existing somewhat independently and in binary (Baudrillard 1996a; Korenic 2004; Latour 2010b; Leddy 2011).

What the models then reproduce through Darcie and her activism is a disposition, that autism and depression are real and objective conditions on the one hand, and autism and depression are two independently existing realities distinguished by the clear boundaries of universal and condition-specific signs regardless of the actor-network within which they performed. Precisely, that is what Tim's and Darcie's narratives composed. What these performances signalled when I looked at them through the lens of the 6D practice was that many informants focused on *a priori* established, apparently universal signs, matters of fact of hidden dis/ability, rather than all the actors performing. Such analysis indicates how it is not the heterogeneity and uncertainty of actors and their associations, and the heterogeneity and uncertainty of signs and signifying processes that compose hidden dis/ability, but the categories maintained through the practices and connections of the informants, the spectators (Latour 2004a p22; Kobyshcha 2018). In other words, disposition of the 6D practice particularly draws attention in the data to how a set of configurations can reduce complexity and create order out of disorders through selecting and noticing actors according to set rules.

I highlighted in the literature review such methodologies as a potential limitation in understanding the everyday performances of hidden dis/ability. Patterning, the apparent universal signs of the various conditions, emerges when details are limited (the number of

actors), dynamics (their connections) and dimensions (extent and scale of their associations) are restricted in advance. Such a process indeed will compose black-boxes (complex system with hidden processes) characterised by a few distinct signs. They seem to be so real and stable that in the performances above, they were often 'seen' more real than the actual performance. "The real appears more true than the true, as too real to be true" (Baudrillard 1983 p84). The hyperreal is then not destruction by violence, but by models of reals where "the model acts as a sphere of absorption of the real" (ibid. p99). Signs and things now are to produce the real performance of hidden dis/ability instead of exploring them in the here and now, as they happen. The analysis led me to reflect on how Tim has never met Brian, my informant with apparent schizophrenia. Nevertheless, if they were to meet, Brian would talk to himself out loud all the time. The ethical committee has never met Jane and Nick, whom I recruited to the project and have an intellectual disability. Yet, they have already positioned them through the categories limiting the capacities to understand my research and give informed consent so 'an expert spectator' must judge their capacity. (I was told that only someone independent of my research needed to assess the mental capacity of my participants with intellectual disability). The secondary teacher, Darcie, has not met Monique either who has depression and anxiety, or Bob, who has an obsessive-compulsive disorder and let me observe their everyday performances. However, she already knew that without the models of the categories, she could not possibly teach them. And Tina, the activist or Ken, the social worker, have never met with Peter or Anna who have autism. Yet, both projected in their arguments about autism that such performances would be mostly the same displays.

It appears that the universal health and social care signals through the categories became a significant actor in many of the everyday performances. This is a reoccurring pattern in the data sets collected and the performances observed. I argue from the analysis that such actors act so as to separate the condition, its performance and its witnessing from their

creation, the processes, and the world-making activities of the actors themselves that participate in any given performance (Latour 1993; Wróblewski 2015). Latour (1987 p2; 1993 p242,259) and Baudrillard (1993 p56) through the 6D practice offer me a way to analyse and explain such apparent objectivity of hidden dis/ability. How earlier observations, tests and debates settled and condensed the performances into black-boxes like the ICD (2015) or DSM (2013) and separated the conditions from their composition. Once they become a template, they can be replicated whilst other ways of 'seeing' and judgements become sort of impossible. When I applied the 6D material-semiotic network practice to the data, it could make it visible how the distinct categories travelled into the performances. My analysis with the 6D practice allows me to see the questions limiting the possible number of answers in Tim's account, the unequal position of the performer such as the person with a condition and the spectator such as the professional schoolteacher; the predefined questionnaires designed to establish the performance in advance according to set criteria in the mental health examination; and the not so hidden agenda of ordering by comparison in a social worker's account. Baudrillard argues (1983), this way of selecting, ordering and noticing of actors and their connections screened for the people who would fit specific boxes that have already been composed.

The 6D practice can reveal in the data first, how 'expert spectators' compose and separate as many disorders as imaginable. Second, how they purify each disorder into distinct signs (some belonging to the natural and some to the cultural). Third, how categories then start to build and grow their connections, for example, through Tina, Darcie and Ken. For John, the psychiatrist, hidden dis/ability is a genetic disorder that has evident material and visible signs. For Ken, the social worker, and Tina, the activist, it is society and those people who bully people with autism when they wish to follow the instructions. For neither of them, it is the actor-networks of the everyday performances, including themselves as an active composer of such realities. My data documented many such performances whereby

apparent universal signs of hidden dis/ability have overdriven the actual everyday performance as it happens. The categories have lost their functions to hide the absence of real hidden dis/ability, and instead, transform everything into banality (Baudrillard 2005b p25).

The problem with such approaches that distress is not the result of the complex connections of actors and their actions, a hanger holding a coat instead of the shirt that Peter's carer, Boris paired up that the analysis of the 6D practice suggests, but the category that was always already there to order, predict and explain Peter's performance. It follows when looking at the performances with the 6D practice that distress and routine are actors and not universal signs of hidden dis/ability as Julie, the manager of a charity implied. That is to say, in many performances, such routine and affects were not visible when spending time with Peter or Anna (my participants with autism). Hence, I argued in the literature review about the importance of data collection and analysis methods where we can 'see' continuity but also change. Whilst the everyday performances are temporary and erratic, the collection of signs that the categories bring into the performance (for example, through their connections with Tim, the neighbour, the storying in the pub) appears to stay the same regardless of other actors present and the associations they form, hinting the appearance of a universal hidden dis/ability. My analysis with the 6D practice rendered noticeable how in many performances when a category was present, the informants often engaged with a few 'visible' actors and the 'universal signs' brought into the performance. Still, my data could establish with the 6D practice that routine was not one of the essential signs that composed a permanent and fixed hidden dis/ability, in this instance, Peter's or Anne's autism, that later sections will detail. It follows, one of the main concerns of this thesis is that such theories about the everyday performances of hidden dis/ability base their argument on either nature or culture, on specified, apparent and separated actors and universal signs. They generally neglect the diversity of actors participating and the

connections between them. In other words, for many spectators, such as Tim, the academic, Darcie, the educationist, John, the psychiatrist, Ken, the former social worker, and carers like Tina or Boris, certain health and social actors do not only already exist to position the everyday performances of hidden mental and cognitive dis/ability but offer a way of 'seeing' and justify their existence.

6.2. The categories mask and hide the potentiality of everyday performances

Dataset

Jane is in her late 50s. She received a diagnosis of intellectual disability at a young age. She was sent to a special school, far from home in a different county and it was not until she was in her twenties that she could move back, closer to home. She told me her story while having a glass of water in the café where we first met. Jane is vegetarian and does not like alcohol or hot drinks, except an occasional cup of hot chocolate. I learnt a lot about her life that day, how her mother used to be her carer until she recently passed away. I listened to her narrative of how it is her sister, Lulu, who now supports her and how much she likes horse-riding (pronounced as "horsee") and swimming. Jane came across as a confident middle-aged woman who knew what she liked and did not like. At least, this is what her tone of voice, gestures, and eye contact with me suggested.

We were sitting in Jane's flat. Jane grabbed a tick folder and gave it to me so I could explore its messages. It was her carefully assembled care file. She asked Barbara too, her friend, whether she would show her care file to me. We left Jane's flat and went downstairs to Barbara's flat. Barbara first walked me around her flat then brought up her care file to Jane's flat, so that I could inspect it. Nick, Jane's boyfriend, also shared his folder with me the following week when I visited him in his apartment. I read Jane's folder and she gave me permission to take pictures. Jane had a thick dossier comprising dozens of pages with over 20 different headings like profile, support needs, DLA, banking or miscellaneous detailing various assessments, letters, and important documents from key organisations like the Local Authority, the Care Company, or the GP.

The application of 6D practice

The data continued to show me when I analysed with the 6D practice, that if there is no link with the origin - the actual performance - with no referentiality any longer except the universal signs of hidden dis/ability, the models fill the gap by providing a (referential) prototype to reproduce itself endlessly. Hidden dis/ability in everyday performances entered the simulation by signs and things in a Baudrillardian sense, where the signals of apparent universal hidden dis/ability mask the actual performances like tea making, tickling and laughing I observed. When we look at the universal signs of hidden dis/ability in the care files removed from the connectivity of all the actors, like Nick's inability to read, the autonomy of the performer like Jane's needs to have someone showing her how to travel before she can go independently, the formal excellence and perfection of their actions, the performance can be seen as something obviously distinct from the universal signs of 'abilities' and 'norms' and judged as hidden dis/ability. The opportunity to explore how Jane in connections with other actors compose and composed by their apparent reality is missed. How other actors (networks) might be present and as such not only perform but dissolve hidden dis/ability is occluded. 6D practice reinserts these actors, namely, creativity, virtuosity or the various objects that through their connections form possibilities in the everyday performances of hidden dis/ability. I will discuss this in more detail in the following chapters. Here, the focus of the analysis is disposition.

The data analysis shows that most of the performances did not replicate what the model of the categories portrayed. I could not notice and thus record, for example in Jane's performance in the café when we first met, a low IQ, an inability to learn new skills or the lack of capacity to decide whether she wanted to participate in the project. Conversely, I have recorded performances that the usual apparent universal signs of hidden dis/ability

somewhat fail to describe. These performances were a few of many that, once I examined with a critical material-semiotic eye of the 6D model, drew attention to various actors and performances but not hidden dis/ability *per se*. Jane's, Nick's and Barbara's performances of hidden dis/ability when explored with the 6D practice were a composition of many actors and their connections, the sofa, the tea, the memories, the joke, at a particular scene forming capacities and moments of potentiality to laugh, talk and drink rather than exhibit fixed signs of inabilities. The pre-defined categories and the networks that maintain them such as the dozens of pages long care files, make it difficult for the academic Tim and the social worker Ken to notice the details, the many actors, their dimensions and dynamics. How connections form, and how such associations and their significations can lead to various capacities and dislocation like the art of tea making and the creativity of story-telling as opposed to, for example, a vulnerability that far too often the literature tends to highlight. This is another limitation I highlighted in the literature review and aim to challenge with the development of a novel methodology. Everything, all the possible tensions, contradictions and surprising affects are resolved in such actors, like the categories that disposition in advance.

I collected and organised my notes into various symbolic domains such as virtuosity, creativity, humour and connectedness, amongst others. Eventually, these domains came to form theme three and will be discussed in more detail in chapter 8. There was one thing that was not visible and thus detectable in many performances for the researcher, and I argue, for the performer and the spectators either: the universal signs of intellectual disability, the category that has been assigned to all of them, Jane, Barbara and Nick. If we approach the everyday performances of hidden dis/ability with such universalist modes and models, we assume Jane needs help with heating the water to make tea for her friends all the time as the care files indicated. That only fit humans can carry things, so Peter's bodily weakness will result in a permanent and fixed inability to pick up and move objects. Yet,

Peter has taught me something else: 'the board game carries me to the table'. Such dislocation and dissolvment can be made visible if we apply the 6D practice as opposed to predefined and selected measures of 'abilities' to illuminate how these performances compare to the ideals.

Such actors, like the care files, composed a very different image of my informants and as such, positioned a potential performance of Jane in advance as they detailed all the universal and static signs of her not so hidden dis/ability. Such a contrast, contradiction and tension between what I have observed and what I have read! The ordering of hidden dis/ability had travelled into the everyday performances through the networks of categories, like carers and other actors. It is no surprise then how it is difficult to know a real world now, the actual everyday performances of hidden dis/ability. Latour and colleagues (1979 p177) argue that once a category begins to stabilise, reality will be attributed to the newly born classification until the created signs become the reason why the observation has started in the first place. "At the onset of stabilisation, the classification was the virtual image of the condition; subsequently, the condition becomes the mirror image of the reality out there". Now the medium is the message (Baudrillard 1983 p35). The analysis of the data with the 6D practice more than supported dispositions.

This process of (dis)positioning hidden dis/ability made it possible to create apparently identical groups of disorders and assign unique identifiers to people in the form of numbers (F70-79 for Jane and Nick), names (intellectual disability) and restricted signs (Mild Mental Subnormality) that were mirrored by the care files, for example, as the dataset showed us. Peter's and Anna's autism become an impairment in social communication, imagination and interaction, repetitive and restricted behaviour or interest. Brian's schizophrenia might be 'seen' as hearing voices, strange speech or reduced emotional expressions. Jane's and Nick's intellectual disability is a reduced intelligence and the inability to learn new skills (APA

2013) ignoring the actor-networks of the vibrant everyday situations and how they are the actors themselves through their connections that position but also dislocate. The concerns of such apparent universal and essential order of the everyday performances are that such models assume Jane cannot make a cup of tea or joke with her friends like any one of us as she has an intellectual dis/ability, a permanent and fixed hidden dis/ability. The deletion of the details, the many actors and their dynamics and dimensions composing capacities for dislocation is an important tool of universalisation, as disposition, the orders and the models promise the possibility of indefinite reproducibility and apparently universal signs, thus the certainty of hidden dis/ability. In other words, the discrete mental and cognitive conditions and their reductionist, universalising definitions signal the production of identical similarities and differences reabsorbing every originality, spontaneity, virtuosity and creativity in my participants' everyday performances.

These distinct categories produce one kind of appreciation in terms of the mostly visible and material signs. What traditional health and social approaches share, through the professionals, carers and often the people with hidden dis/ability themselves, is that by focusing on distinct and universal signs they ignore the movement, the dissolvment of hidden dis/ability as analysed in the data. In other words, they ignore the constantly changing actors and thus networks, and the capacities formed to affect what will ultimately perform (or not) hidden dis/ability. Peter might be unable to carry and hold things as he has a weakened arm, thus he is dis/abled. Yet, when I observed him in the everyday performance and analysed with the 6D practice, it was the object, the board game that carried Peter to the table. With the 6D practice, we could learn from Peter how to compose a reality where there might be an unusual arm and active objects but not a dis/ability (Latour 1988a; Shea 2013). I highlighted the importance of learning from the actors, as an approach, in the literature review and the methodology chapters.

This process of universalisation of the various conditions up until our postmodern age still allowed for the appearance of the imaginary and of the actual performances of hidden dis/ability and for both the performer and the spectator to assume a degree of agency over these appearances. In our present time, it is much more difficult because simulation hides and masks the real as well as the imaginary. As the data analysis showed, every performance can become a sort of copy, an imitation. A plethora of identification symbols through signs and things simulate hidden dis/ability, defining the current state of hidden dis/ability (Baudrillard 2005b p80). These categories of the disorders have become so stabilised that we have forgotten how they were created and for what purposes (Turowetz 2015; Wróblewski 2015). The categories became part of the everyday performances through various actor-networks: the care files, social workers, academics, and mental state examinations. These actors, the categories or the care files in their own right do not only have the capacity to affect but show the disposition of the conditions of possibilities as a result of their dimensions and dynamics (connections) with other actors. However, what performance of hidden dis/ability might be possible in everyday life is theoretically countless as Jane, Nick and Peter showed us when explored with the 6D practice. This is another example to show how most research methodologies, as addressed in the literature review, miss opportunities to see how the actors forming our data might connect differently in a different context.

As noted in the methodology chapter, such actors and connections albeit rare can order and position other actors and the whole performance, so paying attention to such configurations will be important in the 6D practice otherwise we miss the opportunities too to explore how the everyday performances of hidden dis/ability emerge from complex connections and actions rather than static and universal signs. I argue, the present groups of disorders, the way they have been ordered into manuals and spread into most parts of our everyday life, have created temporary patches of order to resolve all contradictions in

advance. I will explore to what extent it delivered such aspirations and how such dispositions often excluded my informants from performing the many capacities the everyday performances offer by inclusion in the definite categories. These examples, when analysed with the 6D practice show how the groups of disorders have become an enduring actor in strengthening and maintaining an apparent objective and justified hidden dis/ability through the affective disposition of ordering.

In other words, what my analysis of such performances has demonstrated with the 6D practice is that when a category enters the performance, it often prevented other actors from shifting the focus from a static position to the processes by which the visibility of hidden dis/ability might be composed. It imposed boundaries on the possibilities to experience a performance as a multi-dimensional and dynamic act amongst signs and things to reveal the connections that present and the myriad capacities they could compose for dislocation (Hennion 1989; Latour 2013a; Bilodeau and Potvin 2016). In an attempt to reduce complexity, create order and discover patterns, some of the included terms in the disposition domain of the 6D material-semiotic network practice (and replicated by the care files), we fail to 'see' the many possibilities to reveal something hidden and obscure. I argue it is a concern when in everyday performances such universal signs as the inability to read, or a bodily weakness are given the same semiotic interpretation as being 'disabled' because it prevents us from 'seeing' other semiotic-phantasmic-material relationships and the rich performances they might offer. Reading and the inability of doing the reading perform more than one simple task, preventing Nick from getting the information that the words aimed to transport. I found with my participants that this was often not the case as the next chapters will explore.

6.3. Signs and things are not passive actors but active makers of the performances

Dataset

When I attended the autism support group, Michael's communication difficulties were observable in the room. On a Wednesday morning when talking, a noisy and large room with a terrible acoustic that radiated and enhanced the softest sounds connecting confusion with the group discussion, the people suddenly changing the topic to abstract arguments, left Michael puzzled and eventually performed communication difficulties. Michael, after a few minutes, cannot follow conversations and will walk away. Once Michael leaves the conversation, he goes to the kitchen, makes a cup of coffee, and starts chatting with Julie (the manager). Later, he had a chat with me and the others.

Julie, the charity's manager supporting the autism group, was aimed to enhance the potentialities of the group. She noticed how they should be the autistic people themselves to decide what was happening in the group, rather than promoting the carers only to make such decisions. Julia did several things throughout many weeks to try to achieve this. Voting, papers, arguments between autistic people, carers and volunteers at meetings, news from the Council, rights through advocacy and the experts to teach people about the skills needed to run a committee all required to first, compose capacities to form a committee led by autistic people and second, to an organisation (Julie and her charity) to eventually walk out from facilitating the group after carers complained. The charity leaving ended the possibility of having a committee, made many autistic people leave the group and made the group buy its insurance so they did not have to find another organisation to support them.

The application of 6D practice

My analysis of the data shows how repetition, like the acts between the walls of a theatre, appears almost pathological. Categories, and their unique signature when travelling into the everyday performances promote the notion of sameness through acts of separation. What is significant in everyday performances is the differences, not in the form of the distinct conditions and their specific signs, but the actors composing the performances, the performer, the spectators, and the scene. The data analysis shows that when we dismiss dimensions and privilege signatures (the categories), it can have many consequences through ordering (disposition). Such privileging neglects and dismisses alternative ways of

'seeing' and performing in everyday life. I addressed in the literature and the outset of my thesis the issues of binary oppositions, separation and fragmentation. When I analysed the above data, it showed how not only the categories proliferated but every social response, mirrored the categories. I analysed how Michael's inability to contribute to a discussion, and the details and complexity of social communication are not separated. They come together to perform Michael's action in leaving the group and going to the kitchen to have a cup of coffee. In other words, there is both the formation and dissolution of a dis/ability. The alternative understanding arises from the details of everyday objects and practices: large room, high ceiling, fans blowing his face, complicated words, noise, people, walking and talking. It is all the actors' actions, the mainstream issues of the everyday performances of hidden dis/ability that renders everything like a work of art that must be composed, because it is shared, appreciated and judged.

We only think we know what a 'disability' is and what it is we 'see' supported by apparent universal health and social care signals, with existing scientifically induced and deduced disabilities to make decisions, vote, and barriers of noise, confusing conversations or mental health issues. A judgement that aims to be objective as it tries to identify some sort of universal signs, like Michael and his activities. The 6D practice asks us to consider when and where the performance takes place, what actors are present, and together with the inability to respond and the noise, the bodily weakness and the carrying of the objects that exist in webs of connections, 6D practice makes us inquire about the details of what other affects might be there that have the potential to enact capacities for dislocation. The details, the contradictions and tensions become key to society that has such aspirations as opposite care, services and inclusion for people with hidden dis/ability. Actors, humans like Michael, as well as the material and abstract world, like rooms and words, affect the performance, embody and objectify through associations and significations. The detail brings forth capacities of associations, potentiality and actuality: a material actor and abstract sign. A

large room with noise, people and confusing conversations does not refer to something existing separately from the performance of walking away, being shy or making a coffee but is a constitutive part of what it expresses which otherwise cannot be known, as noted by Law (1999 p7).

The complexity of dispositions (ordering), details (all the actors) and dimensions (the connections between actors) analytically show how hidden dis/ability is not a fixed state but composed of dynamics (forces acting between the actors) and particular dislocations (transformation and dissolution). This is where the story of hidden dis/ability transposes, dissolves, blurs but rarely ends as it often happens in the literature. The literature showed how methodologies tend to approach the categories as all-encompassing static actor-networks that appears to be universal, pre-existing and relatively stable. The categories and models create order and as such restrict capacity so universal signs to be performed and mirrored. Michael has social communication impairment. Michael is autistic. Michael lives with hidden dis/ability. Michael cannot communicate in social situations. It appears, Michael and his hidden dis/ability is done unto and only fragmentarily authentic. If the medical is about cure, treatments and diseases, the social is “a right, a need and a service. A use value pure and simple”, as stated by Baudrillard (1983 p76).

I argue the 6D practice can show opportunities for dislocation and dissolution as opposed to a universal appearance of Michael being autistic or dis/abled only, a key aim set for this thesis. It is possible to show with the 6D practice how categorisation may aim to resolve all the possible tensions, contradictions and surprising affects in advance to perform the same hidden dis/ability following a script, but eventually create false (or at least no more real) order out of disorder. The performances of hidden dis/ability like a piece of art were given a signature in the form of the categories symbolising the completion of the work. Such signatures aim to mark the authenticity of the performance. Therefore, they can be

recognised by spectators to differentiate the performance of one 'disorder' from another 'condition', and a 'disability' performance from an 'able' one (Koziczak 2017; Guichard 2018). The separated and purified categories and their dimensions like the attached practices create specific identifiers through the signatures that other actors, particularly the expert spectators, can use to judge the value and function of performances. A signature to work requires repetition through its dimensions (Young 1988; Dutton 2003).

I argue, based on the data analysis, that when we move away from the essentials and universals, there are no such obvious repetitions in the everyday performances, and no such visible signature of disorders like social communication difficulties but actors, dimensions and the capacity to form, dislocate and thus transform hidden dis/ability to a cup of coffee. When the dimensions and dynamics of everyday life are ignored, we can see a coherent picture of hidden dis/ability and that of the signatures of the separated conditions. For example, people with OCD like lining up things. The data analysis shows, through diverse performances, how similar performances emerged from similar conditions, but similar narratives were also composed out of seemingly different conditions as a result of the actors and their agency (capacity to affect and be affected). Actors and their dimensions changed, adapted, and grew over time regardless of the signature in order to compose a different, hopefully, better performance. The performances often shared very similar values of the formalist and functional characteristics of friendship, for example, when analysed with the 6D practice. In other words, very different performances and as such hidden dis/ability can all be performed, and very different dis/ability can all be present at the same time for the same as well as different signatures.

I argue then, there is more than one account, more than one reality, more than one right, and as such more than one performance of hidden dis/ability (Callon 1999; Law and Urry 2004). When I explored such performances with the 6D practice, my analysis failed to show

any specifics regarding what the signatures hint at, I could have assigned to one participant or the other, one group or the other, one performance or the other in everyday life. Rather, I observed specifics and similarities as well as differences based on the actor-networks. They shared similar adventures when certain actors (so-called quasi-objects) such as the categories played the role of the connector or the dimensions of the actors limited the capacities regardless of people's conditions. Networks changed, the performance was a dimensional process of composing, it depended on actors' agency, the capacity to affect and be affected and how then those affects effected them. Affects are not effects, but the capacity to affect and be affected that is a characteristic of all the actors as a result of agency. Dimensions of actors, and what capacities they compose are important considerations that the 6D practice lets us analyse and consider as a potential contribution to the field. There are many ways of connecting, forming, maintaining and changing associations that the analyses started to reveal.

I could never be certain how actors would interact in any given performance even if specific predictions, a pool of acts rather than a particular action, were possible. When everything becomes a sign of dis/ability, every actor can "have its fifteen minutes of fame" (Baudrillard 2005a p108, inspired by Andy Warhol). Despite such uncertainty, my data and the application of the 6D practice suggest that it can provide us with more opportunities if we look at the details, dimensions and dynamics, the capacities. In everyday life, there are ever-shifting actors and connections. They compose capacities and not static actions of cause and their effects. Friendship and intimate relationship, as well as conflicts with loved ones, were just one of those 'detailed' shared cultural experiences of my participants. One could argue, they are not even unique to people with hidden dis/ability, not like the act and complexity of disclosing their diagnosis that I detailed in my book chapter (Goldschmied Z 2020). I had set out ten potential affects from separation through fragmentation to multiplicity, as it was never possible to predict what happened when an uncertain actor,

disclosure, entered the performance. The 6D practice makes visible how they are the details and the dimensions, when disclosure, an uncertain actor, enters the scene that compose dynamics and eventually the shared as well as distinct performances. Whilst the models and signatures hint that there is a universal sign of hidden dis/ability belonging to distinct categories, I argue, when we approach such performances with the 6D practice, it is mostly impossible to recognise and thus detect such signs and their distinct descriptions in the everyday performances of hidden dis/ability. Many of the examples in the data aim to demonstrate this. My participants experienced similar, as well as distinct, detailing effects. Conversely, I noticed that such separation and purification of categories often prevented the shared experiences and cultural practices of the many so-called hidden dis/ability maintaining the illusion that they indeed were different. They are the details and the dimensions that might make a difference for us in the everyday performances of hidden dis/ability as we focus on the shared performances rather than seemingly independent actors.

I conclude then that the more order was created, the more disorders were defined, and the more effort invested in keeping those categories growing and static (through the many connections), paradoxically, have decreased capacities for dislocation, particularly the shared cultural experiences and the rich everyday performances of hidden dis/ability as argued by Latour (1999b p7). Whilst the logic of ordering in the categories supposes a specific, objective and universal hidden dis/ability, an ideal and perfect act based on models, it does so by highlighting imperfection through resemblance and comparisons (Baudrillard 1994). Whilst comparison and grouping are possible and can be beneficial, simplifications are always discontinuous, arbitrary and discriminatory (Latour 1988b, 2005a). I argue that we need approaches like the 6D practice that turns the act of 'seeing' away from single and detached actors and direct our attention to acting itself, the noticing of details, dynamics and dimensions, the extent of composition at a specific scene. Instead of looking at what

hidden dis/ability is, with the 6D practice, we can focus on what actors are there, when, where and how they dimensionally form associations, and what dynamic capacities arise from connections to decide what they form. In other words, how a performance might form and perform, solve and dissolve, produce and reproduce hidden dis/ability.

Summary

In this chapter, I analysed how dynamically there are no universal models and passive objects to guide the everyday performances, in what Baudrillard (2002 p15) claims, “there is no longer any God to recognize his own”. I analysed first, that when we apply the 6D practice, it can show how dispositions are produced, held together, and reproduced by the actor’s capacity to affect and be affected. Second, how in any one performance, there are many different actors composing dynamics and producing capacities for actions. Dimensions become entangled with other actors and their actions. Third, how without the details, there is no noise, large room, conversations, and confusion that went away by the time Michael reached the kitchen. Fourth, how confusion were often significant actors for many participants with different conditions that come with distinct universal signs. Fifth, the 6D practice revealed how the performances dislocated the participants’ intellectual disability, autism or mental health as they talked about similar ordinary topics, experienced corresponding mundane stories and shared specific experiences. There were often materially the same actors present in the various performances that semiotically either played (or not) a role. Moreover, they shared similar narratives of how the spectators contributed to the performances of hidden dis/ability and what dynamics other actors, for example, objects brought into the performance. These performances became examples of shared cultural experiences and practices and a nice reminder of a Baudrillardian (2002 p14) sentiment: there is no gold standard of spectators’ judgement any longer. The next chapter will explore the spectators’ actions.

CHAPTER 7

Theme two – Spectators are dimensional and active makers of hidden dis/ability

The previous chapter explored how the relations of coproduction are deleted from the traditional health and social care practices. Groups of conditions were composed out of limited actors and their restricted connections, limiting the making of potential other acts. Categories and other actors like care files present rigid signs of political, economic and moral causes focusing on how hidden dis/ability should be seen as well as performed: what is appropriate, how it should be represented, valued and used, where and to whom, and what its truth content is. I analysed how models favoured apparently universal signs as they could imitate a standardised performance of hidden dis/ability. Such approaches lost connection with, mask and hide the actual, the temporary and unstable characteristics of the everyday performances and as such judgements are no longer grounded in reality. The 6D practice approach aims to reverse these trends and reassemble hidden dis/ability.

In this chapter, I highlight the role spectators play in reinforcing how seemingly passive and separated actors, with apparently essential and universal signs, can give the impression of an objective, permanent and real hidden dis/ability. The 6D practice can show in the data the actors' capacity to affect and be affected through connectivity. It explores the scale and extent of connections, the complexity of the networks, the types of associations. Spectatorship in this sense is a significant dimension of the performances, as its connection is realised through the capacity to affect and be affected. The production and consumption of such capacity involve the manipulation of signs, things and the symbolic values of composition. Such analytics show or at least allude to just how 'unreal' the disability/ability

binary actually it is. My thesis kept on questioning how we think we 'see' the performances of hidden dis/ability in everyday situations as we are now left asking what ability is, just as much as what disability is.

7.1. Staged theatre shows or live performance art?

Dataset

Jane moved into a new house. We spent most of the day unpacking. Jane was in her new bedroom, occupied with going through bags of clothes. She had many. She loved her dresses and did not easily throw them away. I was asked by her sister, Lulu, to spot any item that might be ready to leave her collection. I was quite reluctant to do so without Jane's approval. Jane's advocate, Sarah, stepped into the bedroom. She asked Jane, "do you want the lilac or the brown lampshade in the hallway"? Jane quietly responded, "I don't mind", not even looking up as she continued with sorting out her clothes, what goes into the chest of drawers by her bed, and what should hang in the wardrobe, positioned at the other end of the room at the corner. Sarah asked Jane again. "Tell me, do you want the lilac or the brown shade"? Jane responded with slightly more frustration in her voice. "I do not mind you choose. I like both." as she continued with her garments. Sarah then told Jane: "you have to choose". When Jane still refused to choose or rather chose that her advocate should choose, Sarah eventually finished the conversation with the comment, "I will do it, but do not blame me later".

The application of 6D practice

A defining characteristic of live performance art that I adopt for the 6D practice is the relationship between the performer, the spectator and the scene, the body, the materials, time, and space (Abramovic *et al.* 1995; Parr 2010; Johnson 2015). In live performance art, we cannot rely on images only, the simulation of the real by apparently universal signs such as rights and choice. For example, how categories as actors or the advocate, Sarah, through chains of actors like assessments, values and questions compose capacities for performances judged as hidden dis/ability. When I analysed the above data (performances) with the 6D practice, actors did not represent an objective or universal hidden dis/ability but

composed affects through their dimensions (connections with other actors). It is the many actors, including the garment, the lampshade and Sarah's role being an advocate that will together ultimately form and perform, solve and dissolve, produce and reproduce the performance. The categories, the scripts performing Sarah, when she was repeating "you have to choose", like Tina, when she was referring to "autism, is not an intellectual dis/ability" do two things that I analysed with the 6D practice.

First, it alludes to the possibility of how categories dimensionally extend through connections like the policies, training and the contract Sarah received, eventually becoming an actor in Jane's bedroom when choosing a lampshade. Second, it deletes the performer and the spectators' actual actions as well as other actors on the scene echoing the voice of the experts and their judgement in the distance how social services wished to lump together various conditions. Such dimensions as Sarah's advocacy on how to empower someone with an intellectual dis/ability will only draw attention to the singularity of specific signs of disability like Jane's IQ, mental capacity or vulnerability. However, the dimensions of actors can also make visible through the 6D practice, the associations and significations that embody, enact and can potentially transform Jane's (and others) hidden dis/ability. Traditional approaches focus on separated actors, and their specific signs without much emphasis on dimensions, as shown in the literature review and noted as a limitation. The categories through the expert spectator's position Jane's activities whilst dimensions of the 6D practice, as an analytical frame, point up how other connections are ignored in possibility of dissolution.

In all of my data, the potential affect, like having the choice not to choose, can be hidden, yet the capacity is present. In other words, the 6D practice draws attention to the many performances enacted in various situations in the streets, institutions, homes with the involvement of frequently changing actors and how their connections could be analysed as

being scripted into staged shows by the signatures and their dimensions (the extensive and vast connections that maintain the categories). Staged shows appear to have a clear beginning, a distinct end, and a linear, unidirectional appearance, performed as they are through dimensions of, what Carlson (2003) might term, recurrence and reproduction. Such preference for a visible past and continuum, a myth of the origin, as suggested by Baudrillard (1994 p10), reassures us of the real. I showed in the literature review how it was the preferred methodology and way of seeing hidden dis/ability. I also noted its potential limitations that I wished to reconsider. A real by where actors can actively choose, ignorant of how they are connected in order to enact and be re-enacted. Such actions call into question human's agency and intentional actions (Mol 1999) and when semantically analysed with the 6D practice, the everyday performance of hidden dis/ability is a continuum of material, semiotic and discursive practices, that connect 'disability' and 'ability', and "merge the banality of art with the banality of the real world" (Baudrillard 2005a p106), as everything becomes an object of the act through the dimensions of the actors and their activities in the performance.

The practice of art and the practice of life do not exist as two distinct worlds in the practice. In the words of Serres (Serres and Latour 1995 p142,148) "when we place society on one side and science on another, we no longer see anything ... the law and social sciences remain without a world – cosmic – and the natural sciences, without the law, become inhuman. Today we live and think at this crossroads." What I have found that at this crossroads is the everyday performances of hidden dis/ability. If we view the everyday performances through the lens of live performance art being in a transient state, with the 6D practice we can re-evaluate how the actors and their dimensions enact them. The relationship between the performer, the spectator and the scene, the dimensions of time, scale, size and place of the actors (both localise and decentralise the performance composing capacities) will eventually result in a politicised, moralised and economicalised

performance of the various realities of hidden dis/ability. For example, dimensions of the signature affect the spectators like Jane's advocate limiting the capacity of Jane to choose or not.

A material-semiotic analysis of 6D practice makes visible such dimensions whilst consequently revealing actors and their connections to 'see' other affects, capacities for transformation like to choose not to choose, leaving someone else to choose, or choose at a later time. (This will be explored in more detail in the next chapter). In the everyday performances, it could be that traditional analysis make use of binary opposition as a method for structuring knowledge but what if there are no more binaries just co-dependency and co-existence, chain of actors, where the tensions and contradictions between the actors, between the performer and the spectator, lead to simultaneous effects of 'abled' and 'disabled'. What then? When we do not select the signature in advance, or it is not visible in the act? The 6D material-semiotic network practice promotes questions like who is 'disabled' and what is the affect put in a different light. Could we use the term 'dimension'?

If we see the performance of two people having a conversation, Jane and Sarah, or two men juggling with objects, Finn and Nick, the 6D practice might show other affects. It could be that the person carrying a few bags of clothes (Finn) is the one who could be labelled 'disabled' rather than Nick, who is in visibly better shape and against all the odds grabbed the old-fashion microwave and made his way up the stairs. Yet, when the dimensional signature enters the performance, the narrative would be so habitual in dis/ability studies so that Finn (has no known disability) was the 'abled' one knowing the comfort of the lift and Nick (has a diagnosis of intellectual disability) the 'disabled' and oppressed who did not refuse but followed the instructions and carried a heavy microwave. I argue that once we look at such performances through the lens of 6D practice, there is no such thing as the binary of 'disabled' and 'abled', or better and worse performance. And we do not judge the

performance either based on predefined models or evidence, instead we explore the actors and their dimensions. The details: there was no need to carry objects up the stairs as a lift was present; that the heaviest object was carried on the steps; that it was Finn who decided about the actions as there were no negotiations; that Nick did not question Finn, although Nick looked fitter than Finn. None of these considerations and potential affects were visibly connected to the signature of Nick and could be performed between any two actors like a shared performance. When analysed with the 6D practice, the everyday life of hidden dis/ability look different from a staged show as such it is animated, spontaneous and temporary.

There is a blurring of boundaries between those who act and those who observe the action, and as alluded to by Baudrillard (2005a p76) and others such as Coogan (2011) and Haedicke (2012), the immersion of the spectator in the spectacle as dimensions connect distant actors composing dynamics and capacities for disposition as well as dislocation. The spectators are active composers of hidden dis/ability in the everyday performances, where their presence, their actions and their connections with distant actors will compose affects. I have already shown how actors formed by distinctions and set connections have the capacity to order and position other actors and thus the performances through their dimensions. In many performances, the categories become the explanations of hidden dis/ability as their making: the mundane, the ordinary and the specifics, do not have to be explained anymore (neither how spectators bring them into the performance) (Latour 1988a,1993; Law 2008a). In the end, it did not take long before a spectator's action formed capacities and a potential performance of hidden dis/ability.

It is the production and consumption of capacities by the spectators (and the performers) that compose the performance of hidden dis/ability, not the actors themselves as they involve the manipulation of signs and things, whilst it hides the symbolic values of

signification. It is not that we can prove that hidden dis/ability is illusionary and unreal, but that we cannot verify that is causal and real either (Baudrillard 2005a p47) as the analyses shows. Thus, my analysis kept on questioning, how I think I 'see' Jane's and others' performance of hidden dis/ability in everyday situations. The data analysis shows this when we explore it with the 6D practice, how these actors as materials (objects, humans, the built environment, money, time, professionals, policies, procedures, memories, information, hopes, concepts) form and perform. In such everyday performances, hidden dis/ability was not pre-given. It comes into existence through dimensions and dynamics with other actors particularly the spectators. It performs differently, if it performs at all, in various everyday situations.

The performances of everyday life I recorded, analysed and retold continue to question the conventional signs and ways of 'seeing' hidden dis/ability and challenge assumptions of performances as the fixed and independent reality of hidden dis/ability. Such performances are dimensional and situational. They provoke participation in the same way Sarah did through the notion of advocacy. Hidden dis/ability is composed through involvement. I keep on highlighting, without noticing the many actors and their dimensions, the spectators at a particular scene, the performance of hidden dis/ability in everyday life cannot be explored in its making. The everyday performances do many things at the same time, as opposed to purely mirroring some universal signs, and it remains complex to recognise, comprehend and narrate when even someone chronological age can manipulate the signs and things composing hidden dis/ability. The 6D practice shows how norms and set health and social practices of hidden dis/ability can re-compose, share and negotiate realities, and transform the real or the hyper-real hidden dis/ability into a sort of artwork leading to multiplicity of experiences.

Such understanding provides us with an embodied and enacted narrative of hidden dis/ability and the sharing of experiences as opposed to separation, purification and ordering of performances through the signatures and their dimensions of spectatorship like Darcie, Tim and Sarah (Law and Singleton 2005; Latour 2009a). It is my thesis that the 6D practice shows how hidden dis/ability might be rethought as perFormed, disSolved and reProduced and as such reveal varieties of realities of hidden dis/ability. In everyday life, the participants as well as the analyst experience, narrate and historicise performances and compose how the story of hidden dis/ability appears. The 6D practice has helped render the invisible visible: how the performances of hidden dis/ability and their multiple reality artfully present in everyday life as there exist no essential and universal signs of hidden dis/ability but dimensions and dynamics, complex connections between signs and things.

7.2. The material and semiotic relationality makes hidden dis/ability visible

Data set

When Jane received a letter, she did not open it, read it or put it in her bag to look at it later. She identified her name on the envelope and passed them onto me to deliver it to the sister, Lulu, who would read it. Jane then continued with her activities and went to do some shopping. Throughout the days this event and performance were narrated in many ways. “She is disabled she could not read it” as Lulu the sister commented when I gave her the letter. “She does not need to read it” as the care files communicated that Jane gave me. “My sister will read it”, said Jane when handed over the letter. She continued with her activities without considering reading as an important act as was narrated by one of the spectators, myself, the researcher, when I made notes of the event.

Garry, the autistic young man from the support group, likes talking at length about the secrets of vodka making. He had an Autism card from a well-known organisation so that he could expect certain support. For example, he could skip a queue when it became intolerable, as Garry narrated, when he was waiting to pop on the London Eye. A self-made autism card that Thomas designed with specific messages on the back in the hope of transforming his difficulties and needs were often judged as fake, said Thomas. Thus, this card risked the provision of any support, Thomas told me disappointedly, when he tried to use it at the airport. The card did not lead to the expected transformation. He eventually stressed out whilst going through the security check.

The application of 6D practice

The case studies and analysis of data with the 6D practice show that when I shift the focus from what hidden dis/ability is to what actors are present and how they do what they do, hidden dis/ability as live performance art discloses not one universal but multiple realities. The spectators are flexible and uncertain actors of a live performance art just as the scene, the objects and other actors. Spectators can join and leave the performance at various points of the act as I analysed in the data, and their actions more often than not were somewhat unpredictable just as many of the other performing actors travelling into the performance, as also noted by O'Dell (1998), Heathfield and Gendinning (2004) and Fischer-Lichte and Jain (2008). The dynamics between the performer, the scene and the spectator through their dimensions (the connections that translate quasi-objects and quasi-subjects into the performances) create tension as they all play an active role in the performative constituting of hidden dis/ability. In other words, performing hidden dis/ability in everyday life is, by definition local, conflicting, and shared when analysed with the 6D practice. Performance within the walls of an institution such as the clinician's office will respect the set boundaries and rules, the restricted numbers of actors including the spectators and their possible dimensions composing limited capacities for actions and dislocation, the formation of new associations for transformation, as also argued by Crowther (1993), O'Doherty and McEvilley (1999) and Say (2015). For a universe of signs of hidden dis/ability to exist, we need more and more categories, and also more and more objects to transport them. Conversely, this excess of formalisation, the excess use of the categories leads to the disappearance of the form itself, as there "is no worse enemy to form than the availability of all forms" (Baudrillard 2005b p74).

In the everyday performances of hidden dis/ability the spectators become dimensional actors of the performance, as they play an active role in such transportation. The analysis shows how the performance of hidden dis/ability cannot exist without the spectators as the acts are either co-composed, or as noted by Nuttall (1979) and Haedicke (2012), require the audience to complete the work. The 6D practice highlights how spectators are part of the performances I participated in, like carers, professionals, friends, parents and laypeople, and they also translate distant actors (through dimensions). What was also noticeable in the data was that spectators were not objective or distant from the act, as the modernist logic of formalism would dictate, but composed the performance together with other actors. The capacity to change and transform lies in all the actors having agency, the possibility to affect and be affected, disrupting boundaries of the visible and the invisible, objects and subjects, medical and social and eventually perform one or the other, so when observing everyday performances, what is not composed is not a work of art. It follows, art might give us better tools and access to the everyday performances of hidden di/ability than science, be it natural or cultural. I propose if we turn our attention towards art and the artists' tools of everyday materials and signs that the 6D practice incorporates, it can open up new ways of seeing the everyday performances. As noted by Jones (1998), Howell (1999) and Korenic (2004), it brings into the performance lights, optics, and shadows; human perception, interpretation of space, and connection of objects; spectators' reactions, texture of materials and unorthodox actions.

In everyday life, we are all spectators like Sarah, Thomas, Finn or the security guard at the airport. It is the nature of live performance art, where representation is opaque, as we are faced with looking through the significations of the signs (Holyoake 2009). Spectators are drawn into the performance. Spectators do not just receive the performance from a distance to be judged and talked about but are a constituting part of it. They make it and retell it, as highlighted by Atkinson and colleagues (1997) and Doubleday (2018) and the data analysis

showed. Thus, there is a great instability in the everyday performance of hidden dis/ability. When hidden dis/ability becomes visible in analysis, most of the time, it concerns an awkward spontaneousness. In most of these performances, I found a range of judgements like pleasure, joy, anger and beauty. They affected other actors and led to effects of diverse emotions, responses and appreciation but never a particular and universal hidden dis/ability.

These performances and their judgements were a result of the details of the actors, dimensions and dynamics of their connectivity (notably the spectators) and not the fixed and universal health and social care signals, even if these things often travelled into the performances. These performances that can be assessed and judged many ways are often overlooked by the traditional approaches. How these performances artfully present in the world and the multiple ways they affect, oppose, unite and confront: a question of how it does what it does, and not what they are. Objects such as pencils, papers and tables that dynamically connected Zeke with his drawing; jokes, random comments and one-liners that dynamically composed Peter's humour as well as impoliteness. Whether any of these performances will be assessed as hidden dis/ability dynamically depended on other actors' actions and the spectators. I found no essentials in the everyday performances of hidden dis/ability when observed or analysed with the 6D practice, but acting and connecting, actors and their dimensions with things and signs. The performances were composed out of these dynamics. There were no individual creators in the performances, but rather processes and the making of hidden dis/ability where what has performed inside the body was inseparable from what has acted outside of it and the actions they performed together. The associations and the actions that effected connections are produced, but they also composed further capacities (Mol and Law 2004; Latour 2004b; Law and Singleton 2005).

I wonder then how we could take back the everyday spaces from the experts and from the apparently universal and essential signatures they have created, to explore how hidden

dis/ability is composed through participation in art-making with a greater focus on all the actors, and their dimensions, the associations and significations. When we look at individual and separated actors, be it singing, reading or running a committee, and the way they configure others without the dimensions and dynamics, such performances can appear to replicate a universal and essential hidden dis/ability. Yet, 6D practice can make visible how actors always affect. In other words, the 6D practice has shown how the inability to read or the playing the guitar differently results either in the performance of hidden dis/ability or not. It does not reside in the person such as Jane and her inability to read, nor in the external world such as in the letter, but it will depend on first, how all actors connect and what other capacities might emerge to affect and second, how spectators consume such capacities composing various descriptions.

Whilst they are the diverse actors that compose various capacities, the judgement of what performances are 'seen' as hidden dis/ability is completed by the spectators, often in advance through the dimensions of the categories and related actors. Otherwise, how would the carers know that this group of autistic people were unable to run their support group? I could not observe and explore with the 6D practice any performance that revealed the effect of one actor or a collection of fixed actors that in isolation led to a cause of hidden dis/ability, even if the categories, the signature of hidden dis/ability often positioned the connections. It was the dimensions of actors, the inability to read, the letter and all the other actors such as the postman, the radiator that holds the letter, the researcher, Jane and the sister that composed capacities together for either transporting the actions without a visible and thus recordable effect of hidden dis/ability or transforming the performance through a visible change. Such judgements do not predetermine the effects but compose capacities for hidden dis/ability but also, for its dissolution. Many of the performances I observed or listened to suggested that the various classification of the disorders once illuminated in the performance as an actor had the capacity to create more predictable and, of course,

seemingly uncomplicated affects. The carers insisted that people with autism should not run their group ignoring the many other potential affects that were present such as doing things together, trying it or at least discussing it.

The signatures dimensionally configure connections, and the spectators are significant actors producing and consuming apparently real signs, performing a seemingly self-contained hidden dis/ability with set capacities and apparently universal signs. Such dimensions then compose capacities that seem to be a thing, a permanent and fixed affect, as they simulate cause and effect relations. Other actors are defined by contrast against a semantic backdrop as they enact and embody those affects. Alternations from such performances tend not to bring the dimensions of actors to the front but are attributed to the performer. In other words, the categories seem to enter everyday performances as a thing through their dimensions, notably the spectators (and policies, professions, assessments, the cause-specific organisations, carers, advocates, laypeople). Whilst such performances might look straightforward, with the 6D practice, we can explore what other actors have dimensionally travelled into the scene.

I analysed how spectators often restricted the performances to a few predefined dis/abilities and their apparently universal signs like the looking at children's pictures, crying, drinking, or taking medication. I argue that my participants did not express themselves in those performances but were constantly surveyed by the spectators. These actors anticipate responses and, in the sentiment of Baudrillard (1983 p32), they are coded and controlled, so that very object aimed at is excluded. Yet, and on the contrary, in my fieldwork analysis with the 6D practice, I could also show how there are many performances of hidden dis/ability and not just one reality of the big organisations and what Latour (1997) terms their few fetishized actors. The autism card, for example, alludes to universal and objective autism on the back of it in the form of all-embracing issues for a group of well-defined

people. Furthermore, it is objectified and factualised by the credibility of the organisation itself through their dimensions, their extensive networks. One could argue, rendering invisible dis/ability visible.

Once facts have been composed, like the autism card from the Autism West Midlands, myths can be identified like Thomas's own design, as if depression and the medication were the only actors performing mood and engagement with the tasks that day. Then we have the illusion of connections between them, as hidden dis/ability is composed by equivalence and separation, yet both the medical approach or the West Midlands Autism card and the social approach or Thomas's card remains arbitrary and function to hide the absence of a fixed reality. The 6D practice allows for such analysis exploring performances as a continuum of material, semiotic, discursive and circulating appearances of practices. Whilst the objects were the same materially and aimed to symbolise the same thing, a level of support, their dimensions, the associations and significations, were significantly different. The official and as such perceived as factual, objective and uniform story of Autism West Midlands is just one among the many narratives I have heard, recorded, analysed and retold. As the data show, many stories were coming from various sources, and the same story from the same source was told in many different ways. Once being in the field, looking at the performances with the 6D practice, I could not participate in a performance of a clear cause and effect of set actor-networks but multiple possibilities of dimensions and dynamics, contradictory aims and competing desires. Every closure, as well as the start, is arbitrary, but temporary modes of synthesis are possible where we actively bring together different capacities in relation to different sets of actors (Goldschmied Z 2018b). As the data show, my participants were living and performing themselves into existence. It was possible not through the extensive connections of the universal and essential signatures only, but through the various actions, composed out from many actors and their relations.

7.3. Uncertain actors challenge conventional connections and the spectators

Dataset

Early on whilst at the autism support group I observed for the first time that I could not find a visible, and as such, universal and essential sign that could help me decide who was there the person with autism and who was there to support them. I was confused. Even after talking to the people in the room, this task did not become easier. Eventually, after the second visit, when I still could not make such decisions, I asked Susan, the facilitator (it was Julie's colleague).

When walking with Monique one afternoon, she fancied going to a cafe and had a hot drink. We found a quiet corner at the back far from the counter, as Monique did not tolerate noise well and could not focus or have a good chat if the place was noisy or others were talking too loudly close to us, she explained. Monique then shared with me some of the actors and dynamics that could make her everyday performances challenging, such as doing the shopping at rush hours or going to unfamiliar places.

The application of 6D practice

Actors like the categories or care files seem to have a role in making the uncertain and unstable everyday performances of hidden dis/ability more predictable; almost like the illusion of a signature. By turning a live performance art into a staged show, it gives permanency to artworks, as noted by Kuittinen (2014), that would otherwise be dissolved by the next performance. The analysis shows how, without the signatures, there is no clear difference between the performance of hidden dis/ability and any other performance we engage. Signatures set the questions but also contain the answers, the reality of the performance becomes a construction by images, pre-established details of selected materials and signs. The analysis of my participants' performances points into the direction that we cannot expect people will know all the disorders, our category and that of others. There are too many detailed signs being turned into categories. The expectations that such signs will appear the same way in live performance art as they were rehearsed in a staged show of the theatre could not be established in the analysis. In the everyday performance

art of hidden dis/ability, spectators only 'see' fragments of performances and never the full show. There is only an artificial beginning and end, segments of existences relying on believable realities of the moment.

The 6D practice shows how it is a mistaken view that Anna's and Peter's autism will enact the same performances on a hospital ward but will be different from Monique, Nick, Jane or Bob (as they have a different diagnosis). Or that we can teach hospital staff not only about dementia but all the individual categories and the countless capacities they compose. It is now impossible to prove a real autism or intellectual disability, as shown in the data. However, the 6D practice can draw attention to details, dimensions and dynamics, how discourses, objects and standards together can make someone look dis/abled. It also helps notice what capacities are composed for dislocation when they cannot read or engage in a conversation. There is no more real illusion than the belief in certainty, the certainty of the categories and that this certainty composes certainty of performances in everyday life. That rigidity of order brings predictability. My examples and analysis illustrated how the categories did not deliver universal performances, but paradoxically, uncertainty and confusion. Looking at these performances with the 6D practice, we can explore how they form and perform, solve and dissolve, produce and reproduce multiplicity of hidden dis/ability. In everyday life, hidden dis/ability is connected, thus dynamic. By focusing on dimensions and dynamics, we can explore what alternatives might be possible for dislocation.

The performances of the participants become a process of composing unexpected actions, a temporary set of possibilities. We do not have passive spectators and absolute objects when working with the 6D practice, but co-creators of actions and a range of issues of hidden dis/ability, which for Monique means crowded places. Her performance becomes the embodied site of dislocated hidden dis/ability, norms and universals in ordinary places.

Spectators no longer simply watch a performance, but the performance observes the spectators too. Spectators, the waitress, Sarah, Darcie, the coffee, the conversations, the care files are no longer passive objects in a pre-written act but active participants of the performance. They enjoy and reject, debate and question, applaud and yell composing hidden dis/ability in the here and now (Latour 2004a p50,66; Leddy 2011). As Latour (1993) puts it, they are passive and active participants, intermediaries and mediators. It is dynamics that turn any actor from a passive intermediary to an active mediator or the other way around either transporting or transforming a performance. It is this dual role of the actors, being both passive and active, to be able to affect and be affected, a seemingly irreconcilable co-existence that Monique's inability to tolerate crowded places or be at a noisy place did not prevent her from enjoying a cup of coffee or doing her shopping as those actors played a part too.

I propose that our relationship with things and associations, and our relationship with signs and signification do more than passively assisting us in our actions that performed Zeke's drawings. The way they dynamically connect with the person and other actors, a different set of capacities are composed in the performance that in exchange offer opportunities not only for dispositions but also dislocations, the transformation of the performance (Malafouris 2013 p83). The use of things and signs become actualised in the composition of hidden dis/ability and such connections shape each other in a way that hidden dis/ability might perform but also dissolve. Things as well as signs, the various actors have affective possibilities and compose various capacities through their connections (Grossberg 2014; Grossberg and Behrenhausen 2016; Latour 2016). When we shift our focus from passive actors, things and signs to these active processes and the networks within which associations take place with the 6D practice, conventional boundaries no longer apply but complex performances and the composing (or not) of hidden dis/ability.

Connections that appear more stable and durable usually help because of dynamic simplicity. As analysed earlier, simplification can be beneficial in our busy, complex and hectic practice. However, such dynamics should not be 'seen' as essential and universal signs or causes of hidden dis/ability. The everyday performance once looked at through the 6D practice, rarely mirrored or reproduced the signatures and the related practices but revealed the ordinary, the mundane and the specific (the cup of coffee, papers, tapes, potatoes, shopping, playing). A piece of art is always a representation of something and different from the real, as argued by Korsmeyer (1998) and Adorno (1999). Live performance art, on the other hand, is the here and now, the mundane, the ordinary and the specific. It is the representation and the real at the same time. The connections between the performers, spectators and the scene form, last, change and disappear like a hug or a newly learnt word. The 6D practice focuses on these movements. The performances of hidden dis/ability are much richer once we explore the details and shift the focus to the connections. That something that appears irrational, unusual or abnormal for one spectator might look very different for others, as argued by Goldberg (1979) and Say (2015). I analysed how people with hidden dis/ability perform, dissolve and reproduce a variety of performances to try to achieve certain outcomes that can be judged more pleasurable or enjoyable for them. As Latour said (1987 p99) "we can never use the outcome, nature, to explain how and why a controversy has been settled".

The performance of actors and the networks constantly performed, dissolved and reproduced hidden dis/ability. In this sense, every performance becomes the making of art (detailed descriptions of performances). When in the everyday performances, a different practice of noticing, selecting and ordering of actors is applied, it is possible to 'see', there is no complete and perfect image of an independently existing hidden dis/ability, but people at different ages, places and times, with different lengths and types of the practising of hidden dis/ability: their history, diagnosis and the health and social care signals (Latour

1988a; Atkinson *et al.* 1997; Mol 1999). These case studies together provide a fluid, collective, and non-traditional genealogy, definitions and possibilities of hidden dis/ability. It shows how actors can compose acts and emergent capacities, affects and transformations of everyday practices. Looking at hidden dis/ability in the everyday performances through the 6D practice, we can 'see' the blurring of the boundaries between art and life, 'disability' and 'ability', individual influences and institutional power. It brings into the foreground the scene and the idiosyncratic activities of the actors with its implications of fluidity, flexibility and complexity of alternative performances.

My data analysis shows there is a problem of taxonomy and documentation, naming of hidden dis/ability and categorising its performances and how the presence of certain actors alone produces signs of hidden dis/ability preceding the performance. How specific actors, like stickers, turn movements and transformations into images and simulations taking our practice away from the here and now, from the action and the immediate performer-scene-spectator relations. The performance of everyday life renders the invisible visible through associations and significations that encompass directly the material and immaterial details: bodies, language, objects, scene, memories, technology. The impact of such resonances on meaning and interpretation of signs depends on the connection between the details, the dimensions and dynamics between the performer, the scene and the spectator. It is this anomaly, singularity, and the possible multiplicity of capacities that we focus on. It is not sufficient to just talk about hidden dis/ability in terms of forms, functions and values but actions, details, dimensions and dynamics that ultimately compose the performance.

The crisis of the sign is when we engage with the few visible forms, ideological values and practical functions of dis/ability at the expense of the details by which the visibility of hidden dis/ability is composed in everyday life. How do we judge whether Monique's performance is an act of dis/ability or the consumption of the signs and things that produced his

dis/ability? The everyday performances do not transport the object of the action, such as the categories in its completed and fixed form, but are themselves, processes of transformation. The material and the abstract constructing the signs are not simply there to carry a message in a pre-existing reality but the actual details and dimensions that compose the everyday performances of hidden dis/ability. This is how the material world and semiotic relationships can make hidden dis/ability visible. The letter, the font, the picture, the value and function of reading and the making of such instructions through their associations and signification materialise and make visible the inability to read as well as dissolve it.

The complexity of hidden dis/ability lies in the diversity of the actors (details, dimension and dynamics) and their irreducibility to set signs or individual actors. They do not merely interact either, like two fixed and existing independently reality, as noted by Goldberg (2011) and Latour (2013a) but perform dynamically. It goes to show that there is no consensus, there is a resistance to the social, as argued by Baudrillard (1983 p35), and surprising dynamics, as observed by Latour (2004a p79). The many performances made visible how and what the performance produced in the form of friendship, shopping or a bank transaction; cooking, learning languages or going to the hospital. None of those performances was possible without the presence of many actors, and their signifying dynamics as my analysis indicated. Hidden dis/ability, in my data, when I apply the 6D practice in the sentiment of Latour and colleagues (1979 p126) and Spencer (2004), in the everyday performances offer novel, unusual and exciting acts.

The many performances I observed were the result of the connections made with borrowed materials including the body and objects and borrowed abstracts, including the notion of offence or equality. Together with their existing and newly established connections in a way that produced and consumed capacities to affect and be affected (Carroll 2003; Latour 2013a p160). Such somewhat unexpected dynamics were the use of the white stick, the

giving of a hug or the picking up the tins from the shelves. Whether it is the board game that carries Peter, the wishes of the potato that cooks the meal or the noise that hold together autistic people, such actors act and enact diverse performances. They affect others in the performance and dynamics ultimately can make a change, move something or someone. Peter managed to take the board games to the table; Monique cooked mashed potato on this occasion and Anna has a conversation. These are embodied and enacted affects, as they emerge from the complex processes of many connected actors such as the noise, the music and the constant chattering in the pub, never one person or one event, not even one act or support (Ursin 2014).

Summary

My 6D analytic has begun to expose how the 'so-called' normative behaviour, health and social standards, the spectators' expectations are detailed. How the production and consumption of hidden dis/ability, the performers and the performed role operate. Today this extension of performance art implies a kind of deferral (Baudrillard 2005b). My field analysis failed to establish any universal or group-specific signs in the everyday performances that the medical manuals, the DSM (APA 2013) or the ICD (WHO 2015), suggest and the social stickers on the board replicate. We use the notion of ability and its symbolic features to assure us of our own health and worth when, in my experience from the data, the universalising tendency of health and social care signals are mostly about maintaining order (Latour *et al.* 1979 p247,251; Baudrillard 1998 p50). Moving from the clinicians' room into the shopping mall, the streets, the cafe or the pub brings many diverse actors, where new connections and thus capacities become possible. Hidden dis/ability becomes a continuously unfolding story in everyday performances. Instead of thinking about dis/abled people and their performances as actors distinct from all the other actors that promote exclusion, we can use the opportunities offered by the 6D practice to render visible the

details, thus often invisible accounts. This could mean, participation and inclusion are not just a symbolic act but active, dynamic and expressive actors between spectator, performer and the scene. I composed descriptions from the analysis, where the many realities of hidden dis/ability are visible and not only one unified story. The 6D practice reveals how actors are composed, made durable and persist and how possibilities for dispositions proliferate. However, the 6D practice also shows how details, dimensions and dynamics can make visible what alternative history of hidden dis/ability tends to hide. There are no artificial divides and boundaries any longer that makes it difficult to decide what we 'see' and how we think we 'see' hidden dis/ability in everyday life. In the live performance of hidden dis/ability, it can be frightening and intimidating not to have set coordinates and fixed dispositions, as observed by Ayers and Butler (1991). However, it is also those undecided and surprising connections that compose opportunities for transformation of hidden dis/ability that the next chapter explores.

CHAPTER 8

Theme three – hidden dis/ability is transient as well as transformative

The previous chapters explored how details could reveal that actors were composed through associations, and not things in themselves. Some connections are more solid than others and collections of relations can travel together into a performance and be maintained by other actors' actions (like the care files, advocates, carers or condition specific organisations). Our present era then can be characterised by the stabilisation and reinforcement of conditions through separation and fragmentation. However, the details and dimensions, the complexity of disclosing a diagnosis, getting the right support or having friends were just some of the actions that many of my participants were made to perform and enact. Yet, the dynamics of the participants' performances I observed showed many uncertain actors, unexpected connections, and alternative actions not anticipated by the apparent or so-called universal signatures.

I have explored and demonstrated how an analysis of dispositions, details, dimensions and dynamics offers a novel way of re-examining who and what affects and how action takes place in the here and now. How a new way of looking can liberate everyday performances of hidden dis/ability. My analysis has defragged the production and consumption of things and signs of hidden dis/ability as potential commodities. I now discuss how signification is of value, how dislocations show us how actors hide in front of our eyes in everyday performances. The data and the examples illustrate that there are a range of complex ways in which actors connect and how those associations affect performances, make meaning

and compose as well as dissolve hidden dis/ability. How connection operates is never certain. Dislocation is about this instability, uncertainty and complexity.

8.1. Anyone and anything can affect and be affected in everyday performances

Dataset

Peter went out bowling with the blind and partially sighted group one Friday evening. To be a 'visible' and thus an acceptable member of such a group, he carried a white stick that, as I observed, he did not use on other occasions. He proudly showed me a small piece of material that he had designed. They placed the material at the beginning of the bowling, on the foul line, to 'see' where to stop and release the ball. I took notes on how Peter went to pick up the ball, how many pins he hit, and how he reacted. I also noted how he carried the white stick under his arm most of the time as opposed to touching things with it to 'see' his way around the arena. My observations showed that he was playing and enjoying bowling like any other non-disabled people along the other lanes; until Peter's mum, Tara drew my attention to an incident and talked to me. A photographer was taking pictures of Peter at the moment of rolling the ball. The flash made him dizzy, disturbed his otherwise weak eyesight, and he could not continue with the game. The photographer had to be asked to stop using the flash. Tara shared this with a slight annoyance and surprise in her voice, accompanied by rapid and disordered gestures. "He should know this".

Jason is an 'autistic' young man in his early twenties, who attends the autism group and related services. Katie is a young lady in her late teens with an intellectual disability and she has a personal assistant. Jason and Katie will be highly unlikely to meet as services are organised around the categories, and they have different diagnosis. It was Harper who changed this. Harper is Katie's mother, who is also a volunteer in the autism group. One morning Katie's carer was not available, yet Harper did not want to miss the autism group. She made a spontaneous decision and took Katie with her. This meeting started a friendship between Katie and Jason and many shared experiences.

The application of 6D practice with discussion

What traditional health and social care approaches seem to ignore and the 6D practice highlights is that drawing, playing, walking, drinking, travelling and applying for a job open up affects in the everyday performances richer than the apparently universal categories can

appreciate as they draw attention to vulnerability and oppression only, as shown in the literature review. By 'seeing' in a different way with the 6D practice, details give opportunities to not only form and perform but dissolve hidden dis/ability, as any actor in a performance will not be positioned absolutely, providing us with a new sense of connectivity. Hidden dis/ability will emerge from the associations and significations between the actors present in and travelling into the performances and not from the historical accounts of fixed points offering a narrow range of ways of 'seeing' and performing. Details are not passive because they embody hidden dis/ability, as Crowther (1993) would suggest, they are integrative. Performances of hidden dis/ability in everyday life give opportunities to form dislocation and transformation, such as spontaneous and flexible connections and activities. The data illustrate when analysed with the 6D practice how the details and dimensions as connectors are crucial. Rigid and stable actors like the categories prevent (or at least often limit) dislocation and signification of everyday performances. I have highlighted many such performances, how ordered actors prevented or favoured specific dynamics and capacities, and how spectators are significant in affecting the capacities for dislocation and how, also, they were directly linked to the categories and the apparently universal signs they brought into the everyday performances. This was even more apparent in the groups I attended and observed.

The separating networks like the autism group, blind or partially sighted or mental health group can be analysed with the 6D practice as a mini representation of society. One composing and composed by dislocating networks, held together with the capacity of the categories constituting them. To experience the performance of hidden dis/ability as something distinct, universal and essential, the categories and their fragmenting and separating capacities are vital preconditions to individualise, commodify and discriminate. In the sentiment of Baudrillard (1993 p36,37, 1998, 2005a p88), having a classification,

belonging to a particular network is an integral part of the process of joining groups of people considered to be disordered into the order of production and consumption. My thesis, through the 6D practice, proposes an alternative way of exploring hidden dis/ability in everyday performances, and I see one of the main benefits of dislocation in offering opportunities for shared cultural experiences and practices. Such actors in everyday performances will not connect merely with the universal signs of the categories.

I will use Baudrillard's analogy of the gift to help explain how 6D practice analyses the signs and things that produce, perform and thus consume hidden dis/ability. A gift, like a diagnosis, is unilateral. In other words, informants regardless of their condition may accept a diagnosis. This diagnosis then becomes an active actor in their everyday performances. Or, they can reject it, thus preventing any connection that comes with it. Alternatively, they can accept it but not share it and not consume its connections. What we can also learn from the informants is that accepting hidden dis/ability is a way to dislocate long-held connections composed by the affects of disposition. However, the 6D practice shows that regardless of my participants' preferred way of dealing with the 'gift' of a diagnosis, the categories (and the gift itself) remain active actors. They affect performances and are affected by other actors' actions and, as such, are never fully controllable.

Focusing on details and what dimensions and dynamics they might afford, rather than on apparently universal signs, only reveals capacities for dislocation in the data with the 6D practice. For example, for Jason and Katie, the everyday performances are not merely the mirage of the apparently universal signs of the categories and the connected medical and social practices. When, Harper (the volunteer in the autism group and her mother) took Katie (she has an intellectual disability) to the autism group one day (a group where, paradoxically, Harper's two autistic sons cannot be present as they are not old enough),

she met Jason. My data and the analysis show how Katie and Jason have not been engaged in apparently universal dis/ability signs but the details and dynamics of talking, smiling and laughing in the company of a hot cup of tea and a few biscuits. Such live performance art offered alternative performances and 'seeing' as there were many actors participating like Harper's car, time, love, the coffee, the biscuit, the photos, the jokes, youth offering capacities for dislocation, a new friendship to be formed and performed. Details of the 6D practice help focus on dislocation to form new associations and transformation. The data repeatedly showed how failing to focus on details can result in a (dis)position limiting dislocations, opportunities for transformation like Katie's and Jason's friendship.

The 6D practice analyses how the performance of hidden dis/ability is not based on 'real' signs and functions of humans and things but the material-semiotic-phantasmal connections between actors at a local scene. Hidden dis/ability is embodied and enacted from the connections within which it performs, and as such, hidden dis/ability is not a permanent and fixed thing but a temporary conflict, contradiction and limitation. Not between a person and his/her body, or the person and other persons or the person and the environment as the literature review often implies, but rather as an effect of various actors and their webs of connections that are dynamically present in the performance. Details, dimensions and dynamics of the performance become important considerations as there are multiple ways to perform. The data analysis with the 6D practice shows how actor-networks have dimensions, varied size, shape and scale. For example, actors like the Autism Act has more connections with other actors than the autism card issued by the Autism West Midland group. The dynamics formed in such actor-networks compose various capacities. These are the important dynamics as they alter, constrain and facilitate the performance on the one hand, and reveal the complexity of connections on the other. Such associations and significations indeed can compose power, vulnerability and inequality just

as much as competency, resilience and parity in the everyday performances of hidden dis/ability.

When we observe and interact with dynamics, the positioning of the actors that are present in a performance and how they form connections, we can notice how an actor like the Autism Act was composed by diverse actors and maintained through many dynamic connections, from the government through bulletins and websites to the support group and Max, the manager. Dynamics play an important role in mediating the performance nine years after its creation through its dimensions. How different autism is, composed at this particular scene, from Jason's autism, as actors themselves, like the Autism Act, are not fixed and static either but multiple. Places are dynamic actors, too. The shops, cafes and groups, the leisure centre, workplace and pub, where performances constitute networks are vibrant actors. Everyday life is not a static scene, a staged show like the clinical office, a scene that already exists with pre-arranged actors in a particular order. Hidden dis/ability in everyday life is participatory, it emerges from the associations and significations of the connections and comes into existence through its users: humans, objects, concepts, meanings, discourses, memories, and their dynamic entangling and disentangling. New actors entered the scene, and old actors brought symbolic dynamics with them in the form of memories, stories or materials and appearances. New connections formed that constantly disturbed and recomposed dynamics, and as such, new capacities emerged. One example was Katie and her 'intellectual disability', another was the establishment of a committee with all its materiality (papers, boxes, votes, letters) and immateriality (meetings, arguments, fears, rights).

The capacity to affect and be affected is the dynamic of interest for my analysis, how unexpected and surprising actions and thus dislocations (friendships were formed, carers were banned, the organisation walked out) are generated. Dynamics show how everyday

performances of hidden dis/ability exist in an undecided and dynamic relationship, as the performances involve the spectator and the scene with ordinary objects, specific concepts, and mundane memories composing multiplicities of hidden dis/ability. There is the existence of many possible hidden dis/abilities coexisting, and as my analysis emphasises, always under composition forming and performing, solving and dissolving, producing and reproducing the performance as a temporal site of shifting associations (Latour 2013a, 2016). Such performances can reveal us the semiotic, semantic, symbolic and simulated signification of dynamics when we analyse them with the 6D practice that I will describe using data from the night Peter went out to play bowling.

The semiotic level explores the signifier, the white stick, and how it signified; Peter was partially sighted. However, it does not reveal the whole performance, how he was moving around comfortably and playing bowling like anyone else. The white stick aimed to signal his dis/ability, yet it symbolised through its multiple semantic relationships many other things. For example, the white stick *is a way to do* friendships with those whom Peter has been playing bowling for years, it *is a reason for* participating in competitions and *is used for* inventing a piece of material as easily as a new persona. The white stick is an important symbol of separating and purifying conditions, justifying how we belong to groups. Inclusion always immediately composes exclusion, the operating principle of binary oppositions. Coming and going between such networks is not a straightforward act any longer. The white stick dynamically connected Peter with others in the blind and partially sighted group just as much as it disconnected him from other people playing at the arena or the people from the autism group.

It was not until an unexpected actor, a material object, a camera entered the scene, a non-human, that through its agency (the ability to affect and be affected) not only composed but made Peter's hidden dis/ability visible for Peter, but not others, until it could be 'seen'

through another narrative actor, Peter's and his mother Tara's account. Now, it is not only the white stick that can be connected with the symbolic domain of blindness but other symbols like the camera, the carer, the flash, the documentation. However, it is the process of simulation that reveals how dynamics composed Peter's hidden dis/ability. The materiality of the camera and the flesh, but also the immaterial value of managing a place that is 'disability friendly', so to speak, is ironically why the camera was there in the first place. The camera was there to record the manager's speech who opened the dis/ability bowling event and welcomed the players who against all the odds were enjoying the whole event, organised to support people with dis/ability, presumably to gain better acceptance for them. Paradox itself is a dynamic actor for my analysis. I argue whilst it is the case that Nick cannot read, Jane cannot count, Peter cannot use his left hand, and Bob often refuses to meet with others, none of these apparently universal signs will result in a permanent hidden dis/ability.

The 6D practice turns our attention to ontology, actors, connections and capacities composed for dislocation regardless of whether we know the specific category. We are connected with everything in a way that cannot be reduced to individual actors, language or reason alone. We turn our attention towards dislocations, to the question of when and how something becomes affective through associations and significations of signs and things to notice whether there is any other possible capacity. I have observed and participated in the never-ending unfolding stories of hidden dis/ability. When I analyse these performances with the 6D practice, it is possible to see how actors cannot choose to partake. The 6D practice can reveal more exciting performances than the usual rhetoric of most health and social care approaches briefly explored in the literature review. The performances were judged as sad, funny or empathetic but not as hidden dis/ability. How any of the performances I have observed and participated in compose (or not) hidden dis/ability, or rather beautiful, upsetting or visionary acts (and for how long, and visible to whom) depended on actors travelling from various times and places, in diverse sizes and

shapes and their dynamic connectivity. As such, my analysis of dynamics and dislocation has been anything but straightforward and in the words of Baudrillard (2001 p193) we encounter “all possible interpretations, none of which can fix meaning: the equiprobability of every cause and of every consequence — a multiple and aleatory ascription”.

8.2. Hidden dis/ability is enacted from the connections within which it performs

Dataset

I had many discussions about how we could make visible that someone has a hidden disability. For example, when we were in the library, Peter told me that he was asked to wear a badge by the manager to make visible his hidden epilepsy and autism. Peter explained how he had refused it. The week after, I visited Peter in his home. Although Peter lives in a supported living, he spends every weekend at home with his mother. I interviewed Peter's mother, Tara, in her house, and she started talking about the badge. Mum said, too: "it is discrimination, why would he wear a badge?". A few weeks later, I noticed a post from Julie, the charity manager, on a social media site in relation to making hidden dis/ability visible. She asked the question: "should shoppers not be treated the same? Is there a less obvious way to say someone needs additional assistance? Without making it obvious to all who is shopping?" Julie has responded to an argument about a sunflower lanyard that a supermarket had introduced recently to help shoppers with hidden disability.

The application of 6D practice with discussion

The 6D practice helps to specify how spectators tend to focus on either the persons and their in/ability to look into someone's eyes, limited social interactions, whether they can travel independently or they turn their attention towards the environment, notions of social barriers such as the bus route, noisy places and the social rules of looking at someone when speaking. Autism is not depression or intellectual disability in such a 'seeing' of the performances. They are different things requiring specific care. The 6D practice further shows in my fieldwork and data how details, the various objects, abstracts and discourses

make hidden dis/ability visible and perform signals. None more so than in the subtle ways participants demonstrated an inability to read and understand money, for example. Conversely, when my participants performed such expectations in the live performance (the health and social care signals, specific acts and details attached to the signatures) such as the use of particular objects, or application for support, they were often accused of 'manipulating the system'. There, objects do not signal autism but are the symbols of other conditions.

Objectively, it cannot be said whether Peter simulated a dis/ability or not based on the data when analysed with the 6D practice. Any sign of hidden dis/ability can be produced and performed. Therefore, signs and things cannot be taken as a fact of nature any longer. In a Baudrillardian vein (1994 p3), every hidden dis/ability can be considered as "simulatable and simulated" as "truth, reference, objective cause has ceased to exist". Thus, the crises of the signs, and we are now left asking what ability is, just as much as what disability is. Hidden dis/ability is ambiguous today, and we never know all the performances people encounter. In the words of Baudrillard (2005a p76), "when everyone is an actor, there is no action any longer, no scene. It's the death of the spectator as such".

With the 6D practice, such details are significant in rendering the performance of hidden dis/ability visible and examining how it dissolves. Details of the performance had different dimensions and as such capacities for disposition or dislocation. However, I also analysed how objects and objects are not the same, so it is not only the details that matter materially, but the signification and semiotic relations between actors, the dimensions they bring and the dynamics they form. When they are connected and enacted, both the 'simulated' and the 'real' hidden dis/ability are produced by the same semiotic network. I do not know, still wondering about the data, why would Peter have a white stick or a wheelchair but not a badge? But Julie, Peter and his mother Tara were not the only ones who thought that the

materiality and visibility of the different conditions, the details, were not and should not be the same. I was left pondering how a white stick is a discrete sign of blindness? How could blind people be treated the same as people who use their eyes to see, and how it could not be visible to everyone else? And for what reason? What is it then that a white stick and a wheelchair can do but a badge or a sunflower lanyard cannot? What is the difference between being blind or not being able to walk long distances and staring long into space or not being able to read the price of the baked beans? What judgements and ways of 'seeing' do they evoke?

The company who advertised the sunflower lanyard for people with hidden dis/ability, in this campaign to give them additional support, used someone with a Down Syndrome in their short advert. Ironically, this is one of the few hidden dis/abilities (intellectual disability) that is rendered visible by the unmistakable details of their facial features and in fact, strictly speaking, does not form part of this doctoral project (even if we know that their performances are not fixed either). The materiality and the visibility of their difference is not a question that distinguishes Down syndrome from other hidden mental and cognitive dis/abilities. When we explore such performances with the 6D practice, unpacking the details, their dimensions, the associations and significations, it can reveal how the material world and its semiotic relationality makes or not hidden dis/ability visible and composes realities (Latour 1996b; Sullivan and Williams 2012). Hidden dis/ability in everyday live performance art can be found in this complexity of details, as they perform and make spectators enter the scene and compose together moments of possibilities for dislocation requiring negotiation (Latour 2004a p113; Greenhough 2011). The objects, for example, the white stick that turns Peter into a member of the blind and partially sighted group or technology and the tests that can measure Jane's and Eric's IQ have travelled into many performances as actors. However, this was not the case for the badge, the home-made autism card or the lanyard.

Various values, functions and forms that tell us what we mean by the medical and how it differs from the social also travelled into many performances. I argue that the 'details' domain of my analysis replicates what Latour posited (1993 p95), that if we aim to explore the vibrant everyday performances of hidden dis/ability we need to move away from the notion that nature and culture represented by apparently essential and independent actors, like the categories, offer sound approaches to the everyday performances, as it appears nature and culture are part of the problem, not part of the solution. The details of hidden dis/ability are composed in the constantly changing connections, the dimensions of the actors, the dynamics of the scene, humans, things and signs. The 6D practice can highlight this connected and complex scene, unlike the separating and apparently fixed approaches. By focusing on the signatures for too long, like Anna's inability to decide what to wear, we fail to notice, select and order the details, other actors, such as her confidence, feelings of control and her joy of achieving goals.

The 6D practice treats the detail of every event and situation as an uncertain performance with the potential to generate discussions about what we mean by hidden dis/ability that the many descriptions documented. It approaches the act with the notion that there are many actors present in the everyday performances that, on the one hand, have the capacity to affect the performance, and on the other, to make particular performances more likely than others, and as such be influenced by the lasting dimensions of connected actors. Details reveal not only dimensions and what makes such actors enduring and stable, but also, what other actors are present to form capacities for dislocation. Throughout the fieldwork, I have seen many performances, some had composed and as such made visible a sort of dis/ability, as when Peter used his wheelchair to go to the library, or Bob cancelled his meeting with me. Whilst other dynamics have not performed such capacities, for example, when Peter was copying documents at his workplace or Nick went for a walk and bought some take-away. Traditional approaches often fail to reveal such dynamics, as I also

showed in the literature review. However, when exploring these performances with the 6D practice, we can show how all such performances started from the same uncertain position with the potential to perform one or the other. The categories aimed to reduce complexity as well as the uncertainty of the actors and their dynamics. Nevertheless, in the everyday performances, I analysed many uncertain actors, often composing dynamic capacities and unexpected performances as their connections were rarely solid and lasting.

I argued how signs of ideal performances had been established where the inability to look into someone eyes, comments considered to be rude or an unusual attire could all be 'universal' signs of the presence of hidden dis/ability. Yet, in this chapter, I continue to demonstrate with the 6D practice how dislocation lets us see such performances as an illuminating surprise, the potential dissolution of hidden dis/ability. How it advances discussions about hidden dis/ability in terms of approaches, values, and proposed solutions as the source of life is singularity and multiplicity, not sameness and uniformity. Conversely, as a practitioner, I appreciate the benefits of simplification in practice to reach our goals and negotiate our realities. I believe the 6D practice meets this expectation too by moving towards diverse actors, connectivity, and that hidden dis/ability is openly and constructively complex, whilst appreciating the approximating value of stable and durable associations or dispositions. The 6D practice refocuses our attention onto acting, the illuminating surprise of hidden dis/ability by moving away from the sole agency of apparently universal and essential actors, such as the categories and the binaries of 'medical' and 'social'. In the formation and dissolution of hidden dis/ability, we explore how actors and their connections sustain but also challenge long-held assumptions. We are ascribing agency to transient relational networks whilst we are aware of potential connections that give durability and stability to actor-networks.

We encounter many performances that in our complex everyday life consists of a relatively small number of actors and manageable connections even if there remain many potentials and capacities for dislocation, as analysed in the data. The 6D practice does not model or predict like most traditional health and social approaches but notices and maps out strings of actors, possible actions, consistent inconsistencies, capacities and affects that have the potential to order as well as dislocate. I pursue an idea from Serres (in Serres and Latour 1995 p148) who argues, "... we should invent a theory of obscure, confused, dark, non-evident knowledge - a theory of 'adelo-knowledge' ... something that is hidden and does not reveal itself...". The sentiments of which (in the form of the 6D practice) offer an alternative to traditional analysis that works with binary oppositions and the separating of actors in advance into natural and cultural elements. Such distinctions tend to prevent us from seeing the performances "in the light and the shadow of real" simultaneously. The 6D practice attempts to offer this new way of seeing hidden dis/ability because it does not limit everyday performance to a hermeneutic, rationale or historical account of unified narratives, but encourages a broader embodied and enacted experience through which we can encounter dislocation. I argue, hidden dis/ability is forged in dislocation. I call this affect alternative possibilities and illuminating surprise, as it transforms long-held dispositions and challenges norms and assumptions.

The 6D practice reveals a myriad of ways of 'seeing' performances. My analysis shows how the unity of hidden dis/ability, as noted by Law and Mol (2010) and Nimmo (2011), is best found in multiplicity between and within the various performances. Dislocation lets us see how the illuminating surprise of the performances composes conditions of possibilities for transformation and the forming of new associations, thus dissolution of hidden dis/ability. In other words, a change in any may result in dislocation, as the notion of hidden dis/ability is sufficiently complex to reveal something new each and every time (Crutchfield 2002; Johnson 2003; Sage *et al.* 2011). It is the diverse performances and not the definite

classifications that enact at the same time. I argue we can all benefit from the illuminating surprise where actors make temporary connections with borrowed objects, abstractions and discourses in a novel, disrupting, controversial and unsettling ways. With the 6D practice, we are not looking for universal signs, ordered connections, and predicted dispositions only, but remain responsive to dislocations, the unexpected of the mundane, the ordinary and the specific simultaneously. This includes the body, objects, the environment, the various activities my participants performed like cooking, shopping, joking or arguing. These are not performances of a fixed or a permanent hidden dis/ability. They mirror and are able to be seen as details, dynamics and descriptions with the 6D practice. Dislocations show us how conventions are easily disrupted and easily disrupt the everyday performances as spontaneity, complexity and uncertainty enter the scene. The everyday performances of hidden dis/ability tap into this dynamic of potential dislocation which undermines notions of permanent stability and certainty claimed by medical and social explanations.

8.3. Hidden dis/ability is anything but an independent reality

Dataset

I interviewed Harper one morning. We left the autism support group and went to a quiet room where no one could disturb us. She was sitting at one end of the table whilst I positioned myself opposite her with the Dictaphone running in the middle. Harper explained that she knew very well how her son's autism would present and what to expect, as one could learn over time. Hence, she argued that professionals and alike should listen to the expert spectators, carers, and narratives. She gave me many examples from school and the everyday life of her son. She provided detailed descriptions of how her son, Orion would react, for example, when she was late for picking him up from school. One week after the interview with Harper, we participated in the usual weekly support group, and we were having spontaneous conversations. When the event ended, we started putting away tables and chairs, doing the washing up and cleaning the desks. We stepped outside to lock the door. Suddenly Harper began to explain how she was late that day from picking up Orion from school. She continued telling us that she just never knew what would happen if she arrived late to pick up Orion.

The application of 6D practice with discussion

The idea of symbolic exchange that I take from Baudrillard (1993) and that of agency from Latour (1993) in the 6D practice relate to the performance of exchange and the actors' capacity to affect. Both symbolic exchange and agency in my reading, in the 6D practice, see actors (humans, objects, non-humans, abstracts) with the potential to act and enact. It is this symbolic exchange and agency that can be made visible with the 6D practice. In particular, how it (re)establishes (re-assembles and reverses) connections between signs and reality, as the performances are expressive, intense and unpredictable, dislocating established meanings, norms, images and appearances. It is this capacity that the 6D practice promotes to reverse and re-assemble hidden dis/ability. Dislocation is Jane's art of tea making that has affects. It is exchanged for Nick's and Eric's creativity of storying, where neither the materiality of the tea nor the value of storying can be analysed through exchange-value and use-value (usefulness, satisfying needs and the model of intellectual dis/ability) but the symbolic, the material-semiotic relationality of things and signs. This commotion of surprise, the unstable actors and their actions must be shown if we are to negotiate how conflict, as a motif of dislocated mischief, is used to uncover the hidden. Because it is dislocation through which we can incorporate the act of negotiation of our realities into the process (Latour 1999a; Law and Moser 2012).

When we turn our attention to dislocation, Peter's bowling, Nick's missing tooth, Bob's travelling, Anna's inappropriate comment, Monique's shopping or Jane's inability to count are no longer pathological representations and signs of hidden dis/ability, but opportunities to make visible the beautiful hidden and 'see' alternatives to hidden dis/ability. Hidden dis/ability can be analysed then as not one objective and independent reality but being multiple. What the data shows, when applying the 6D practice, is that only staged theatre shows have a defined beginning, middle and end, a scripted narrative and a rather non-

participative audience. The everyday performance of hidden dis/ability is live performance art. There are immediate performer-scene-spectator relations at various vibrant places with the actors being more or less accidental. In live performance art anything can happen as the everyday performances of hidden dis/ability are complex and connected with the capacity to disclose different aspects of our most basic contact with the world. Our hidden vulnerabilities, apprehensions and frailties are conflicting as well as overlapping stories. The 6D practice lies in this capacity to dislocate ordered connections between perception and meaning, the objective and subjective, fact and fiction, 'disabled' and 'abled' and as such, to intervene with the visible to reveal contradictory realities, generate debate and make 'real' conflict.

In everyday life, the performances of hidden dis/ability are merged with other acts of life. Here, the participants are artists. In everyday life, we can all be artists and live our life as a work of art under constant composition and dislocation. This approach liberates a range of possibilities, it brings to the fore new pictures, new representations; new seeing of hidden dis/ability. I argue when an everyday performance no longer creates such discussions, debates and re-considerations of our values and practices, no longer evokes diverse responses, it is no longer a live act and cannot achieve its capacity to dislocate, transform and change the images and appearances of hidden dis/ability. My participants show, when analysed with the 6D practice, how dislocations are significant in everyday life if we aim to provide people with hidden dis/ability with apposite care, services and inclusion, and not with a symbolic act of equivalence, or the blunt tools of resemblance and equality. This thesis thus questions hidden dis/ability as a fixed, objective and independent reality and is intrigued by the actuality and potentiality of everyday performances as a site of agnostic processes to challenge the assumptions of norms and clear boundaries.

The everyday performance of hidden dis/ability should leave us with a sense of uncertainty as we can never see the whole performance but only fragments. It affects our ordinary and mundane activities in specific places dislocating compositions (Boje 1995; Goldberg 2011). They allow material rearrangements of signs, images and discourses, as noted by Latour (2013a p46,161) and Haedicke (2012 p7). I asked the question earlier, how could we reclaim the space from the expert spectators to move away from universals, grand narratives and unified stories of hidden dis/ability to the mundane, the ordinary and the specific? The 6D practice renders visible how hidden dis/ability performs as well as dissolves. It is forged by actors (performer, spectator and the scene) who co-compose it. Expertness becomes a process of dislocation, one of value with 'real' life consequences. It is not that the capacity for dislocation has been overlooked, but it makes into an awkward and cumbersome device for political, moral and economic actors. It has always been easier to collate, group and club together universalising signs rather than consider details, dynamics, dimensions, dispositions and dislocations.

The 6D practice renders the possibility of making visible an entire spectrum of dislocation: the complex, the hidden, and as such, the beautiful in the everyday performances of hidden dis/ability. The 6D practice considers the performance of the here and now, how hidden dis/ability is composed of details in the ordinary, the mundane and the specific; how capacity is always dislocating, unstable, and the symbolically signalling. My interpretation of the performances is relative as its assessment depends not only on the performer but also the spectators and the scene; how participants encounter alternative realities. It follows that hidden dis/ability can be considered as being constantly dislocating because it is signal driven. The 6D practice is an analytical reminder that appreciating the richness of hidden disability is not an act of individual agency alone or an effect of apparently universal signs. Valuing the ability of performances to provoke and challenge long-held assumptions these categories hold dear, they pick on the novel, funny, ugly, beautiful, creative, imaginative and

awkwardly illuminate conflicting judgements I witnessed, analysed and retold. Dislocation displays the complexity of hidden dis/ability shared openly through our common dilemmas, tensions and contradictions (Latour 1997; Westcott 2003).

The actors disclosed contradictions, how Harper's son was sometimes fine waiting peacefully in the account of an interview (or staged show), but upset and distressed other times especially in a spontaneous discussion (live performance). Apparently one son, autism and mother but two different details, dynamics, dimensions and thus dislocations, composing two different reality of hidden dis/ability. There is a methodological challenge too, as I addressed in the literature review and analysed in the data. How in the live performance, I could observe details, many actors and acts, but not in the staged show, the focus-group discussion, when I asked Brian about his everyday life. How he could not recall the details other than being a prisoner of the category. How Stella, the volunteer, could not move him either to share the activities I heard about before. The performances then show how the categories do not transport universality, certainty and predictability into the everyday performances but compose multiple realities of hidden dis/ability as they themselves are multiple.

The 6D practice enables us to (re)consider how we see the everyday performances of hidden dis/ability (regardless of whether we are a scientist, social care professional, a person with hidden dis/ability or a by-passer) by shifting the focus from disorders on 'essentials' to complexity, instability, connectivity and the affects of shared as well as distinct cultural experiences. My analysis repeatably showed how actors and their connections composed tensions, conflicts and contradictions. The challenge is that most spectators expect repetition and predictability. However, what the informants continued to exhibit is surprise and the unexpected in the everyday performances, the beautiful hidden, the passive and unstable, which only become visible once they connect and enact those

connections. But how could it be any other way? Noise is not always an obstacle in a performance. It was for Monique in the cafe but not at the party when she was dancing. Ester does not always feel as though her body is so heavy it does not want to move or meet but connect only through Twitter. Eric, Jane, Nick, Peter and other's comments did not always evoke annoyance but also laughter, shock or silence. Such notions of fixed performances might belong to the staged theatre shows, but not to vibrant and exciting everyday live performance art, where more acting means more dislocations, and as such dissolvment of hidden dis/ability in laughing, talking, playing and cooking.

The 6D practice turns our attention to the mundane, the ordinary and the specific. That is to say, in everyday life, I propose the 6D practice as a promising analytical tool to negotiate the increasingly complex everyday performances witnessed. It asks us to consider what approach we need for a shopkeeper when the shelves make Jane feel lost as the numbers trick her, or the similar tins of baked bins affect her choice? The bus driver when the closeness of others or redirection of the route make Monique's acts uncertain? The photographer, when his flash makes Peter dizzy and confused? The noise when Michael feels the words conspired against him, and he has an urge to leave the room and have a coffee? When the machines make Jamie look disabled in the hospital ward, as he is unable to express that he is, in fact, just hungry. I argue traditional approaches have not yet delivered aspirations in understanding the palette of everyday performances that, as my participants showed, remain vague, unpredictable, and obscure. The 6D practice does not aim for reductionist answers about apparently isolated and stable signs, but its strengths lie in exploring details, dynamics, dimensions, and dispositions to see opportunities for dislocation.

My analytic of hidden dis/ability demonstrates how it is not only the categories that prevent us from seeing such capacities for dislocation in everyday performances but the ongoing

debate whether we should socialise the medical categories or medicalise social functioning rooted in the binaries of natural and cultural. I developed the 6D practice to offer a solution (or at least a new way of seeing). Latour's (2016 p68) observation was helpful here when he said there was always something between us, humans: things, abstracts, and signs. That it is difficult to connect with each other. I applied this to the medical and the social models, so I wonder, what if the 6D practice suspends both? Interrupts the distinct and defining domains as well as separated essentials and universals of the categories? What then? If we stop designing autism-friendly, dementia-friendly, depression friendly and other condition friendly places? Instead, we compose ordinary, mundane and specific places that are responsive to many actors, the dimensions and dynamics, and the capacities they form to 'see' what dislocations might be afforded. I hypothesise we could promote our aims better for apposite care, services and inclusion and, as such, reconsider how non-humans, objects and abstracts too like dogs, earphones, and confidence are crucial actors in a 6D practice informed approach.

I explored earlier how we created one way of medical seeing and mirrored it to compose the social way of seeing. I never attempted to use the 6D practice to forge some type of connection between the medical and the social, because what my analysis has made apparent is, there is no single line, no unique parallel or even circularity which can account for the dislocating affects of judgment and appreciation. Instead, the 6D practice has a different centre offering a space outside of them to explore how each and every time minute and detailed performances occur. The 6D practice moves away from a person, social barrier and biological centred view towards a relational-compositionist way of seeing (Latour 2013a, 2014). We are now focusing on what can happen in a cafe, in a shop, in the leisure centre or when the participants walk the streets. We can reopen the discussions charged with contradictions and tensions, about what we hope from the spectators when they 'see' an unexpected performance, the illuminating surprise of hidden dis/ability. The 6D practice

in everyday life could reverse and re-assemble the medical and the social models, the advocate and the carer, and the people with various hidden dis/ability to explore opportunities for dislocation, as this way we are not focusing on the categories but the performances with all their makings.

If we move away from looking at the essentials, what the universal signs signal to be 'disabled' into the realms of connectivity and networks, then the performance of hidden dis/ability turns out to be something very different. It transforms into a temporary set of possibilities and dynamic capacities that can be assessed in various ways. The everyday performances of hidden dis/ability can always be observed as political, ethical and economical when we consider how it is culturally situated and as such assembled. That is to say, hidden dis/ability in everyday situations is transient as well as transformative. Their form, function, and value are dynamic and connected rather than universal and essential as generally promoted by mainstream health and social practices.

Summary

My analysis has allowed me to focus on details, dimensions and dynamics and shift the focus to multiple actors to see what capacities connections compose for dislocation, the transformation of dispositions, and the description of new associations. The performances were upsetting, funny and tedious, showing us multiplicity of reality, not one objective and real hidden dis/ability. The result is my exploration of how, by focusing on apparently essential and universal actors, traditional practices fail to see these opportunities for dislocation, the dissolution of hidden dis/ability in everyday performances. I argue, if identifying one truth of hidden dis/ability is not possible, then a unified sign is not the only actor affecting in everyday performances. During the project, I observed uncertain actors, unexpected connections, and alternative actions. Thus, I argue, the everyday performances

of hidden dis/ability can be viewed dynamically as it is not a stable place but the site of unstable connections. There are surprising actions that challenge assumptions of clear boundaries as they confront us with unexpected dynamics leaving us with a sense of uncertainty. The analysis and application of Latour's and Baudrillard's ideas to the everyday performances of hidden dis/ability signify how hidden dis/ability is anything but an independent reality, regardless of the framework around it. They are rendered real and visible by complex webs of dimensions and dynamics they compose and are composed by them. When we shift the focus to how valued things and signs dimensionally and dynamically perform, we have a new way of seeing hidden dis/ability. Hidden dis/ability in everyday performances is the surprise of instability, potentiality and possibility that can be reconsidered as being in a constant state of dislocation, as audiences grapple with a bewildering dynamism and signal driven acts. Hidden dis/ability then, is not about being 'real' or 'unreal' but how the performer, the spectator and the scene together perForm, disSolve and reProduce hidden dis/ability.

CHAPTER 9

Hidden dis/ability in everyday performances is complexity rendered visible by descriptions

I conclude in this final chapter with what I learnt from my participants, to whom I am very grateful. To do them justice, I explore what I have done as well as the limitations which became apparent as a result of my research. In particular, I summarise the development of the 6D practice and how descriptions are our tools to explore the everyday performances of hidden dis/ability as perFormed, and disSolved. Descriptions are visibility interpreted. They are complex, intricate and affective. As such, there is a beauty in the process: a spirited, adventitious, provocative and of course, transformative becoming in the dissolvment of hidden dis/ability. In a Baudrillardian (1983 p2) sense, the performance of hidden dis/ability, driven by potential energy, pulses between passivity and wild spontaneity and as such, resists any totalising of original stories into grand narratives told (or described) by a unifying expert voice. What there is, is the beautiful hidden, the indescribable in the description, rendering the invisible visible. These performances are the mundane, the ordinary, being described into the specifics, the here and now. In such descriptions, there are performances with all their makings to provide us with opportunities to negotiate the multiple realities of hidden dis/ability.

9.1. The 6D practice reverses and re-assembles hidden dis/ability

This thesis set out to investigate how, by the end of the 20th Century, expert spectators pushed hidden dis/ability into a particular space. First, through apparently objective judgments and universal signals; and second, as categories of performances of what it is to be dis/abled. In addition, and as a consequence of the project, third, the thesis also

explored how actors could remind us of the injustice and suffering of hidden dis/ability. How recomposing our histories is to encompass new or previously excluded stories at the expense of other accounts: the mundane, the ordinary and the specific. How dynamic and dislocating performances are usually considered in terms of an objective 'real', but are also temporal, imagined and dependent on remembering and nostalgia to fill gaps within stories. And as such, challenging apparent origins and signs of reality with an escalation of the truth and desperate production of the real. There is a binary dynamic between causation and their effects, of the referential and of the material (Baudrillard 1994 p5; Latour 1999 p21). This thesis is thick with descriptions and reflects how in our postmodern era there is now analytical room to consider proliferation, separation and fragmentation as part of the details hiding shared cultural experiences of my participants and practices as judgement is no longer needed. It is there already, actualised and realised through models and images of hidden dis/ability.

The descriptions of the participants' everyday performances revealed how difficult, if not impossible, it is to play bowling with the blind unless we perform the signals of being blind. It is irrelevant and even insulting, to have mental health difficulties unless we signal constant suffering and struggle. How pointless to attend the autism group unless the signature of intellectual disability, depression or obsessive-compulsive disorder are the producers of signification; unless unifying narratives as signatures of categorising conditions produce an appearance that hidden dis/ability exists as an independent and coherent universal reality for people like Tim, Sarah or John. The drive for totalisation, the desire for perfection, fragmentation and separation repeats itself endlessly for Tina's and Darcie's performances producing a mirror image itself in a simulacrum of itself and the movement making the hidden dis/ability disappears (Baudrillard 2005a p185; Latour 1996b p1). Traditional approaches (like those discussed during the literature chapter) respond well to this mirroring, separation and fragmentation by ensuring actors and actions remain autonomous

and unmediated as there are no dimensions and dynamics that make actors do things but mostly fixed individual factors. Such approaches use the person with hidden dis/ability to justify their mode of travel rather than looking at what makes, or not, a journey possible.

The analysis of the performances leads me to conclude that developing novel ways of seeing performances is about observing hidden dis/ability as fluid and temporary event; as something that performers and spectators need to perform in order to consume themselves into existence. The analysis also made visible how health and social care practices seem to have forgotten how to describe the mundane, the ordinary and the specific: Jane's shopping, Peter's photocopying of documents, Nick's storying, Anna's and Bob's shared narratives of haphazard thoughts or Monique's contemplations over a cup of coffee. The performances I observed and participated in could be seen, described and thus made visible in many ways. This replicated my main argument that hidden dis/ability in everyday performances is not a fixed and permanent state but perFormed, disSolved, and reProduced by webs of connections. It made me reconsider what approach could reverse and re-assemble such universalist and essentialist notions of hidden dis/ability.

I developed the 6D practice to become attentive to the many actors (signs and things) and their connections, the complex, the silenced and the beautiful hidden that compose capacities for transformation. Descriptions are the tools then, that when emerging from the everyday performances of details, dimensions, dynamics, dispositions, and dislocations and not from images and appearances, can explore hidden dis/ability as live performance art. As such, descriptions cannot be deduced from apparently universal and essential signs of hidden dis/ability. Instead, the 6D practice responds to the challenges of our postmodern age (separation, fragmentation and proliferation), as it works with a connected, localised and decentralised performer, spectator and scene simultaneously. It moves health and social care practice from the safe place of a theatre (consulting room, focus-group

discussion, laboratory, experts' offices, inductive methodologies) to the streets (pubs, shopping malls, special occasions, here and now participation, abductive performances) exploring capacities for transformation. The 6D practice offers a new way of seeing as there is never any permanent equilibrium or completion of work that cannot suddenly be destabilised by reversibility and re-assembling (Baudrillard 2005a p185; Latour 2006 p16). The data analysis has convinced me that reversibility and re-assembling can be actualised in the descriptions by making visible not only the affects of universal and objective signs but by exposing the surprising acts of hidden dis/ability, the unstable actors and uncertain connections composing tensions, competing affairs and contradictions that other approaches rather hide.

The performances I have observed and participated in were often idiosyncratic. Some were excessive, subtle, or rigid, whilst others spontaneous, controversial, or monotonous. My participants transcended, reversed and re-assembled conventional performances offering alternative experiences. They are the uncertain actors and the material, semiotic and discursive connections and not the apparently universal and separated signs of hidden dis/ability that compose capacities for transformation, the formation of alternative experiences with people and things. The 6D practice focuses on actors (spectators, performers, scene) up close as active makers of hidden dis/ability. Performing is using the available signs, things and their connections often in unusual ways rather than judging the act from a distance. The descriptions of Jane, Nick, Peter, Anna, Monique, and Bob's performances show that hidden dis/ability is not a thing, an inherently ethical, political, economic or identity question. They are the apparel of production and consumption of things and signs that compose hidden dis/ability variously each and every time as actors (the white stick, letter, camera, voting papers, coffees, the price tags, memories, dreams) and have the capacity to dislocate apparently solid and durable connections thus reversing and re-assembling what we mean by hidden dis/ability.

9.2. The 6D practice focuses on the world-making activities of the actors

I learnt from the informants and analysed with the 6D practice how solutions are present in the descriptions, what is already embedded in the connections and the capacities they form. The difference between traditional approaches is that descriptions of the 6D practice do not transport ready-made answers into the performance, but let the solution emerge and be unlocked from the binaries of representation (if there is black, then it is the result of white). It emerges from perceptions of here and now, from the world-making activities of actors with particular attention to the people with hidden dis/ability. Mol (1999 p85) noted how in descriptions alternative realities do not merely coexist but are also found inside one another. It is because descriptions reveal how actors like categories, letters, badges, advocates, care files, academics, social workers are multiple in themselves. They affect and are affected, thus showing the material, semiotic and discursive continuity of hidden dis/ability composing shared cultural experiences and practices such as topics discussed, issues complained, experiences narrated.

The more visible the composition of performance becomes the better the position we are in to let surprise not only compose contradictions and tensions but present itself in emergent solutions. I argue such descriptions as emerge from the world-making activities of the actors (details, dimensions, dynamics, dispositions and dislocations) offers potential for not only negotiating our multiple realities of hidden dis/ability but finding temporary closure and solutions through shared cultural experiences and practices; until the next descriptions make us re-negotiate our values, ideals and expectations of apposite services, care and inclusion. The 6D practice then can be particularly significant in the everyday performances of hidden dis/ability where shared experiences and cultural practices help notice what might otherwise go unnoticed.

The 6D practice does not aim to bridge the medical and the social or dismiss one of them to favour the other. It does not delete the categories either but collapses order, separation and proliferation by composing a space that is natural, cultural and discursive at the same time. In the 6D practice, those separated disciplines, professionals and conditions become complete and full on their own terms. They exist only in connection with details, dimensions, dynamics, dispositions and dislocations. The descriptions of the 6D practice can render visible how invisible social norms and medical practices have been composed and how they affect through connectivity. We have no more facts and myths, objective and subjective, only actors, connections and capacities. Here, the only tool we are left with is the descriptions to compose our typically conflicting concerns openly. Nurses and social workers, disability and ability, autism and intellectual disability are not in binary oppositions any longer but both overlap and are discrete simultaneously as they perForm, disSolve and reProduce multiple realities of hidden dis/ability that we need to negotiate and take responsibility for.

The 6D practice offers this novel way of seeing as we do not absolutely position or define ourselves or others (based on apparently universal and essential signs, separated and fragmented groups, disciplines and approaches). Nor reduce the performances to set actors and limited connections, instead, we make visible the invisible processes of our shared cultural experiences and practices (Latour 2010a; Mol and Law 2004; Law and Moser 2012). Descriptions are the possibilities for negotiation and thus transformation, as there is nothing we could not touch upon, imagine or describe. We share the witnessing of performances by moving away from binaries of spectators and performers to doing, connecting and performing through tensions, perplexities and disputes developing means of negotiations. Yet, many of the descriptions also reveal that neither the spectators nor the performers really want to know how a performance came about, how actors connected, and what possibilities might be afforded. The danger for humans is that if there is nothing left to

hide behind, after a performance has evoked and provoked a range of possibilities, then surprise and the unexpected can hurt. Ironically, it seems unsurprising that most of the time we fail to see what is right before our eyes and adopt traditional categories of medical and social knowhow. It is dangerous to reveal and render visible the makings of appearances since they hide and mask the fact that there is no real and objective hidden dis/ability behind them (Baudrillard 1994 p4, Latour 1999b p3) and as such cannot hide no longer as we become responsible for the realities of hidden dis/ability we negotiate.

I argue, however, everyone can benefit from this new way of seeing hidden dis/ability that the 6D practice offers, as it allows anyone to become singular and non-identical. "Once this obsessive fear of the unreality of history, in the sudden collapse of time and the real, has been warded off, everything again becomes real and meaningful" (Baudrillard 2001 p192). From this position we can reverse and re-assemble hidden dis/ability. Hidden dis/ability now is not about being a hero or a victim but about complexity, the beautiful hidden. I offer this type of curiosity as an alternative way of seeing hidden dis/ability, not one truth and one reality but many truths and many realities. In everyday life, we have the mundane, the ordinary and the specific where hidden dis/ability as a universal and essential thing is now dislocated, transformed and as such, dissolved. The 6D practice restructures, reinterprets, retells, destabilises, dislocates, protests the notion of the real, including our social norms and medical practices. It shows up possibilities to reconsider the function and value of our practices and to fill the public and private space with arts. The scene is not pre-existing any longer and the audience is not detached, but they compose together with the performer moments of possibilities for transformation. The 6D practice lets us embrace the performances with all their makings to debate, contemplate and constantly re-evaluate where we are and what future we wish to negotiate.

I conclude, our focus cannot be anything else but to select, order and notice the range of heterogeneous actors travelling from various places and times. Best done in diverse scale and shape to appreciate how connections offer capacities to form and perform, produce and reproduce but also solve and dissolve hidden dis/ability. By its nature, the process of description, the act of noticing, selecting and ordering of the 6D practice is imperfect and battered by multiple performers, spectators and scenes. Therefore, the question must not be which description reflects an ideal and perfect performance of hidden dis/ability, but how we can connect and reappraise the diverse realities they bring to light. I argue the people with hidden dis/ability do not need to be protected, managed and liberated, ordered, controlled and predicted. Not all the time, not at all the scenes and not because they do not know what they do, what is best for them or what they want. If we explore how the various realities are composed, we can work with them to ensure no one is left behind, if this is what society wishes to do.

9.3. The main analytical points and the contributions of the thesis

The notion of origin applied in this thesis replicates the idea that people with hidden dis/ability are *(dis)positioned* unto typical health and social care signs. It emphasises how signification has overdriven or overwritten the performance. This makes it difficult to know the 'real' world. I theorised that If the origin was no longer a precursor of the 'real' performance, then new regimes could emerge to compensate. I explored how we have entered a phantasmic escalation and hyper-specialisation of signs and practices of hidden dis/ability (categories, professions, approaches, policies, organisations, campaigns) which helps hide the gaps in our knowledge. That the images of hidden dis/ability have no connection with the real, the actual everyday performances, thus neither the medical nor the social approaches can provide sound theories.

My analysis showed how the everyday performances, the mundane, the ordinary and the specific can be explored in a novel way, as live performance art. As immediate, diverse and uninhibited affects of the performers, spectators and scenes making hidden dis/ability. Spectatorship being the significant *dimension* of the performances, as connections are realised through the capacity to affect and be affected. I continued to evaluate how the proliferation of medical and social care signs eventually consumes practice. I referred to the crisis of signs, as we are now left asking what 'ability' is just as much as what 'disability' is. I analysed how *details* of the performances let us see that the universalising tendency of health and social care signals is mostly about maintaining an order of form and function and neglects the significations and associations of signs and things.

I developed a new analytic and theoretical way of seeing how the everyday performances of hidden dis/ability are associations and significations of things and signs composing capacities, as hidden dis/ability is transient as well as transformative. Their value and function are relative and *dynamic* rather than universal and foundational, as posited in most mainstream medical and social sciences. There are uncertain actors, unexpected connections, and alternative actions. I theorised how the surprise of instability, potentiality and actuality *dislocate* assumptions and long-held connections. This alternative way of seeing reveals *descriptions* where hidden dis/ability is in a constant state of transformation emphasising just how 'unreal' the disability/ability binary is. Hidden dis/ability in everyday performance is audience-driven and therefore, signal driven.

From the analysis and the application of the 6D practice to the everyday performances of hidden dis/ability I conclude hidden dis/ability is anything but an independent reality regardless of the framework around it. My thesis offers this unconventional way of seeing the performances in everyday life and how valued signs and things of hidden dis/ability are produced, represented and thus consumed. That is, performances are constantly formed

and performed (perForm), solved and dissolved (disSolve), produced and reproduced (reProduce) by diverse human and non-human actors in webs of connections. Hidden dis/ability is complex. Complexity is the beautiful hidden rendered visible by the everyday performances.

9.3.1. Original contributions of the thesis

- 1) I have applied a novel theoretical and methodological approach to old concepts and a set of practices in hidden dis/ability. As I argued in the literature review, the simultaneous application of contemporary theorists, in particular, Latour's and Baudrillard's philosophy and the tenets of Actor-Network-Theory to studying the everyday performances of hidden dis/ability could add to our understanding of hidden dis/ability. I believe by moving away from a political, identity, and a moral positioning of hidden dis/ability (as these are all effects) to the PerFormed, DisSolved and ReProduced is an original contribution to the present dominant positioning of dis/ability.

- 2) I noticed in the literature that the exploration of hidden dis/ability with the tools of art and material-semiotics was very limited. The vast amount of literature favoured approaches of linearity, returning to and or starting from existing evidence, focusing on a handful of actors, and conducting one-off projects mostly at well-defined contexts with the involvement of distinct conditions. I approached hidden dis/ability as performance art offering novel ways of working with the various conditions as they penetrate boundaries of the performer, the spectator and the scene with all the material, discursive and immaterial signs, their associations and significations. I argue that working with many conditions in changing and fluid contexts shows the complexity of the performances as they happen and this is an original contribution to the present literature.

3) I used an original design, Actor-Network-Ethnography, to collect data. Even more so, I developed the novel 6D material-semiotic network practice based on those above analytical and theoretical considerations to analyse the performances (data). I argued in the literature review how complexity and network thinking applied to social phenomena using insights from Baudrillard and Latour had a lot to offer to the disability field that has hardly been realised yet. I have contributed to knowledge with the 6D practice that incorporates these considerations. The 6D practice (details, dimensions, dynamics, dispositions, dislocations, descriptions) offers a new way of seeing and working with hidden dis/ability. I offer four specific contributions of 6D practice to knowledge:

- i. The 6D practice moves away from looking at the essentials and the universals of what it is to be dis/abled (categories, evidence, facts, health and social care signs, also highlighted in the literature as potential limitations) towards the mundane, the ordinary and the specific. Whilst there are works exploring the everyday performances, I add to this knowledge by taking into account the realms of all the actors and their connective networks to explore hidden dis/ability in terms of a temporary set of possibilities for transformation.
- ii. I offer a new way of seeing to reverse and re-assemble universal, essential, separated and fragmented notions of hidden dis/ability. The performances are not about being analysed as 'real' or 'unreal' with the 6D practice, but rather, how associations and significations compose, amongst other taxonomies and domains, surprising acts, unstable actors and unexpected connections revealing contradictions (a novel reflexive way to discuss our values, approaches and expectations). It works when analysing all conditions, carers, professionals, objects and concepts. There are no victims, heroes, disabled and non-disabled, just performances that offer alternative potentials.

- iii. The 6D practice explores performances with all their makings, renderings and assemblages where the spectators, the performers and the scene are active dynamics, descriptors, dispositions, details and other markers of hidden dis/ability. If we are all involved in the composition of hidden dis/ability, we are all responsible for what we mean by apposite care, services and inclusion. I offer this alternative way of negotiating, noticing and accounting for. The 6D practice makes all the actors, including us the researchers, the audience visibly responsible for the futures we consume. I questioned in the literature how certain actors seem to remain stable even in the contemporary methodologies. The 6D practice challenges this, as here, nothing is pre-given.

- iv. The 6D practice reverses and re-assembles hidden dis/ability to be in a constant state of transformation. It composes capacities for shared cultural experiences and practices as a means to provide apposite care, services and inclusion. It dismantles long-held ideas of working with separated conditions and the binaries of medical and social approaches. One of the main limitations I addressed in the literature review has been answered in an original way. The 6D practice opens up possibilities to see exciting and vibrant acts and discourses of hidden dis/ability rather than being something different, fragmented and separated from the rest.

In summary, I offer 10 points on how the 6D practice can be an alternative analytical model for practitioners and change the way we work. The 10 key characteristics together are also what makes the 6D differ from other models.

1. 6D is detail-oriented, making practitioners attentive to the smallest and mundane contributing factors of events. Details are important to achieve small successes for

disabled people as practitioners focus on what is happening in a situation and what changes are possible.

2. 6D observes every (f)actor as much as possible, making practitioners attentive to the context, including the objects, the non-humans, and the people (what they say, but also what they dream about or bring with them into the event). Exploring all the possible (f)actors like the objects are important as they modify our experiences including what we say, when and how. So, it is possible that practitioners need to change the environment, or the connections between two objects and not the person with a disability.
3. 6D focuses on the processes, helping practitioners move away from static biases, facts, assumptions, and past events, explore what is happening in the present and see what is possible in the future. This approach can be critical in disability, where practitioners tend to react to present events based on past happenings, usually in the forms of deficits, taking away from the clients the possibilities to do something differently. Many people with disability mature and develop specific skills later in life, and practitioners need to give them opportunities repeatedly to try something new.
4. 6D is solution-focused, helping practitioners have conversations about what can be done and how rather than dwelling on what happened or what cannot be changed. Although 6D helps understand the past connections and present constraints, too but only as much as it is necessary to explore present pragmatic steps.
5. 6D works with connectivity and networks as it does not aim to find one cause but understand how the relationship between things and people lead to events and can offer solutions. The life of disabled people tends to be complex and entangled rather than straight and linear.
6. 6D focuses on what is significant to the people and how people compose their world (always considering the role of the objects and other factors) rather than what is true. This approach makes practitioners attentive to the myriad ways of living and seeing.

This also means that a disabled person's view on disability is neither better nor worse than someone else's opinion. They are just different standpoints, and we need to learn from each other.

7. It follows, 6D helps practitioners negotiate differences when they happen as it starts with the assumptions that we are all experts. Our many worlds and beliefs can be equally correct with and without disability or from various disciplines.
8. 6D distributes responsibility as we are all connected with each other and the world. We all have a role to play, and we all affect events, so we must work collectively to find solutions and move things forward. This approach is a move away from a blame culture promoting innovation, positive risk-taking and learning.
9. 6D is transdisciplinary as it takes that all disciplines and practitioners are equally important, and we must use each other's knowledge for the benefit of disabled people.
10. 6D highlights the temporal and shifting nature of all events giving practitioners and people hopes and dreams as it means change is possible. This approach can be critical in disability, because some practitioners tend to think that if someone has a disability, s/he is disabled all the time, affecting every activity and area of life.

9.3.2. The potential application of the 6D practice

The 6D material-semiotic network practice I developed from this thesis aimed not to reactivate traditional positioning, functions and values. Instead, it aimed to consider unexpected actors, unstable connections, and potential capacities. It turns our attention towards the performer, the spectator and the scene together to explore details, dimensions, dynamics, dispositions and dislocations of performances composing descriptions for transformation. This way, the 6D practice is a novel way to move away from binaries, separation and fragmentation to offer alternative ways of seeing how material, semiotic and

discursive relationality compose performances. I offer a few practical examples of how professionals, researchers and people with and without hidden dis/ability can apply the 6D practice.

1. The 6D practice makes visible how actors travel into the performances, form relations and achieve stable and durable connections as well as how such associations can be transformed. In other words, it explores orderliness and disruption, unity and division simultaneously to reveal alternative solutions. For example, the awkward questions, comments and one-liners of my participants composed unexpected performances and sometimes resulted in laughter, other times in argument, whispering or annoyance. The presence of the categories often positioned other actors in the performances. However, the diagnosis *per se* has not provided any guidance in terms of what capacity to expect. The unpredictability of the performances (and the reactions of the spectators) was similar when the diagnosis did not visibly enter the performance. The 6D practice brings to the front the dynamics of the actors and the dimensions of the spectators. It reveals how they together compose capacities and ultimately multiple effects. This way, we can see more opportunities to make a difference as suddenly the diagnosis is not the only actor acting and affecting.

In short, instead of jumping to conclusions that an event like shouting is an effect of someone's disability because we know that the person has a diagnosis of autism, for example, we explore 1) what are the many (f)actors present (as many objects, people and abstractions as possible), 2) how they connect and affect each other including the person whilst 3) we also consider our role including assumptions, past events and values. These three points together can help recognise that shouting might be an expression of autism but might be a sign of several other things like being in pain, enjoying the moment or asking for something by a person who speaks no English. This

approach requires an understanding of how the 6D works rather than applying all the Ds individually as a framework.

2. To reduce a person with hidden dis/ability to an objective 'reality', to universal and essential signs is to order, control and predict. These predefined categories and other health and social care signifiers composed in advance (regardless of whether they are a positive and empowering 'reality' or a negative and stigmatising 'reality') limit the opportunities in everyday performances. The 6D practice offers a different approach. For example, in a hospital ward, there are actors in clanking machines, pain, patients, smells, fear of dying, jargon, uniforms, restricted movement, medications, loneliness, white walls and loud noises. In the community, in the home, we have furniture, appliances, postmen, kettle, soup, memories, steps, neighbours. On the bus, we have a driver, tickets, passengers, road work, routes, smells and sunshine. We have beauty, confusion, wondering and the soon forgotten, but not pathological individuals and categories. At present, most practices promote the idea that someone with dementia or with an intellectual disability being confused in a shop requiring similar attention represent two distinct performances, thus attracting different training, campaigns and support. Such a system maintains the promise that actors, like the inability to sustain focus or memory problems, must be a permanent disfunction and as such be essential, objective, fixed and belong to one network only regardless how they connect with actors at a specific scene (time and space).

In short, another strength of 6D practice is moving away from disability and category-specific solutions and actions. 6D practice asks practitioners to consider the event and creatively explore both the event and the possible solution. Practitioners are allowed and encouraged to think out of the box, for example:

- how we can develop training on recognising pain for all people who have difficulty communicating pain
- provide anyone with support in completing complex health or job forms
- support people travelling on public transport who find such activity stressful
- develop tools so people can do the shopping for themselves
- have stickers on a hospital ward linked to compromised memory

as opposed to condition-specific approaches like dementia stickers, autism training, depression support group, and intellectual disability hospital passport. This has the advantage of focusing on events people experience and the solutions emerging from the same event rather than disability and the categories. This approach requires some understanding of what the 6D stand for but still will not be an application of the Ds as a framework.

3. The previous point leads to the third practical contribution for professionals, researchers and people with and without hidden dis/ability. The 6D practice highlights how multiple actors compose capacities for shared cultural experiences and practices. My argument and the aim of the 6D practice is not to lump together the various conditions in every area of life, but to turn our attention towards the opportunities of everyday performances. When we do not start from separated terms and groups, from normalcy or the different hidden dis/abilities, but from the performances, we notice more opportunities in the form of capacity. Why would be a piece of material on the foul line (referring to Peter's bowling) operate as of does, defying the logic of the category? Such an actor composes multiple capacities through dynamics and shifting connections. There is no direct link between who are the actors and what will be the beneficiary at the end as dynamics compose diverse capacities.

In short, 6D can be particularly beneficial as practitioners remain open and creative to find solutions by learning from each other and the various disabilities. The paintings of Esther (a young lady who has severe mental health issues, mostly depression and self-harm related to an abusive childhood) expressed various emotions that she found hard to verbalise. I asked permission to distribute the cards that come in a paper box. These individual cards were appreciated by many people, including an autism mentor who uses them to help her autistic clients express themselves. Rather than working with separated groups and people based on the medical categories, 6D allows practitioners to create broader opportunities, share best examples, and work collaboratively. It promotes shared practices and experiences. This approach requires some understanding of what the 6D stands for but still will not be an application of the Ds as a framework.

4. Whilst opportunities are key to transformation, we also need to focus on actors that have fixed and permanent connections as they can limit the performances. The 6D practice can reveal such actors and 1) how they have been composed, 2) how they produce affects, 3) how they position other actors and 4) what capacities they prefer. For example, it helps understand how legislation (Mental Capacity Act, Equality Act, Autism Act) or narratives (Peter's rejection of autism, Ethical Committee correspondence, benefits forms) operate and affect the research, the performance or our experiences. This can be significant to see what opportunities are more likely to be performed. I will briefly introduce how the 6D practice can be used to explore such actor-networks.

a) Ordering – the number of actors composing an actor-network, their connections, the size of their network, the length of time and effort made to compose them are a good indication of how ordered they are. For example, categorisation has been

composed, adjusted and maintained over 120 years. Thousands of professionals, advocates and 'disabled' people have contributed to the making of the categories together with thousands of tests, research and other documents; meetings, media events and narratives. Most of them bring other actors and *details* into the composition and maintenance.

- b) Connectivity – the number of connections an actor-network has with other actors (and the embedding network) are usually a good indicator of how stable they are. Stable and durable actor-networks tend to connect with more than one network, mutually strengthening each other, as one existence depends on the other. Expert spectators like psychiatrists, psychologists, social workers but also my participants are just some of the human actors connected to the categories. I could list here many dimensions of non-human actors like research, policies, NHS guidance; manifestos, awareness days and Twitter campaigns; diagnostic manuals, NGOs and special symbols. It is a huge task to map all such *dimensions*.
- c) Unification – the more that direct actor-networks are related to hidden dis/ability, the more they unite by bringing together actors from various times and places. The categories of the conditions are directly related to hidden dis/ability, whilst others, a care file, might have a less direct relation with hidden dis/ability as they have connections with other actors, too (used in diverse context). Psychiatrists, social workers, the politics of benefit, an autism group are just some examples that appear to form separated networks with well-defined aims, yet, the details and dimensions of the categories unite them in the apparently universal signs of hidden dis/ability. Such unification appears to be more *dynamic* in limiting capacities than in enabling more flexible actors.

- d) Inseparability - the flexibility of the connections between actors composing the actor-networks are important considerations. Rigid and fixed connections make actors more manageable and predictable (possibly due to appearance) as they are less changeable and adaptable. For example, the connection between the different categories and adjoining networks determine the nature of signs that hardly anyone can change or modify. When occasionally they are altered, it is by a few privileged actors. If ADHD and Autism are mutually exclusive actors as they were up until the latest update (APA 2013), no connection can change such *dispositions*.
- e) Opportunities – if only one narrative of hidden dis/ability is offered, it is not because the categories are universal, essential or objective, but they are ordered, connected and united. Thus, exploring performances with the 6D practice extends the significance of opportunities for *dislocations*, providing *descriptions* of multiple realities of hidden dis/ability.

In short, this is one of the most prominent examples to show how the 6D can be applied as a model or framework using each 'D' and the definitions as reference points. One of the most important areas I can see the application of 6D is an alternative to traditional root-cause analysis, for example, in health care to understand errors or in social care to explore failed care provision. By examining the events through 6D practice, we can have a novel understanding of what happened. 6D is based on connectivity between many things (objects, people and abstracts) and does not try to identify one root and one cause. It avoids making one person responsible without considering the broader context. It focuses on creative solutions and learning for all. It works in a transdisciplinary way where all practitioners and clients are experts, and all objects, places and times can be significant influencing (f)actors.

5. Whilst most practitioners and researchers aspire to see hidden dis/ability beyond its limitations, such aspirations do not always translate into practice. The mainstream approach is that hidden dis/ability becomes visible when it substantially breaks with existing modes of handling the actors. I argue the 6D practice can show how these performances enact more dynamic and richer outcomes. The 6D practice unpacks what actions were performed and how, what roles actors played, and what capacities they composed to perform multiple realities. One could argue, Jane and Nick were oppressed when in the restaurant, when Lulu delivered her speech, or when Max used her power when reminding Zeke not to repeat the same thing over and over again. I dispute that either oppression or power acted here as independently existing actors. There are no central controllers, invisible hands and independent facts writing and narrating the performances, but only performances with their complex making. In all performances no passivity is possible. We are merged into the performance whether we ignore or respond, we become part of it and as such, take part in the composition.

In short, 6D attempts to liberate both practitioners and people with disability. We do not engage in debates about social and health, ableism and disabled, but collaboratively explores where we are and what is possible next. Hidden dis/ability like a drug error or a fight between parents are not purely the result of the body (biology) or the environment (culture) any longer, and not even a linear interaction between them but emergent effects of enacted and complex dynamics between many (f)actors (humans as well as objects). Practitioners focus on the processes, how disability or a drug error or a fight do, what they do, and what connections (between humans, objects and abstracts) shape them producing effects that are always temporary. It is significant to know (or at least believe) that even if we can find patterns in events and their creating (f)actors (noise is often a problem for autistic people, messy signatures often influence drug

errors and alcohol often participates in a fight between parents), they all remain temporary. Such an approach gives practitioners and their disabled clients hope, motivation, and confidence to find solutions and change things. Change in drug errors or fights between parents, or communication difficulty is possible only if the (f)actors and their connections can realistically change. This approach requires a good level of understanding of each D of the 6D practice and can work both as a framework or as a belief system.

9.3.3. Future work with the 6D practice

The 6D material-semiotic network practice is neither a beginning nor an end but an affect of this PhD thesis to compose capacities for new way of seeing hidden dis/ability in future post-doctoral activities. This thesis and the related research activities (Goldschmied Z 2018b; Goldschmied Z 2020) have been a promising journey to hypothesise that the 6D practice has the potential to be applied to diverse topics within and outside of hidden dis/ability and analyse various matters of concern in a novel way.

First, further research is needed to test, develop and fine-tune the 6D practice both within and outside of hidden dis/ability. Second, I aim to apply the 6D practice to diverse yet more specific issues to explore what alternative ways of seeing might be afforded. Developing training materials for hidden dis/ability related issues, designing job application forms for people with hidden dis/ability, offering a novel alternative to root cause analysis, exploring how signatures make forms authentic in large organisations or exploring the affects of tutor awareness sheets in higher education are a few examples of my current projects. Third, future research needs to evaluate the effects of tools and approaches like the 6D practice that focus on the ordinary, the mundane and the specific, the world-making activities of the participants as opposed to standardisation and unification. Fourth, I propose we need

further theoretical and practical explorations of the idea of surprise, abduction and the unexpected in everyday performances. In other words, the affects of moving between order and disorder to disrupt norms and conventions as opposed to rules and ordering and whether they lead to potentially better negotiations, performances and thus solutions. Fifth and last, I argue much more research is needed with the involvement of people with various hidden mental and cognitive dis/abilities rather than mirroring the separated categories in research to explore, evaluate and enhance the potential benefits of shared cultural experiences and practices.

9.4. Limitations

I started the methodology chapter discussing how this research was not about painting a true and objective picture of hidden dis/ability but aimed to do two things. First, I wished to draw attention to the difficulty of composing hidden dis/ability in the everyday performances and second, to advance discussions about how we negotiate the multiple realities of hidden dis/ability. Such an analytical and theoretical project brings certain advantages, but it also has its limitations. The limitations will be grouped together around three key issues. First, the limitations of the methodology, second, the limitations of the chosen philosophies and third, the limitations of how this research was carried out.

9.4.1. Limitations of Actor-Network-Ethnography

Traditionally research is assessed by concepts of transferability, reliability and validity (Denzin and Lincoln 2011; Robson and McCartan 2016). Reliability is connected to cause and effect concerns in the sense that other researchers should be able to replicate the study. Validity concerns how much I could control the external variables, whilst transferability inquires how well the findings can be applied to the population being studied. As Lecompte

and Goetz (1982), Mclaughin (1986), Anderson (2010) and Babbee (2013) amongst others highlight, studies carried out in the natural setting, such as this project, cannot be repeated. There is no internal validity in the sense that the conclusions drawn in this project are not deductive. Such studies are also short on external validity, as it cannot be generalised to all people with or without hidden dis/ability. Such a project is better evaluated by exploring how appropriate was the choice of methodology to answer the research questions, whether the design was coherent, the sampling and data analysis was appropriate and finally, if it was transparent how the outcomes were achieved.

This study aimed to show the everyday life of the participants with all its complexity, tensions and contradictions. In the methodology chapter, I discussed how Actor-Network-Ethnography did not wish to control anything *a priori*. It did not pre-select actors to order and notice only set effects. There are no certainties and facts. This project hypothesised that there was no such thing as a fixed, an objective and a permanent performance of hidden dis/ability in the natural setting. Therefore, the limitations of validity and transferability, the inability to control variables become its strengths. It suspends preconceptions about the nature of things to explore the participants' world-making activities. It follows, it is a limitation that such a study does not offer the exploration of frameworks, laws and rules but possibilities. What I have learnt from the participants cannot be generalised either or turned into universal recommendations to well-defined issues. Conversely, if Actor-Network-Ethnography and the 6D practice were applied to more specific issues and settings, where the scope is smaller, the scene is better-defined, and the actors are less accidental, variable and flexible, it would provide us with more explicit features, whilst at the same time still offering rich details and descriptions of the performances. In future studies, the 6D practice could be applied to better defined concerns, topics and activities that are based on more specific exclusion and inclusion criteria of the

participants and a more consistent approach to the observation of the performances including amongst other factors the scene, time, and length of data collection.

9.4.2. Limitations of the theories applied

The underlying philosophical and empirical tools, Baudrillard's and Latour's philosophy and particularly the tenets of Actor-Network-Theory bring their limitations or rather a specific way of selecting, ordering and noticing actors and their connections to compose a particular outcome. The criticisms of Actor-Network-Theory, and of Latour's and Baudrillard's work is wide-ranging. Here, I will address the most debated limitations. Baudrillard is considered to be a speculative postmodernist who does not offer empirical evidence or solutions. Latour (1993), King (1998) and Sokal and Bricmont (1999) went as far as to say, his ideas are nonsense, nihilist and a sort of pataphysics dealing with the imaginary only. However, in recent decades these assertions have been challenged by Baudrillard scholars, such as Gane (1991), Genosko (1994), Pawlett (2007) and others. The main criticisms regarding Latour's work and Actor-Network-Theory is the question of agency that is traditionally the property of humans only (Cohen 1997; Bloor 1999; Vandenberghe 2002). Yet, Actor-Network-Theory treats everything at the same level of analysis apparently diminishing humans' central role and attributes, for example, free will, intentional actions and even knowledge.

It follows that neither theorists offer specific and fixed solutions to separated problems but aim to explore how they are composed, produced and consumed. Both theorists reject causation, as well as structures as existing independently and distinctively. Therefore, if the context is never the same, and performances are appearances only, it resists establishing universal patterns, rules and the privilege of our existing knowledge. Furthermore, they are

often criticised for ignoring issues of race, power or oppression as they treat such concepts as effects of actors, significations and connections and not as causes. Moreover, they provide a predominantly narrative and descriptive solution, therefore, the researcher does not favour explanations or judgements but uncovers a range of issues and can end up describing complex connections and theoretical contemplations rather than giving specific answers.

It is the case that Actor-Network-Theory and Latour's and Baudrillard's work cannot offer linearity, permanency and cause-effect relationships. Therefore, any evaluative approaches that privilege such outcomes would find this study limited in this respect. Baudrillard (1994), Latour (1999c) and Law (2002) on the other hand argue, different approaches bring different realities to light, and they together can give us a better understanding of the complexity of hidden dis/ability. In other words, the inability to read and getting a letter would be one of the performances that do not necessarily result in hidden dis/ability, an observable, thus measurable and recordable change. However, it is often difficult to observe effects, the change in connectivity, so it is always possible that I missed recording an effect. Moreover, if an effect is not observable, Actor-Network-Theory will not provide any explanation but describe the event, that can be viewed as a limitation if the aim is to provide answers.

9.4.3. Limitations of the study

There are a few limitations that I will address specific to this project. The researcher worked with a small number of participants, applied purposeful selection and observed performances in constantly shifting scenes often with random spectators. Even after selecting the key informants, there were no frameworks applied to decide what actor the researcher would follow or when to observe the performances. The various participants showed different aspects of their everyday life and not the same activities. Furthermore, this

research required enough time, resources and effort not only from the researcher but also the participants. Therefore, the outcome is also influenced by the participants' varying degree of commitment. The number of case studies investigated remains small. Moreover, there can be issues with data collection and recording, how representative my notes are, as there was no second researcher involved in the study.

It also needs to be noted that the literature review could not possibly examine all papers published on the topic but aimed to include a variety of relevant and well-known studies. Therefore, it is possible that significant studies were missed. Furthermore, this study used two theorists, Baudrillard and Latour, together for the first time in hidden dis/ability studies (as far as the author can tell), and no attempt was made to combine the theoretical concepts from both in one single interpretation. Thus, it remains open for exploration of how such simultaneous applications work together. Moreover, this is the first time that the novel 6D material-semiotic network practice has been developed and applied, that brings the potential of intellectual bias to this study. It follows, this study might also be criticised for how Actor-Network-Theory, the ideas of Baudrillard and Latour were used and modified (Law 2007; Venturini and Guido 2012).

Some of these concerns relate to the notion of objectivity and credibility as addressed by Cutcliffe and Mckenna (1999), Patton (1999) and Creswell and Creswell (2018). However, such validation criteria assume that objective and subjective, facts and myth are separate, real and exist independently. In Actor-Network-Ethnography and the 6D practice, the researcher is always part of the process and influences the project as a researcher independent position is not possible. It cannot be said then that this research would reveal itself the same way if someone else was present or it was different participants, or it was a different scene. Conversely, good documentation is important to provide a range of believability that can be achieved by various means that this project aimed to achieve with

tools such as diaries, recordings, the researcher qualifications and experience. Moreover, it aimed to show transparency and openness about how the findings were composed. Triangulation is often proposed to enhance believability as posited as early as 1970 by Denzin (1970), then by Erzberger and colleagues (1985) and Prein (1997).

This study aimed to increase believability by the following actions. *First*, data was collected from various sources that included observations, artefacts, spontaneous conversations, semi-structured interviews and focus groups. Whilst it makes the analysis more complex, data from various sources provide a wider exploration of the performances. *Second*, the study arranged observations at various places, days and times of the week. Such attempts provide more data to show that it achieved what it set out to investigate. *Third*, data were shared not only with the person who was part of the process but with other participants. Such cross-member checking supports the data, whilst bring further controversies into the forefront. *Fourth*, the study aimed to involve participants with various conditions, age, gender and social circumstances. This is a limitation in the sense that without a well-defined population, transferability becomes unachievable. Equally, it can show how hidden dis/ability is not a fixed and an objective thing in the everyday performances, but it is perFormed, disSolved and rePoduced by diverse actors in webs of connections thus promoting shared cultural experiences and practices.

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