

# When whiteness becomes a problem

## (Un)doing differences in the case of Down's Syndrome

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*Down Syndrome is typically considered to be a genetic disease, that is, an abnormality in the chromosomal count. In this paper, however, I will focus on other practices of Down's syndrome. First, I will examine a case of post-natal care, to show how race and disability are made and unmade in relation to each another. I will argue that the 'body of concern' is not so much a somatic individual body as it is a relational body. Differences are not entities "out there" that can be added to our (diagnostic) methods "in here". Instead, I argue that they are effects that come about in specific practices. The second part of the paper analyzes the peculiar case of the Down Doll and focuses on how its body assumes different forms and roles in different social settings. The case will particularly demonstrate how medical 'facts', materialized in the body of a doll, perform a variety of social tasks in different contexts. With the (help of the) doll, Down syndrome becomes not only a medical but also a social 'fact'. In addition, the "medical" (or the biological) itself does not remain unaffected but is constantly changing as the doll moves through different social settings.*

*[Body, relationality, disability, race, Down Doll]*

### How bodies matter

One way to go beyond both the social as well as the biomedical model of disability is to attend to the body itself. The social model has typically located disability in society, whereas the biomedical model has turned to processes in the somatic body to explain the nature of disability. Making the body central as a site for critical reflection, disability scholars are able to reclaim the body from the medical profession (e.g. Hansen & Philo 2007). A similar turn to the body has been taking place within gender studies and feminist science studies. Throughout the seventies and eighties the by now well-known distinction between sex and gender proved to be a very productive analytical tool for feminist politics.<sup>1</sup> Feminists have focused on the concept of gender to argue that the alleged natural differences between men and women are not so much the result of biology but, rather, the effect of social, psychological, cultural, political

or economic hierarchies. In this research gender became the preferred category and sex (and therewith the biological and the body itself) was trivialized.<sup>2</sup> However, from the eighties onwards scholars such as Donna Haraway (1985, 1988) and Annemarie Mol (1985) have argued that the biological body is much too important to leave to biologists and physicians, and much too complex to be taken for granted. According to them, the body requires thorough examination and deserves our attention. In the nineties, we have witnessed the proliferation of gender research focusing on the body, especially on the body in medical practices or in the life sciences. However, there is a tendency to view the biological body as a singular *natural* entity. An entity to be added up to our sophisticated rendering of the *cultural*. The problem with this 'return to nature' (or to *the* body for that matter) is that it suggests that we have an immediate access to the natural, the biological or the body. In this way, such approaches contribute to a reification of the body. A body whose functions are ultimately understood when these can be linked to the genes, the hormones, the brain, etc. This conception of the body is not much different than that of the biomedical reductionist perspective. In this article I want to suggest that the often-used slogan to 'bring the body back in' does not mean embracing a naturalized body which is subsequently acknowledged a role in practice, whether in terms of experience or agency. In order to prevent ourselves from reifying the body as a natural entity it is vital not to view bodies as given entities, but rather as configurations that are made and unmade within specific practices. How bodies are made and unmade is normatively invested. For example, bodies are not by themselves gendered, racialized, ill or aesthetically attractive. But they can be enacted as either (or all) of these in specific practices (Mol 2002; M'charek 2010).<sup>3</sup>

To attend to the body in disability studies is to move beyond the persistent divide between the medical practice and the social. Medical practices are generally represented as involved in curing a reductionist version of the body that *suffers* from a disease, whereas the body that is cared for in social practices is represented as a holistic entity that *experiences* illness, joy, and a variety of other emotions. In reality the 'clinic' is not an isolated elsewhere. Medical knowledge and technology are not merely located in hospital and clinics but also leave these locations and become part of the ways in which we view health and illness in society. Conversely, social knowledge about the conditions of patients, their narrative about the ailments, as well as their experiences of disease enter the clinic and contribute to the understanding of the diseased patient and her body. Thus the clinic is not the domain of scientific discovery of a disease in the body that functions in isolation of the rest of society. Instead, it produces novel configurations of the body, based on a variety of knowledges (e.g. Foucault 1973).

Admittedly, the clinic and its varied modes of ordering society in terms of normality and abnormality and health and illness occupies a central and dominant place in Western societies. In Foucault's view, the clinic, with its technologies of making normality and abnormality contributes in a significant way to the order of society. This does not imply that 'doctors' are in charge of the knowledge produced or of the traffic of knowledges from the clinic to society and the other way around. This work is better conceived of as the achievement of patients and patient collectives (Pols 2011; Epstein

1996; Callon & Rabiharisoa 2003), internet sites, soap operas (Davin 2003), or every day medical technologies that mediate between medical practice and the everyday world (M'charek & Willems 2005). This means, first, that medical specialists have no privileged access to the human body. Second, it means that medical knowledge, concepts, and technologies have become part and parcel of the ways in which we know our bodies. Medical knowledge and technologies are as much part of who we are as other ways of knowing ourselves and our bodies.

In what follows I will present two rather different cases. I will focus, first of all, on how different versions of the body are enacted in the process of diagnosing one person in the clinic, and, second, on how the body of a doll comes to play different roles in different social settings, thereby changing the nature of its body. I present the first case in conversation with notions of the biological body, which have been outlined above, and focus on how disability and race are made and unmade in medical practices. This case makes clear, first, that differences (race or disease) do not inhere in bodies but are enacted within specific practices, or, more specifically, as relations between different bodies, and, second, that bodies are not static objects and that their boundaries are not given *a priori*, in particular that, they often go well beyond the boundaries of the somatic body. In the second case I will analyse the bodies of the so-called Down Doll. One could say that this doll is the anti-thesis of the white Barbie doll that has dominated the social imaginary of dolls and presenting a specific version of the abled-female-body since the 1950s (Urla & Swedlund 1995). At first glance the doll seem to be a materialisation of the medical gaze, but a further examination will help us to see how the doll takes up different roles and identities that go beyond purely medical or social perspectives. The doll makes clear that medical facts are not fixed and finished when they leave the clinic. They are changed in social interaction.

### **When whiteness becomes a problem: A case of neo-natal care**

How to talk about differences and the body? How to take differences, such as race or disability, seriously without locking them up in the body, without transforming them into unchangeable categories? And what are differences made to be in practice? In what follows, I will present an example taken from everyday life to engage with these questions. This case is an auto-ethnography. Since it based on ethnographic material that is taken from everyday life it is important to underline that this story is not meant to be read as an authentic experience. My interest is not to present authentic stories to which some readers could relate and other not. Nor am I claiming a privileged access to the practices that I describe. Instead, I am interested in the kind of questions that these stories might help us to pose. They are mobilised as objects of study and made relevant for the specific theme of this paper.

#### *On making and unmaking differences*

On a sunny Sunday morning in March Aziza was born: a healthy girl with a fair skin, big blue eyes and lots of beautiful dark hair. But this is her mother talking. Soon after her

birth, two days after her birth to be precise, a problem arose. Actually, I had a question. A knowledge question, one could say. Because of Aziza's fair (almost transparent) skin, whenever she was breastfed she tended to turn bluish around her mouth. I grew curious about what was going on. Given that the Dutch health care system provides eight days of postnatal care at home (kraamzorg), I discussed it with the 'nurse' and asked her whether she knew what it meant physiologically. "Yeah, that's called 'marmieren [marbling]', we often see that in newborns. I don't know much about the medical details. But I will call the midwife later and ask her."

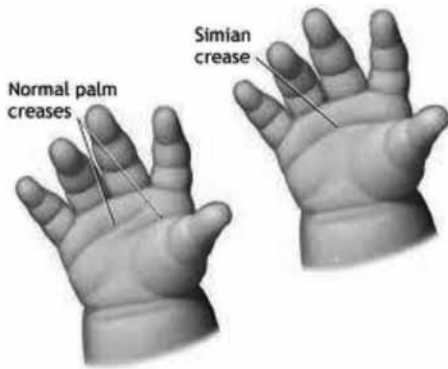
The midwife, however, did not see my question as a knowledge question or as a 'good mother's' quest for information, posed only because she was interested in her child. Rather she translated it into a medical question; a question of a worried mother asking for medical help. At that moment, Aziza had been fed three times, so the bluishness obviously had shown up three times as well. Alarmed by this, the midwife decided to confer with a paediatric physician at the hospital, who wanted to see Aziza.

Because Aziza's father could not be present, a girlfriend accompanied me to the hospital. There, we were immediately referred to the neonatal incubator ward. I was amazed at the heavy protocol that was executed. Within a minute, the two-days-old Aziza, was connected to various measuring devices and her heartbeat, oxygen saturation, and breathing frequencies were displayed on a monitor. At the ward, the knowledge question was thoroughly medicalised and Aziza had become an urgent case.

Despite the fact that her measurements (on the monitor) were said to be exemplarily, the staff wanted to keep Aziza overnight. Upon me insisting on seeing a doctor, she told me that it was the hospital's protocol to keep recently born infants for a 24 hour monitoring period. "But to what aim? What was there to be diagnosed?" When running out of arguments the doctor suggested that Aziza might as well have holes in her heart and that they wanted to rule that out. Although not convinced by their diagnosis, I complied and stayed the night in the hospital.

In the evening Aziza's father came to visit. He stayed a while and talked to the nurse who was working the night shift. The next day the nurse recounted the nice conversation she had with my husband to me. "He is very kind. He told me a bit about his family in Germany. And apparently they are all fair-skinned," she said.

That morning, all the worries and the atmosphere of emergency of the day before seemed to have faded away. Aziza had become an exemplary baby: healthy, strong and communicative. While Aziza was being weighed just before leaving the hospital, I asked the doctor to explain to me their worries of the day before. "What did you suspect?", I asked. "Well," the doctor replied, "because she is so relaxed... her muscles..., we worried about her having this syndrome. What was it called again?" "What do you mean?" I said, a kind of muscle disease." "Oh no, no," she replied, "You should not worry. I mean this syndrome. Ah, yeah, Down's syndrome." I was pretty surprised, and recalled the rhetorical questions or remarks of the day before: about how relaxed Aziza was while sleeping, her pale complexion, her swallowing problems, and, not to forget, 'the holes in her heart'.<sup>4</sup> "Oh," I replied, "and why were you suspecting Down syndrome?" The doctor opened Aziza's hand palm and said: "Well, because of this. This is called the transverse 'palmar crease' [viervinger plooi]. It is a marker for Down, you know."



*Pathological and normal whiteness*

2% of the individuals who do not have Down's Syndrome. In this case the crease was initially silenced. Because, I want to suggest, it was linked to a series of differences that could, initially, not be stated explicitly. The palmer crease was linked to the pale skin colour of the new-born infant and to the darker complexion of her mother. These differences together produce Down's syndrome. In this context, given this coupling of differences, whiteness became pathologized. It referred to abnormalities hidden in the baby's body. It is the baby's father, specifically his skin colour, that helped to unmake these couplings and to bracket Down's syndrome. His colour de-pathologized that of his daughter. This episode indicates that race is not merely located in a person's body. In this case it was made within a set of relations between different bodies. A dark mother, a fair father, as well as an idea of Down's syndrome.

The fact that race, in this example skin colour, is not simply a characteristic of a person's body can be illustrated with the following example. In the Netherlands babies are required to take vitamin K and D during their first months. I was advised to give Aziza 10 drops of vitamin D daily. The prescription of Vitamin D however, reads as follows: 'Children aged 0-3 years, 5 drops a day. [...] children with very dark skin 10 drops a day'. It appears that this advice was not based on Aziza's skin colour but on that of her mother. So whereas her skin colour had become a problem in the hospital because it was too white and was seen as a potential marker of 'abnormalities' in her body, in the practice of vitamin intake her colour was interpreted as 'very dark'. Or, to be more precise, in this practice it was not her colour but that of her mother that was taken as a marker and evaluated as a risk for vitamin-D deficiency in Aziza's body. Both examples make clear that race can function as a diagnostic tool and thus helps to enact a disease or a disability. However, race does not necessarily materialize in an individual's body. Instead, it was in the very relations that were established between different bodies that race was enacted.

In the next section I will focus on how the body assumes different forms and roles in different social settings. The following case will demonstrate how so-called medical 'facts', materialized in the body of a doll, can perform a variety of social tasks. With the (help of the) doll Down syndrome is transformed from being a medical into

The excerpt above mobilizes various issues and invokes many questions. Here I will limit myself to the issue of Down's and how it was enacted with the help of the equally fluid categories of race.

It is clear from the ethnographic excerpt that the transverse palmer crease, a marker, came to stand for Down's syndrome. It reified Down's. Yet, even though, 45% of individuals with Down's Syndrome might have this specific crease, not all of them do. In addition, it can also be found in about

a social 'fact' as well. In addition, the "medical" itself does not remain unaffected but is constantly changed as the doll moves through a variety of social settings.

### **Beyond White Barbie: (Un)making difference with a doll**

A year or so ago, for reasons outlined above, I became interested in the diagnostic criteria for Down syndrome. In my search for scientific and clinical papers I came across the so-called Down Doll. On the internet, different versions of the doll are offered by different manufacturers.<sup>5</sup> The marketing material of the Down Doll suggests that it sells well in Europe and the US, but also in Australia and South America. The Down Doll is obviously part of an ongoing politics of diversity in dolls.<sup>6</sup> The days that the white doll, preferably Barbie, was dominating the shop windows seem behind us. Not only does Barbie nowadays have many 'Barbie-peers' with Asian or African appearances, but a whole range of non-white action heroes have entered the scene as well (Chin 1999). When Mattel, the producer of Barbie, launched Becky, a friend of Barbie who is in a wheelchair, supplies sold out in a fortnight, which indicates that there is a market for difference. Difference sells. Meanwhile a whole array of disability dolls have been developed. In addition to the Down Doll there is chemo-friend (hairless doll), a blind doll (with guide dog), and a deaf doll (with hearing aids), as well as dolls with walking frames, prosthetics limbs, etc. etc.

Many virtues have been ascribed to the Down Doll, just like its peers. It is a doll with agency. It contributes in the education of children and professionals, it is an advocate of emancipation and is thus involved in a politics of diversity. How does the doll do that? And what can we learn from it about the relationship between social and medical facts?

The Down Doll was designed as doll for children with Down syndrome to play with – a toy that reflects their own appearance.<sup>7</sup> Here is the advertisement blurb of one company: 'Down Syndrome Originals© are carefully designed to reflect the special beauty of babies with Down syndrome by faithfully representing the 13 features of Down syndrome'.<sup>8</sup> This quotation makes clear that the doll is able to mix social and medical elements of Down's quite easily. The doll obviously represents medical truth (faithfulness of the representation and exactness (13 features), but it is also about beauty (of babies). This indicates that what counts as medical is not confined to the clinic, and neither is it entirely separate from the social. In fact, both are embodied in one doll. It is this very entwinement of the social and the medical that I will be focusing on below.



*Doing diversity with the Down Doll*

As indicated above the doll plays a substantial role in diversity politics. It is viewed by manufacturers, parents and educators as an object that can help create public awareness about and to de-stigmatise Down Syndrome by its sheer presence at schools or Kindergartens. Since it is a 'disability correct doll' it is also deemed helpful in teaching children about their own bodies and medical students about the presentation of Down syndrome.<sup>9</sup> De Graaf, the chief executive of the Dutch Down Syndrome Association, put it as follows:

First we thought: is it really necessary ('moet dat nou')? [...] We were of the opinion that parents could better spend that money on books about Down syndrome. That way they could at least learn something about their kid. [...]

Meanwhile she has come to appreciate the doll and argues:

Teachers can, with the aid of the doll, prepare their [abled] pupils for the arrival of a new classmate with Down syndrome. And parents can, even better than on the basis of a book, explain to their children how and to what extent they differ from other children (Arends 1996).

The doll is not merely about presenting the medical interpretation of Down's at school. Instead, it helps teachers to educate children about differences and to generate acceptance for otherness. Acquainting children with the Down Doll familiarizes them with Down syndrome and thereby with children with Down's.<sup>10</sup> The doll thus helps to generate a tolerance for difference.

Education is closely related with emancipation. The role of emancipation played by the Down Doll is directed both towards the disabled person in terms of self-identity and building self-esteem, as well as towards society in terms of tolerance and the acceptance of difference. An advertisement text puts it as follows:

The idea behind the creation of this toy is to enable children with Down Syndrome to identify with a doll which reflects their image, thus helping them through play to strengthen and develop their self-esteem. [...] The doll has a very characteristic look, capable of arousing strong emotions, quite unlike the usual 'cute' dolls produced by the toy industry. It is hoped that, in time, it will help foster a better understanding and acceptance of handicapped people.<sup>11</sup>

The dolls' role in emancipating society takes two forms, one is about making room for disabled individuals, the other about representing diversity already present. The quote above illustrates the ideal of making room for differences. By 'arousing strong emotions' and provoking debate the doll can help produce understanding and acceptance of difference. This effect could be strengthened if the doll would be more widely available, making Down's syndrome more visible in everyday life. A mother of a daughter with Down's puts it as follows:

But I strongly feel that introducing the disability dolls into lots of places would make a huge difference to how society accepts those with Down's syndrome. If they were as used to seeing such dolls, perhaps people wouldn't be so shocked when they encounter a child like Victoria. Perhaps they wouldn't stare so much in the street (Fisher 2008).

As this quotation shows, Down's is different because it is not present in everyday life. By making the Down Doll part of everyday life it will normalize Down syndrome. As I have indicated above, the doll is not inanimate. It is an active and a moral agent. In addition to constituting a contribution to social change, the presence of the doll can also be seen to simply reflect the presence of people with Down's syndrome in society. The doll is a signifier of diversity. In the words of de Graaf:

Children with Down's syndrome are increasingly participating in regular public life [...]. They go to normal kindergartens and elementary schools, and are no longer kept separate from the rest of society. Why would you not make such a doll? They are part of this process (Arends 2006).

In this role, the doll is not so much an agent of 'active emancipation', but merely represents society and the differences in it. Since Down's is considered to be normal, the doll is only making visible what is already present. It is thus reflecting social diversity.

In the publications about the Down Doll, the emancipation of individuals with Down syndrome is strongly emphasised. One frequently encounters statements such as the following: 'Children with Down's syndrome didn't have anything to identify with. They carry around baby dolls that don't look anything like them. The children realise they are not the same and want something to identify with, like all children' (Fisher 2008). The extent to which the Down Doll represents the "real thing" is rather curious. The physical characteristics of the doll are often substantiated by sentences such as, 'Designed by a pediatrician, our dolls realistically reflect the following characteristics of Down Syndrome'.<sup>12</sup> Added to such qualifications is a list of physical traits that are found in individuals with Down's: head (flattened back of head), ears (small ears, set low on the head, with top folded over), eyes (almond shape eyes), mouth (small), tongue (protruding tongue), nose (flattened bridge across nose), fingers (shortened), inward curved pink, hands (small with horizontal crease in palm of hand), feet (smaller), toes (sandal gap, gap between first and second toe), shortened toes. Some dolls even have an incision on the chest to indicate open-heart surgery.

The list of markers incorporated in the Down Doll is impressive.<sup>13</sup> It is striking that the Down Doll is praised for its resemblance to children with Down's. This is remarkable because individuals with Down Syndrome do not carry all these markers. For example, the prevalence of heart failure among people with Down is 40%, that of the transverse (horizontal) palmar crease is 45%, fifth finger clinodactyly (curved pink) 60%, and folded ears 60%. This makes clear that, as a kind of amplified medical gaze, the Down Doll is made to represent *all* the externally visible traits of Down's at once. The doll is not a materialization of the visible traits of an existing individual,





but, on the contrary, it represents a group as a whole, a population since it lumps all epidemiological data together.

Even though the Down Doll did cause some controversy (Fisher 2008), it has proved to be a big hit in particular with parents and grandparents, but also with health care professionals. However, it appears that they do not all want the same doll. Especially parents seem to prefer dolls with the mouth shut, whereas health care professionals tend to choose dolls with a protruding tongue. The protruding tongue is generally viewed as a transient phase in babies, but it might also occur when children are tired or suffer from a cold. As a result of better health care children do not walk around with their tongue sticking out of their mouth. Yet the protruding tongue has become a dominant marker for Down's. In contrast to parents, health care professional seem to prefer the protruding tongue both for educational purposes and because 'it so typical' (Arends 2006).

These two versions of the doll, with the protruding tongue present or absent, hint at the presence of different realities of Down syndrome and at different kinds of knowledges that can be at stake in teaching and education. There is not just one reality of a disease that needs to be conveyed to the public. Thus far, we have already encountered two, but there many more. The doll thus sensitises us to the fact that the discourse of teaching and education might obscure differences by presenting a disease as a singular entity, just like the doll, which has all the physical markers of Down's.<sup>14</sup> In general, the focus on education in healthcare often contains biomedical definitions of disease, leaving little space for other kinds of knowledges.<sup>15</sup> The question is: how to keep the variety on board? How to cater for the various practices in which this teaching is supposed to be done? It is often argued that a public understanding of the 'science' will engender acceptance, both for people with disabilities, and for more research.<sup>16</sup> By assuming different roles and engaging in different strategies in diversity politics (emancipation, representation, education in and outside medical practice) the Down Doll, I want to suggest, invites us to examine critically a generalized discourse of education and teaching. While accepting that knowledge is vital for good care as well as for living together, it is equally important to give space to different kinds of knowledges and thus to different realities of disabilities (see Pols 2011).

By way of conclusion let me briefly ponder the role the Down Doll has played in the process of doing diversity. The doll was introduced with the purpose of presenting both the beauty of children with Down's and a faithful representation of the medical diagnosis of Down's. The latter did not reduce the doll to a mere medical presentation. As we have seen, the doll, just like real children with Down, goes to schools and kindergartens. There it is actively involved in undoing differences and normalizing Down's. The doll also acts as a role-model. By being there, it represents children with

Down's and provides them with a self-image in an everyday surroundings. The doll is obviously a social actor, therewith making Down's into a social fact.

But what about the medical facts? Given that the doll has become a materialization of all physical traits one could say that this is a reification of medical knowledge and an essentialization of Down's. However, ironically, it is the toy-makers and not medical professionals who are essentializing Down's. Whereas toy makers have produced a kind of absolute truth about Down's by lumping all the makers together, in medicine the physical characteristics of Down's are treated as probabilities. In addition, the presence and absence of the protruding tongue indicated that in the practice of health care practitioners, the doll was made to represent a handbook version of Down's (protruding tongue), whereas for parents it should represent Down's as a lived reality, one in which children are not going around with their tongue sticking out of their mouths.

## To conclude

I started this paper by discussing the body as a relational rather than a natural object. The first case I presented was an example of the complexities in which disability, race and bodies can be intertwined. It has shown that, in practices, various differences can be made and unmade while producing different realities (a child with Down's versus a child without Down's). As we have seen, neither Down's nor race is simply a marker located in the body. Instead, these come into being as part of different relationships between different bodies that were positioned in the space of the clinic. In this case these relations were not fixed and, consequently, they could be undone. To be sure, such relations can be made durable, e.g. when markers of difference would enter the medical record. In addition, it has become clear that bodies are not given facts either. They are *made* but also *real*. This case thus motivates us to not presume that we know what the body is. It invites us to ponder the question as to what is the body made to be, on this occasion and in this place (Mol 2002).

Whereas the first case focused on the relations that helped to enact specific versions of the body, the second case elucidated how bodies are changed as a consequence of the different work they performed in different social settings. The focus here was on how medical knowledge travels to enter social practices, and on how, in turn, that very knowledge changes. Not only bodies but also medical facts shift and change. The object of concern was the Down Doll. Even though the doll might be seen as a reification of an amplified (epidemiological) medical gaze, it plays an active role in education and emancipation by teaching children about differences, normalizing differences, as well as by representing diversity. The doll, a materialization of medical knowledge, has thus become a social agent and has, in effect, made Down syndrome a social matter. In addition, given that the doll was made to play various roles, the body and that what Down was made to be has changed several times as well. The body was thus not a natural entity to which some individuals have better access than others. Instead, it was *made* (and) *real*, in this case based on various different facts that could be clustered anew, again and again.

## Notes

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- 1 Sex came to stand for 'the biological' and gender for socio, cultural and economic differences (see, e.g. Haraway 1991a, for a critical reading).
- 2 One could say that sex thus became the not so relevant yet crucial foundation for gender. Or as Haraway has it: 'There is nothing about being 'female' that naturally binds women. There is not even such as state as 'being' female, itself a highly complex category constructed in contested sexual scientific discourses and other social practices' (1991b: 155).
- 3 For a phenomenological exploration on how bodies become white, see Ahmed (2007).
- 4 These are recurring foci in the anamnesis of babies who are suspected to have Down Syndrome and are often mentioned in medical literature; see for example Anonymous 1976. There it says: "The skin is pale, the cry weak, the Moro reflex depressed, and characteristically spontaneous movements is reduced" (Anonymous 1976: 835).
- 5 Companies such as, kidslikeme.co.uk and downcreations.com, or downsyndromedolls.com are leading in this market.
- 6 The Down Doll cannot be bought in regular toys stores but can be purchased on the internet through different commercial providers and sometimes via national associations for Down Syndrome who offer these as well.
- 7 The owners of two prominent companies that offer the Down Doll, each have a personal motivation as an origin story about how they came to the idea of making and selling the doll. Helga Parks refers to her late niece Angela, who had Down's and how 'her face light up' when she was given a Dow Doll to play with. Donna Moore felt a 'God-sent' drive to create a Down Doll when her eyesight was deteriorating and she could not continue working. In addition she wanted to give her friend Chris Burke (who played Corky, a boy with Down, in the TV-series Life Goes On), a nicer looking doll to play with.
- 8 <http://www.downcreations.com/doll-features.html>. Below I will go into these thirteen features of Down's.
- 9 The notion of 'disability correct doll' is inspired by the wonderful paper of Elizabeth Chin (1999) titled 'Ethnically correct dolls: Toying with the race industry'.
- 10 The doll also plays a role in teaching professionals including health care professionals. It is e.g. praised by clinicians for its their diagnostic accuracy, which makes it useful during courses or practical examination. For example some versions of the doll have bodies with bean-like stuffing resembling the low muscle tone characteristic of babies with Down's syndrome (Kennedy 2008).
- 11 <http://www.down-syndrome.de/down23e.html>.
- 12 <http://www.downsyndromedolls.com/>

- 13 They are very much consistent with those found in the medical literature although the latter is more elaborate information such as the functioning of the muscles (hypotonia), the Moro reflex, the fair and sensitive skin, diagnoses which are hard to represent in a doll.
- 14 A mother of a six year old daughter thus argues: 'Far from educating others about children with Down's syndrome, these dolls single children like Sarah out and stereotype them just because they have the condition (Fisher 2008)'.
- 15 This example does not stand by itself. For example the Vereniging Samenwerkende Ouderen Patiëntenorganisaties (VSOP, the Dutch association of patient organization) who are very engaged in teaching and educating the public, and the dominant take of genetic definitions of diseases.
- 16 Within the field of Science and Technologies Studies there is a whole branch, the so called Public Understanding of Science (PUS), devoted to research of science and technology in society focusing on education and acceptance.

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