

**Knowing bodies: Making sense of Intersex/DSD  
a decade post-consensus**

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## Summary

In this thesis, I address people's experiences of being born with a body that does not meet the normative definitions of male or female. The situation when sex characteristics develop in ways that do not conform to binary models is referred to as *intersex* or *disorders of sex development (DSD)*. This research has been done in the context of the 2006 medical consensus statement on intersex/DSD, and in the context of repeated human rights claims aiming to curtail medical interventions. Building on transformative and pragmatic theoretical understandings, I propose that what is conventionally considered to be *knowledge*, in this topic area, is built on diverse but specific *kinds of knowing*. I argue that the use of these kinds of knowing creates gaps in research and clinical practice that, in turn, has consequences for people's everyday lives and wellbeing. In this thesis, I empirically explore alternative kinds of knowing that address some of the gaps evident in the current literature.

Because language grounds knowing, we explored how laypeople with and without personal experience of intersex/DSD made sense of current terms and theories in the area in paper I. Ten focus groups consisting of people without personal experience were conducted, as well as semi-structured face-to-face interviews with 22 young people with personal experience and 33 parents of children with experience of intersex/DSD. Most participants across groups agreed that DSD was a problematic term. Many young people and parents preferred descriptive language and found intersex problematic. A majority of focus group participants, however, supported the term intersex. Focus groups preferred the psychological theory over the cultural theory to a significant degree. However, young people did not show any preferences for a specific theory. Results suggest that terms and theories should focus pragmatically on the everyday needs of those affected by such language and theorizing.

In paper II, we explored how 9 young women experienced receiving a diagnosis related to intersex/DSD, in order to better understand the processes that young people go through in developing knowing about their bodies. The analysis showed how participants' pre-diagnosis life experiences framed how medical information was perceived upon diagnosis. All participants had been informed about their condition before the study, but not all remembered the name of their diagnosis. Clinicians' strategies, such as normalizing patients' experiences, were usually perceived as supportive, but were not always considered helpful. After the diagnosis, participants worried about practical and philosophical issues that they had to deal with alone. This research highlighted the importance of clinicians taking an exploratory and individualized approach to the sensitive process of helping young adults develop knowing

about their embodiment.

In paper III we investigated knowing that goes beyond the medical information given by health professionals by exploring various kinds of knowing (Pols, 2013) that parents use when caring for their children with congenital adrenal hyperplasia (CAH, considered a DSD in some cases). Parents emphasized the importance of knowing what CAH is and what support their child needs, but also knowing how to cope and make sense of the new situation, how to attend to their child's medical needs as well as how to talk to their child. Parents also reported challenges related to connecting with their social network, experiences of emergency care, and how to help their children become independent. These challenges require knowing now, which means being able to respond appropriately to unique circumstances. These diverse challenges may moderate the effects of the diagnosis on children's wellbeing.

Finally, the objective of paper IV was to better understand the discursively available resources that parents and young people might draw on when they find themselves in a situation where information about intersex/DSD is presented. In this paper, we investigated how laypeople, without personal experience of intersex/DSD, made sense of and understood the clinical dilemmas of gender assignment, early genital surgery and full disclosure of medical information. By using the theoretical framework of ideological dilemmas (Billig, Condor, Edwards, & Gane, 1988), the analysis revealed how underlying understandings of how people are making sense of sex and gender, how they are dealing with difference and who is understood to be in a position of making decisions are all important, affecting how these dilemmas are approached and responded to. We conclude that engaging with dilemmas in this fashion is a more constructive strategy than favouring one principle over others.

The conclusions made in this thesis are that the specific experiences of having a certain body can be understood as *contributory knowing* that goes beyond what is presented in the medical, psychosocial or human rights literature in the topic area. This knowing involves developing language that works in everyday life (paper I), emotional and intellectual work that goes beyond medical information (paper II and III) as well as developing certain kinds of skills to handle everyday life (paper III). Finally, building on the insights from paper IV, I suggest that engaging with underlying understandings that shape lay and expert knowing might be more appropriate than highlighting certain principles in order to promote good care and human rights in the topic area. The pragmatic and flexible knowing of participants should inform future developments in research and health care, where an essential focus should be to continue to develop knowing that could be useful for people in their everyday life.

*Keywords: Intersex, Disorders of Sex Development, knowing, expertise, bodies of knowledge*

*To the participants who generously  
shared their experiences and knowing  
To Edith and to Åsa*



## List of papers

This thesis is based on the following original research papers:

### Paper I

Lundberg, T., Hegarty, P., & Roen, K. (Submitted). Making sense of "Intersex" and "DSD": Laypeople's understandings of terms and theories. *Submitted manuscript*.

### Paper II

Lundberg, T., Roen, K., Hirschberg, A. L., & Friséen, L. (2016). "It's part of me, not all of me": Young women's experiences of receiving a diagnosis related to diverse sex development. *Journal of Pediatric and Adolescent Gynecology*, 29(4), 338-343. doi: <http://dx.doi.org/10.1016/j.jpag.2015.11.009>

### Paper III

Lundberg, T., Lindström, A., Roen, K., & Hegarty, P. (2016). From knowing nothing to knowing what, how and now: Parents' experiences of caring for their children with congenital adrenal hyperplasia. *Journal of Pediatric Psychology*. Advance online publication. doi:10.1093/jpepsy/jsw001

### Paper IV

Lundberg, T., Dønåsen, I., Hegarty, P., & Roen, K. (Submitted). Moving forward with Intersex/DSD rights and care: Focusing on principles or engaging with dilemmas? *Submitted manuscript*.



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# 1. SETTING THE SCENE: Introducing this body of knowledge

*A body of knowledge [...] is a set of knowledge within a [...] subject area which is generally agreed as both essential and personally known* (G. R. Oliver, 2012, p. 3).

What you have in your hand is a *thesis*, meaning "a dissertation on a particular subject in which one has done original research" ("Thesis [Def. 3]," 2016). This thesis addresses some people's experiences of having physical sex characteristics that do not conform to binary models, called *intersex* by some, and *disorders of sex development*, or *DSD*, by others (Liao & Roen, 2014). This subject area is framed by medical understandings, currently represented by the 2006 consensus statement, on the one hand, and repeated human rights claims aiming to curtail medical interventions on the other. Coming in as a researcher to this topic area has been confusing, exciting, disruptive and challenging. This thesis is an attempt to *make sense* of the context, in which different stakeholders with diverse understandings seem to agree that promoting wellbeing for or improving the lives of people with personal experiences is a priority (Davis, 2015; Lee et al., 2016; Wiesemann, Ude-Koeller, Sinnecker, & Thyen, 2010).

The word *thesis* is also usually considered to mean "a proposition stated or put forward for consideration" ("Thesis [Def. 1]," 2016). The thesis I am proposing, in short, is that what is conventionally considered *knowledge* in this area builds on *diverse* but *specific kinds of knowing* and expertise. These are, in turn, entangled with a range of specific values, ideas, theories and philosophical assumptions. I argue that the use of these *kinds of knowing* creates inevitable gaps in research and clinical practice that, in turn, has consequences for people's everyday lives and wellbeing. In this thesis, I empirically explore experiential *kinds of knowing* that could address some of the gaps evident in the current literature.

In order to assess my claims, I have reviewed a large body of literature from a diverse set of stakeholders. This means that what you have in your hands is not only a thesis, but also a synthesis; "a complex whole formed by combining" ("Synthesis [Def. 2]," 2016) diverse *bodies of knowledge*. These different bodies of knowledge all claim to hold *knowing about bodies*, and therefore they can be understood as *knowing bodies*. The original research done in this project also works from the understanding that having specific experiences and a certain body will put you in a position of having distinct expertise (Collins & Evans, 2002; Pols, 2013). By *knowing your body*, experientially and/or intellectually, those with experiences are considered to be a *knowing body* of people with *knowing about bodies*. This (syn)thesis sets out to engage with these diverse bodies of knowledge and explore if and how they might be able to promote wellbeing for those affected by these specific kinds of knowing.

Setting out to explore knowing inevitably makes this thesis an epistemologically informed, and engaged, project. The rest of this chapter presents the overarching perspectives underpinning this thesis as a whole, which includes outlining the epistemology and terminology used. This chapter ends with a short presentation of the structure of the thesis and the specific overarching research questions that frame this specific body of knowledge.

### **An epistemologically informed project**

Many qualitative methodologies in psychology are informed by the *turn to language* evident from the 50s and onwards in sociology and philosophy (Willig, 2013; Yardley, 1996). Accompanied by critique raised by feminist scholars, this turn led to a criticism of the methods and philosophical ideas underpinning mainstream psychology. Building on a social constructionist epistemology, academics argued that knowledge is constructed and dependent on specific historical and cultural contexts (Burr, 2003). This approach emphasised the performative and productive effects of language, in contrast to those earlier theories that took for granted that language could be merely descriptive of mental states or experiences.

This project is informed by social constructionism in the sense that I understand knowing as constructed and discursively mediated by language, history and context. Throughout this thesis, *knowing* is used instead of *knowledge*, in order to emphasise the processual, dynamic and context-dependent aspects of what being knowledgeable might mean (Snowden, 2002; Sturmberg & Martin, 2008). Knowing is further understood to always be dilemmatic (Billig et al., 1988), partial and “situated” (Haraway, 1988), as well as having specific consequences (Foucault & Gordon, 1980). Knowing implicates power and is *performative* because it opens up some opportunities for discourse, thoughts, feelings and actions and closes down others. Scientific knowing “about” a group of people will, thus, frame how this group is understood and will understand themselves. However, because groups of people are able to (inter)act with or on such knowing the performative power of knowing is not always straightforward (Hacking, 2002; Jenkins & Short, 2017). Foucault argued that societies have different general politics of truth that represent specific kinds of knowing that are made to function as true (Foucault & Gordon, 1980). As such, power is (in)vested in these kinds of knowing, because they are understood to be generally accepted and legitimate. Interrogating what has been counted as *legitimate knowing* during different time periods has been an important feature of social studies of science for decades (Collins & Evans, 2002). In this thesis, I utilize theories on expertise developed within science studies to make sense of the different kinds of knowing that have been and are evident in this topic area.

The performative aspects of knowing makes it inescapably ethical (Mason, 2002). In accordance with some feminist epistemologies, this project works from the understanding that a researcher never can be fully objective or neutral, but is rather entrenched in production of knowing underpinned by particular values and with certain ethical indications. Drawing on these understandings, ethical considerations in research is an inherent part of framing the phenomena of interest, formulating philosophical understandings underpinning the project as well as the questions asked and the specific methodology being used. Mason (2002) recommends researchers to “confront and engage with the politics of social research, rather than assume it is possible to maintain a safe distance” (p. 21) and reflect upon where they stand in relation to ideological issues in their field. This might infer trying to change how a certain phenomenon is perceived or how practices are carried out (Cieurco & Keitel, 1999; Kitzinger & Wilkinson, 1997; Mason, 2002). Such understandings have been used in order to suggest how psychology can be used as a *transformative* resource in order to promote wellbeing and social justice (Gergen, 1982; Mertens, 2009). This kind of transformative potential underpins this research project.

### **A transformative project**

Transformative research has been developed in contexts by groups of people that have been pushed to the margins of society as well as in research (Mertens, 2009). The research paradigm is underpinned by a need to address challenges in society such as discrimination, oppression and inequalities by voicing people’s experiences of such structures and by promoting change. This kind of research is underpinned by diverse perspectives including feminist theory (Haraway, 1988), disability studies (Zola, 1993), LGBT and queer studies (Clarke, Ellis, Peel, & Riggs, 2010), critical race theory (Crenshaw, Gotanda, Peller, & Thomas, 1995), critical psychology (Fox & Prilleltensky, 1997) and anti-oppressive approaches (Kumashiro, 2000). Transformative research acknowledges the importance of challenging oppressive structures and highlighting diversity as well as research ideals such as reflexivity, transparency and using results to enhance social justice and human rights.

Even though many of the approaches underpinning transformative research draw on social constructionist perspectives, scholars are also critical of the exclusive focus on language and discourse. While reclaiming language and deconstructing common sense understandings have been important parts of, for example, gender, queer and disability studies, these disciplines have also pointed to how structures and discourses are related to physical and material conditions. This has led to a renewed interest in the material, sometimes

referred to as *the new materialist turn* (West, 2011). The approach focuses on the agency of non-human aspects, or on materiality beyond human thought, reason or language. While some new materialists are sceptical of social constructionist theories, several are “happy with the thought of co-existent material and discursive worlds” (West, 2011, p. 416) because an approach to the world as material *and* discursive opens up new ways to politically engage with it. According to Yardley (1996), materiality has, however, often been given a subsidiary role in discursive psychological research on health and illness. She argues that these are shaped by material *and* cultural-linguistic aspects and that an interwoven relationship between discourses and the material should be interrogated. This project is informed by understandings that consider the material *and* discursive.

### **A pragmatic project**

In order for a project to be transformative and focus on knowing in a specific area, I argue that research also needs to be pragmatic. Pragmatism is a rich philosophical tradition that has developed in many different directions since the end of the 19th century. Some argue that even though the early pragmatists did have a focus on concrete aspects of life, there is now a huge difference between the philosophical tradition and a pragmatism focusing on *what works in everyday life* (Mertens, 2013). In this project, a pragmatic approach is interpreted as the latter; a perspective to promote things that work in everyday life. The project is guided, not only by philosophical underpinnings, but also the question “what difference does it make?”. As such, a pragmatist would argue that the effectiveness of a certain project “is viewed as establishing that the results ‘work’ with respect to the specific problem that the researcher seeks resolution of” (Mertens, 2013, p. 37).

Just like a transformative researcher, a pragmatic academic would not only describe the world, but try to change it. While some suggest that pragmatism avoids questions of epistemology and prioritizes how things work in practice, others argue that it can open up constructive dialogues between different philosophical traditions (Hickman, Neubert, & Reich, 2009; Johnson & Onwuegbuzie, 2004). A pragmatic researcher can, therefore, accept a vast array of diverse epistemologies, as long as the research is focused on the joint action that people can accomplish together (Mertens, 2013). From a pragmatic point of view, different ontologies and epistemologies are thus to be evaluated on the basis of the concrete consequences they have and the potential change they might be able to promote. In order to assess such consequences, a pragmatic approach would not avoid discussing epistemology but rather it would engage thoroughly with these underlying assumptions and explore the

concrete outcomes that these ideas have on people's lives. This perspective is also consistent with understandings underpinning some discursive approaches (Hickman et al., 2009).

Finally, early pragmatists were invested in research ethics and especially an *ethics of care* of those who were considered unprivileged (Mertens, 2013). Some suggested a democratic model of research where values of freedom, equality and justice should guide the process. This focus unites the discursive, transformative and pragmatic aspects of this project.

### **Terminology used in the thesis**

Several different terms have, historically, been used to refer to the situation when sex characteristics, including anatomic features, chromosomes and hormones, develop in ways that are not captured well by binary categorisations. More than a decade ago, the terms *hermaphroditism* and *intersex* were used in Western medicine. Since 2006, the term *disorders of sex development*, or *DSD*, is commonly used in medical literature. Others use the acronym DSD, but meaning *differences of* or *diverse sex development*, and some still prefer the term *intersex* (Liao & Roen, 2014). Finally, some prefer to use specific diagnostic labels instead of umbrella terms such as intersex or DSD. The kind of terminology that is used in this area reveals different underlying understandings of sex and gender, embodiment, (ab)normality and (a)typicality. Several commentators have also pointed to the ethical responsibility of using sensitive language in the area. However, there is no consensus what a sensitive terminology is. There is not one single term that people with personal experience agree is good (Bennecke & De Vries, 2016; Davis, 2014; Jones et al., 2016; Lin-Su, Lekarev, Poppas, & Vogiatzi, 2015). In the literature, medical perspectives consistently use *DSD* (Pasterski, Prentice, & Hughes, 2010b), while many activists, human rights-documents and literature within the humanities and law consistently use *intersex*.

In the introduction to this thesis, and in paper I and IV, the term intersex/DSD is used. This is done in order to stay in conversation with different parts of the topic area and with different stakeholders at the same time, as well as respecting that people with personal experiences prefer different terms. The term intersex/DSD is consistently used throughout the thesis to refer to the phenomenon under study. This means that the term will be used also when I refer to the time periods before DSD was proposed.

The choice of terms used in the thesis is not an optimal solution and terminology has been changing since the project started. In the beginning, I used the term atypical sex development. This was an attempt to use a descriptive term in addition to the ones proposed by diverse stakeholders in the field. The term was, however, abandoned because I found the

value-laden aspects of the word "atypical" problematic and because suggesting yet another term to the field was not considered to solve the current debate on terminology.

Before moving on, however, I will just make a short note about the acronym DSD used in this thesis. In paper II and III, DSD was used meaning diverse sex development. DSD is usually preferred by those who argue that it is important to address the medical aspects that are potentially relevant in relation to intersex/DSD. *Diverse sex development* is not considered to work in that direction. However, I argue that *if* a medical classification is needed, it could be less pathologizing by not using the term "disorder". Therefore, in order to also address instances where medical knowing might be considered relevant or useful, I present yet another suggestion. The meaning of the DSD-acronym used in this thesis stands for *Diagnoses classified as affecting Sex Development*. I believe that this meaning lends itself to the medical knowing described in chapter 3, but is less pathologizing.

### **Research questions and structure of the thesis**

The research questions framing this project are:

- *How do laypeople with and without personal experience of intersex/DSD use and trouble the kinds of knowing that are highlighted in the literature in this topic area?*
- *What other kinds of knowing might benefit people with personal experience of intersex/DSD, including kinds of knowing that are not evident in the current literature?*

In order to address these questions, the thesis consists of two main parts. The function of the first part is to situate the empirical work done in this project. In chapter 2, a short outline of the history of intersex/DSD is presented in order to understand how knowing in the past still influences knowing in the present. This chapter is followed by chapter 3, which is drawing on the body of medical knowledge and especially highlights the consensus statement on medical management published in 2006 (Lee, Houk, Ahmed, & Hughes, 2006). Because medicine has been, and still is, an influential discipline in the area, current medical aspects considered related to intersex/DSD are discussed. This is followed by an engagement with some of the psychosocial research done since 2006. The dominance of medicine in the topic area is currently being challenged by human rights bodies. Some highlighted human rights arguments and ethical perspectives are brought forward in chapter 5. Building on these sections, I seek to position this specific project in chapter 6. In the second part of the thesis I present the methodology used in this research (chapter 7), the results from the project (chapter 8) and end with a general discussion of the findings (chapter 9).

## **2. MAKING SENSE OF THE CONTEXT: Drawing on the body of historical knowledge**

Historical knowing is often presented in a thesis in order to show how science has progressed. In this thesis, however, parts of the history of intersex/DSD are used to trouble the very idea of progress. Instead, this historical outline seeks to present some values, ideas and theories that historically have been understood to constitute knowing in the field and still influence contemporary research. Since the end of the 19<sup>th</sup> century, medics and researchers have been invested in intersex/DSD with diverse motives (Bondestam, 2010; Dreger, 1998a). While psychosocial knowing has influenced the subject area during some time periods, medical research has dominated (Roen, 2015). In this section, I highlight some important historical events from the 1950s to the early 2000s that inform this research project.

### **John Money: pioneering clinical psychosocial guidelines**

During the 40s the idea that “psychological sex” was separable from a person’s “somatic sex” grew in popularity. Until then, endocrinological and surgical perspectives had dominated treatment in intersex/DSD (Garland, 2016). During the 50s, a team at Johns Hopkins, of which John Money was part, proposed an *optimal gender policy* that included psychological and biological aspects. Based on research and clinical practice, they argued that gender role-development was a process of consistent upbringing and the child’s identification with his or her normatively sexed body (Money & Ehrhardt, 1972). The idea that gender role was a result of rearing also meant that it was somewhat fluid during the first two years of a child’s life. However, in order for an optimal gender role to develop, gender assignment had to be done early. The treatment involved helping parents to accept their child and raise the child consistent with the assigned gender. Money also proposed that children should be told about their embodiment and diagnosis in an age-appropriate manner, even though this might affect their development (Karkazis, 2008b).

The policy also recommended early genital surgery and hormonal treatment in order to assist the body to look and develop as “typically” as possible (Karkazis, 2008b). Having a normal-looking body was understood to promote a stable gender role and psychosocial adjustment. Because surgery was understood to be traumatic, Money recommended that it would happen as early as possible to optimize the chance that the child would not remember it later on. Money did not initially recommend that gender assignment should be based on genital appearance, but his suggestion usually had those consequences in practice. This meant that most children with intersex/DSD born during the 80s and 90s were assigned girls and had

feminising surgical interventions (Cornwall, 2010). However, criteria to review the success of surgery at this time were usually unspecific, hetero-normative and focused on how medical professionals judged appearance rather than function (Kessler, 1998).

Some commentators argue that the combination of medical, surgical and psychological perspectives made the optimal gender policy progressive for its time (Karkazis, 2008b). Some also suggest that the most crucial part of the theory was the emphasis on psychological aspects. However, the surgical aspects of the protocol were usually picked up by other health professionals, overlooking the psychosocial factors in practice (Cornwall, 2010). Inconsistent with Money's recommendations, parents were usually told by medics not to disclose any medical information to their children, in order not to confuse them (Karkazis, 2008b). An ethics of non-disclosure was still in use by medics in the late 90s (see e.g., Natarajan, 1996).

The optimal gender policy seems to have been used by teams internationally (Garland, 2016), and very few criticized Money's ideas publicly early on (Karkazis, 2008b). As early as 1965, however, Milton Diamond argued that hormonal influences, prenatally and during critical periods after birth, determine gender identification. Diamond did recognize contextual effects on gender, but understood these as limited. Even though Diamond wrote extensively and critiqued Money for decades, few acknowledged his ideas of hormonal determination of psychosexual development until later.

### **Feminist theory and academic critique**

During the 70s, Money's emphasis on rearing was picked up by some feminists as an argument against essential theories on sex and gender (Karkazis, 2008b; Sullivan, 2015). With a growing influence of social constructionist theories and the turn to language in some disciplines, some feminists also started to question understandings of binary sex. While many scientists would assume that biological facts were studied independent of gender labels, Kessler and McKenna (1978) argued that social constructions of gender had been taken for granted in research and thus affected studies on bodies and nature. Similar ideas were later used by the feminist biologist Fausto-Sterling (1993) in an influential paper in *The Sciences* during the early 90s. In this paper she described how social constructions of sex as male or female makes variations of sexed embodiment invisible and in need of normalizing interventions. She argued that understandings of gender would be very different if gender labels were grounded in actual embodiment, instead of pinning binary labels onto people's bodies. She also argued that this would change the way medicine would respond to cases where intersex/DSD was evident. Some parts of this paper were criticised by people with

personal experiences of intersex/DSD (Chase, 1993) and by academics (Kessler, 1998) and in a later book, Fausto-Sterling (2000) amended some of these arguments.

Kessler did also develop her early ideas on gender to include intersex/DSD. Her groundbreaking study on health professionals showed how normative understandings of gendered embodiment influenced medical decision-making and led medics to promote irreversible normalising surgery on children (Kessler, 1990, 1998). However, the importance of normality as suggested by health professionals was clearly contrasted by her other studies on laypeople (Kessler, 1998). Results from these studies showed that laypeople, in general, had wider standards for what counts as “normal genitalia” compared to medical professionals and that most participants would not want their parents to agree to surgery if they were born with genitals considered atypical by the medical establishment.

Other influential feminist work in the subject area from this time highlighted historical and ethical perspectives. Historical approaches from the 90s did, for example, demonstrate and criticise how experts had tried to make sense of less typically sexed bodies since the late 19<sup>th</sup> century (Dreger, 1998a). Several academics have also highlighted ethical concerns related intersex/DSD (e.g., Alm, 2010; Dreger, 1999; Morland, 2008; Parens, 2006).

### **Questioning medical expertise via lived experience**

From the 60s and onwards, movements focusing on patients’ rights grew in western countries and patient-centred care was gaining importance in general medical practice (Laine & Davidoff, 1996). It took several decades before such patient-led initiatives materialized in the area of intersex/DSD. However, Simmonds (2012) suggests that activists and patient groups played an essential role in affecting treatment protocols.

The first support groups started to appear in the late 80s and early 90s in the US and the UK (Preves, 2003; Simmonds, 2012). In a response to the article by Fausto-Sterling (1993), Cheryl Chase (1993) declared in a letter to *The Sciences* that the organization The Intersex Society of North America (ISNA), was established. During the 90s, ISNA was one of the most influential groups criticising medical practices. They used confrontational tactics and protested at medical conferences. The organization questioned early surgery and provided narratives of people suffering from complications of medical treatment and interventions (Karkazis, 2008b; Kessler, 1998). By the same time in the UK, the Androgen Insensitivity Syndrome support group (AISSG UK) was formalized. The main critique raised by this group included the problematic aspects of the non-disclosure policy and the lack of psychosocial support within health services (Simmonds, 2012). The formation of activist and support

groups helped people to access information about their embodiment that had been withheld from them within medical services. These groups also allowed people to come together, claim new ways of understanding their experiences, their embodiment and their identity and reclaim pathologizing language (Cornwall, 2010). ISNA used *intersex* but also reclaimed the historical and pejorative term *hermaphrodite* (Kessler, 1998).

Some groups also worked to raise awareness in the general population. AISSG UK, for example, collaborated with the BBC to highlight the problems with the principle of non-disclosure (Simmonds, 2012). During the late 90s, a publicly known case of personal experience where it became obvious that the medical guidelines had failed was called the John/Joan-case. John/Joan, later known as David Reimer, was born as a boy with typical sex features who accidentally lost his penis when he was 7 months old. His parents contacted John Money and decided under his guidance to raise David as a girl (Cornwall, 2010). Money used this case to support his theory (Money & Ehrhardt, 1972), but some were critical of his ideas. Together with Keith Sigmundson, the psychiatrist responsible for David's follow-up treatment, Milton Diamond published information about the case that had not been presented publicly before. They concluded that David identified as a boy and had felt different and unhappy since childhood (Diamond & Sigmundson, 1997b). They argued that Money's theory was not supported by the data he had presented. The case got more attention in the general public in connection to a magazine article by Colapinto (1997) and a later book about David's life (Colapinto, 2000). By this time, the theory of Money and colleagues started to lose its hegemonic influence. In the aftermath of their article, Diamond and Sigmundson (1997a) proposed new guidelines suggesting that pathologizing language should not be used and that a thorough physical assessment of chromosomes, hormones, gonads, genitals and potential underlying conditions should be done before suggesting any gender assignment.

### **Contested collaborations with health professionals**

Some have called the early days of activism and support group activities in the US in relation to intersex/DSD a "collective confrontation" with the medical establishment (Davis, 2015). However, as groups mobilizing people with personal experience of intersex/DSD grew in number, the underlying perspectives, strategies and goals of these groups diversified. Starting as "outsiders" critiquing the medical field, some people with personal experiences collaborated with academics in feminist studies, humanities and the social sciences and published papers themselves to address the unethical medical practices that were still in place during the 90s (Grovesman, 1998; Hegarty & Chase, 2000; Holmes, 2002; Moreno, 1999).

Some support groups, for example in the UK, also teamed up with health professionals to promote better health services (Simmonds, 2012). In the US, ISNA was eventually disbanded and the Accord Alliance was formed in 2008. One main reason was that, due to its history, some did not find ISNA appropriate to effectively promote change in medical management. Accord Alliance, however, was perceived to be in a better position to educate health professionals to provide care that would promote wellbeing to people experiencing intersex/DSD and enable collaboration between stakeholders (Cornwall, 2010). Instead of confrontational approaches, these strategies are described as based on discursive politics and “occupy and indoctrinate” tactics, which includes working to change practices from the inside by narratives of trauma (Davis, 2015). However, not all activists supported these new strategies. Many ISNA-members were disappointed by this development and understood such collaboration as working *for* the medical establishment, not *with* them. Consequently, activists collaborating with medical professionals were understood to accept the gender regime with heterosexist and cissexist frameworks underpinning medical practice, which, by others, was seen as the main problem inherent in medical knowing. Some organizations, such as the Organisation Internationale des Intersexués – Organization Intersex International (OII), continue to be sceptical of these collaborative approaches. The collective confrontation during the 90s has, in other words, today developed into a “contested collaboration” (Davis, 2015).

### **Questioning medical protocols from a psychosocial perspective**

From the late 90s, psychosocial approaches focused on the lived experience of people with intersex/DSD as well as the experiences of their families. Some research was done in collaboration with support groups and pointed to the same problems inherent in medical practices that many activist and support groups had been addressing (Hegarty & Chase, 2000; Preves, 2003). Such research highlighted how the medicalization of intersex/DSD creates feelings of stigma, instead of countering it (Alderson, Madill, & Balen, 2004; Boyle, Smith, & Liao, 2005; Holmes, 2002; May, Boyle, & Grant, 1996; Preves, 2003). Psychosocial approaches have also demonstrated how these medicalized identities can be actively reclaimed as social identities that empower people and the importance of activist and support groups in this process (Preves, 2003).

In this literature, any issues related to intersex/DSD tend to be framed as social rather than medical (Preves, 2003; Roen, 2004). Authors have questioned the effectiveness of surgery to produce functional and normal-looking genitals and, more importantly, questioned the understanding that normalizing interventions would promote wellbeing (Boyle et al.,

2005; Creighton, Minto, Liao, Alderson, & Simmonds, 2004; Hird, 2003; Liao & Boyle, 2004; May et al., 1996; Roen, 2004). This literature has also suggested that neither biology nor genital appearance have a direct impact on adjustment. In contrast to the dominant focus in the medical literature on gender identity and surgical outcomes, these commentators have pointed to other important psychosocial concerns that need to be explored, such as: the experiences of shame and secrecy (Preves, 2003); the emotional distress of not being informed properly about embodiment and emotional reactions of parents when learning about their child's diagnosis (Slijper, Frets, Boehmer, Drop, & Niermeijer, 2000); and the difficulties for young people and adults to engage in relationships (May et al., 1996) as well as to talk about their embodiment with loved ones (Alderson et al., 2004; Williams, 2002).

### **From nurture to nature: a renewed interest in hormonal theories**

At about the same time that activists, feminist academics and psychosocial researchers started to challenge medical protocols, an increased interest in hormonal theories also became more evident. As scientific endeavours such as the human genome project (National Human Genome Research Institute, 2014) were developed in the early 90s, many researchers in the topic area studied if biological variables could predict gender identity as well as gender differences (Jordan-Young, 2012; Karkazis, 2008b). At this point, a range of researchers supported the kinds of brain organisation theories that Diamond had promoted (Berenbaum & Hines, 1992; Reiner, 1997; Wilson & Reiner, 1998). These theories suggest that prenatal hormonal exposure organizes brain structure. Different levels of particular hormones are therefore understood to affect people's gender identifications and sexual orientation. Projects investigating how biomarkers affect gendered playing-behaviour, occupational preferences, cognitive abilities, gender identity, sexual orientation and so on, grew in popularity (Jordan-Young, 2012; Karkazis, 2008b). Some of these studies provided empirical data that suggested that rejection of assigned gender under the optimal gender policy was not uncommon, which further challenged the ideas underpinning the former protocol (Garland, 2016).

### **Establishing new guidelines: The consensus statement**

By the start of the millennium health professionals were more open to listen to some people with personal experiences and establish new medical guidelines (Davis, 2015; Dreger & Herndon, 2009; Simmonds, 2012). Some activist and support groups had been working on alternative guidelines since the mid-90s (Meyer-Bahlburg, 1998) and promoted ideas for changing medical practices as well as the need for new medical nomenclature (Dreger, Chase,

Sousa, Gruppuso, & Frader, 2005). While some professionals had suggested new guidelines (Diamond & Sigmundson, 1997a), others argued that more research needed to be done in order to replace the former policy (Meyer-Bahlburg, 1998). By 2006 ISNA had, together with health professionals, published a first version of their recommended clinical guidelines (Consortium on the management of disorders of sex development, 2006).

The protocol that has had the most significant impact on clinical practice was “The Consensus Statement on Management of Intersex Disorders” (Hughes, Houk, Ahmed, & Lee, 2006; Lee et al., 2006). This document was the result of a meeting with professionals and a couple of support group representatives held in Chicago in 2005 and can be understood to frame the medical discourse today. Medical knowing underpinned by the consensus are considered in the next chapter.

### **3. MAKING SENSE OF BODIES: Drawing on the body of medical knowledge**

Since the beginning of the 20<sup>th</sup> century, medicine has been a dominant body of knowledge to classify variations of sexed embodiment (Dreger, 1998a). The power of medicine to diagnose and intervene on bodies that are considered “atypical” is made possible because of the medicalization of childbirth and the body, leading people to look to medicine for expertise. This legitimacy of medicine is further underpinned by the truth claims made by biomedical research building on realist epistemologies. While medical understandings can be useful in promoting wellbeing, medical language and classifications are also at risk of becoming pathologizing and stigmatizing; interventions can also be harmful. Engaging with medical knowing also means engaging with this inherent tension.

Studies show that current medical practice within the area has adopted several of the underlying understandings and recommendations outlined in the “Consensus Statement on Management of Intersex Disorders” from 2006 (Davis, 2015; Pasterski, Prentice, & Hughes, 2010a; Pasterski et al., 2010b). The statement can, therefore, be interpreted as embodying the professional knowing of intersex/DSD in medicine. In 2016, a global update of the consensus statement was published, concluding that there are still issues that need to be addressed in this area (Lee et al., 2016). Below, I engage with the knowing presented in the consensus statement and the global update.

#### **The consensus on diagnoses classified as disorders of sex development**

The authors of the consensus statement introduced new definitions and nomenclature, suggested new standards for treatment, reviewed earlier research and called for further studies. *Disorders of sex development* (DSD) was suggested as the new overarching term for “congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical” (Lee et al., 2006, p. e488). Building on biomedical knowing, these diagnoses were proposed to be classified on the basis of chromosomes (Lee et al., 2006). Below, some of the conditions mentioned in the consensus statement are outlined.

The most common condition, classified in the consensus statement as a *46,XX DSD*, is congenital adrenal hyperplasia (CAH). Classic CAH affects the function of the adrenal gland and comprises two types, salt-wasting and non-salt wasting. It affects approximately 1:10 000 to 1:20 000 children (Speiser et al., 2010). Symptoms of cortisol and aldosterone imbalances are often evident within the first few days after birth and diagnosis is usually made within the first weeks of the child’s life. In Sweden, newborn screening is used to detect the condition

(Gidlöf et al., 2013), while in the UK screening is currently not used (UK National Screening Committee, 2016). CAH typically requires daily and lifelong medication with glucocorticoids, mineralocorticoids and, for children with the salt-wasting form, sodium chloride supplementation (Speiser et al., 2010). Individuals with XX-chromosomes and CAH are usually assigned girls at birth and children with XY-chromosomes and CAH are usually assigned boys at birth (Lee et al., 2006). However, for children usually assigned girls, the hormonal imbalance, which includes higher than average levels of androgens, might also affect physical sex development (Speiser et al., 2010). These children may be born with sex characteristics such as a larger than average clitoris, fused labia and urogenital sinus, which sometimes complicates the gender assignment-process (Lee et al., 2006). For children with XY-chromosomes, genital appearance is not affected to the same extent, however the condition might impact the function of the testes later in life (Ogilvie et al., 2006).

For a person diagnosed with 46,XX gonadal dysgenesis, sex characteristics develop in ways that are considered typical in women. However, the ovaries do not function as typically expected and this might affect pubertal development (Pertusa & Palacios, 2009). Around 1 in 5000 women are diagnosed with Mayer Rokitansky Küster Hauser Syndrome (MRKH), which means having an XX-karyotype and functioning ovaries, but structures forming a uterus and/or vagina do not develop as typically expected (Fliegner et al., 2014).

Conditions classified as *46,XY DSD* includes complete androgen insensitivity syndrome (CAIS) and pure 46,XY gonadal dysgenesis (also called Swyer syndrome). These are often diagnosed during adolescence, when menstruations have not started as expected (Berra, Liao, Creighton, & Conway, 2010; Jorgensen, Kjartansdóttir, & Fedder, 2010; Lee et al., 2006). CAIS and gonadal dysgenesis are variations evident in approximately 1-5 per 100 000 newborns respectively (Alderson et al., 2004; Jorgensen et al., 2010). People who are given these diagnoses are usually assigned girls at birth and have XY chromosomes. CAIS means that a person has testicular gonads but that the body is insensitive to the androgen hormones that are produced. This means that sex characteristics such as external genitals and breasts develop in ways that are usually considered typically female. A uterus is, however, not developed because of the antimüllerian hormone produced by the gonads. In pure 46,XY gonadal dysgenesis, however, testes are not functioning, which means that a uterus develops. This also means that pubertal development might be delayed compared to average teenage development.

A person with partial androgen insensitivity syndrome (PAIS) has XY chromosomes and the body is sensitive to testosterone. Because this sensitivity might vary, people with

PAIS might have diverse experiences of sex development and differ in the gender they were assigned at birth (Berra et al., 2010). A person with 5 $\alpha$ -reductase-2 deficiency has testicular gonads and sex characteristics that are considered more typically female or neither typically female nor male, because an enzyme that converts testosterone during gestation does not work as expected. However, the testosterone produced will usually affect pubertal development in a way that is considered more typical for men. People with 5 $\alpha$ -reductase are usually assigned female at birth but many do not identify as women in adulthood (Cohen-Kettenis, 2005).

There is still a debate if some conditions are to be covered by the umbrella or not (Lee et al., 2016). This includes hypospadias; the situation when a child is born with the urethral opening not on the centre on the top of the penis. Another debate relates to the inclusion of some conditions under what was labelled as *Sex Chromosome DSD*. This subgroup comprises of diagnoses such as Turner and Klinefelter syndrome, but also variations where a person has a mosaic of different chromosomal patterns. These debates make any estimates of intersex/DSD problematic. Some commentators suggest that any kind of bodily variation that do not fit the constructions of typical male or female development is as common as 2% (Blackless et al., 2000). Others have suggested a rate of 1:200 to 1:300 (Lee et al., 2016).

### **Introducing evidence-based guidelines to multidisciplinary care**

In the second part of the consensus statement, processes for investigation of management of DSD were outlined. It was proposed that a multidisciplinary team (MDT) with expertise in the area should do an evaluation before any suggestions on gender assignment are done. After thorough investigations, all children should be assigned a gender. Long-term management was also suggested to be located in specialist centres and that families and patients should be invited to be fully part of any decision-making processes. In addition to biomedical knowing, these recommendations could be understood to reflect a shift towards kinds of knowing that includes patient perspectives and psychosocial knowing. Inclusions of other, non-medical, kinds of knowing were also evident in the appendices to the consensus, where contributions of support groups as well as legal aspects related to intersex/DSD were included.

The authors of the consensus statement also reviewed the literature supporting specific investigations and interventions as well as outcome studies, suggesting that any interventions done, including gender assignment and surgery, should be based on the best evidence available. In the document it was stated that there is not enough scientific evidence in support of early surgery. When it comes to clitoral surgery, for example, clinicians and parents were asked to only consider clitoral surgery "in cases of severe virilization (Prader III–V) and be

performed in conjunction, when appropriate, with repair of the common urogenital sinus” (Lee et al., 2006, p. e491). Other surgical interventions such as gonadectomies and vaginoplasty were also addressed. Any interventions on lengthening the vagina should not be done before adolescence, according to the authors. Gonadectomies were, however, recommended if there is a later risk for malignancy, but fertility potential also needed to be considered. In the statement it was also noted that many gaps in understanding the determinants of gender identity remain. While there is some scientific evidence supporting a certain gender assignment in some cases, such basis is not evident for all specific diagnoses. While other kinds of knowing was highlighted as important in some parts of the document, as stated above, these paragraphs clearly point to the importance of scientific biomedical knowing to provide a basis of evidence on which any medical decision-making can be based.

### **The global DSD update and the importance of promoting quality of life**

Even though the consensus statement has had an impact on clinical practice, there are still many important issues to be addressed within the area and the discussion on how to improve health care continues (Asciutto, Haddad, Green, & Sandberg, 2011; Brain et al., 2010; Cohen-Kettenis, 2010; Liao & Roen, 2014). Several updates and guidelines have been written since 2006 (Ahmed et al., 2015; Brain et al., 2010; Lee et al., 2016). The latest and most extensive document is the “Global Disorders of Sex Development Update since 2006” (Lee et al., 2016). In this paper the changes in clinical approaches, knowledge and perspectives that have happened since 2005 were addressed. The aim of the document was to provide patient care that promotes the best possible quality of life (QoL). Comments regarding DSD nomenclature, incidence, support groups, clinical evaluations (including biochemical and genetic assessment), psychosocial aspects, gender assignment and reassignment, information and decision-making processes, medical treatment (including hormonal and surgical interventions), fertility as well as ethical, legal and cultural issues, were included. However, some of the main dilemmas raised by the consensus statement were also addressed in the global update, and these are outlined below.

### **Underpinning ideas of dilemmas identified in the medical literature**

In both documents it was stated that while there is scientific evidence supporting a certain gender assignment in relation to some cases, such basis is not evident for all specific diagnoses. This means that dilemmas in relation to *gender assignment* still persist in the area. In the update similar solutions as stated in the consensus were suggested in order to address

this dilemma: to involve parents and a MDT of professionals in the decision-making process and do more large-scale research to find a biomarker of gender identity. In each specific case, it was also proposed that the gender identity development of the child is assessed continuously, in order to assist if later reassignment is needed.

Another dilemma raised in these documents is related to early surgery. Arguing from a human rights-approach, some commentators have called for a moratorium on early genital surgery, due to the fact that such interventions lack consistent scientific support (Diamond & Garland, 2014). However, on the same basis, the authors of the consensus suggested that surgery might be relevant in some cases (Lee et al., 2006). Issues of early genital surgery should, therefore, be handled by involving parents in decision-making, privileging function and fertility potential over cosmetic outcomes, as well as doing more research on the effects of surgery in relation to timing and technique. In the recent global update it is noted that there is still no clear information with regards to indications, timing, and procedures in relation to surgical interventions (Lee et al., 2016). Research in the area show that even though the guidelines from 2006 suggest surgery only “in severe cases”, these principles have only had an uneven effect on the amount of surgeries being performed (Creighton, Michala, Mushtaq, & Yaron, 2014; Michala, Liao, Wood, Conway, & Creighton, 2014; Pasterski et al., 2010b).

Finally, the importance of full disclosure of medical information to patients was highlighted in the consensus statement: “disclosure concerning facts about karyotype, gonadal status, and prospects for future fertility is a collaborative, on-going action that requires a flexible individual-based approach. It should be planned with the parents from the time of diagnosis” (Lee et al., 2006, p. e493). The importance of full disclosure to patients as well as the need for effective communication skills were also emphasised in the global update (Lee et al., 2016). Even though there is no current debate about this ethical principle, both documents still call for more studies on how and when information should be delivered to be effective.

Some underlying understandings that become evident in the outline of these dilemmas are notions of sex as binary (and that this binary is considered “real”, see critical comments by e.g. Morland, 2001) as well as expectations that scientific knowing will be able to solve these dilemmas in the future. However, as shown in chapter 1, binary understandings of sex have historically been contested and are still being challenged by critical psychosocial scholars as well as human rights advocates. Critical perspectives and human rights approaches are also challenging the assumptions that scientific biomedical knowing will be able to solve dilemmas of surgery and of who should deliver information to the patient as well as how and when it should be disclosed.

Similar criticism of the underlying perspectives informing medical knowing is especially pertinent to the discussion of DSD as a term. I argue that the controversy of DSD, in many ways, illustrates how diverse bodies of knowledge, building on different assumptions and values, had (and still have) different concerns about language in this topic area. This includes the way that language is understood to function and what language is expected to do. The controversy over DSD is therefore understood as a site where the tensions of medical knowing, as promoting or prohibiting wellbeing, as well as tensions between medical and non-medical knowing are played out.

### **The controversy over DSD**

The classificatory system of DSD was initially proposed to replace earlier terms, such as intersex, hermaphroditism and sex reversal, because these terms were understood to be confusing and potentially stigmatizing (Chase, 2006; Lee et al., 2006; Vilain et al., 2007). For example, critics of the term intersex had argued that it was understood as a reference to identity; that it implied that people have an unclear sex or gender identity; and that the term sexualized children (Chase, 2006; Dreger & Herndon, 2009; Feder, 2009a; Lee et al., 2006; Pasterski et al., 2010a; Vilain et al., 2007). However, while several commentators did not think that earlier terms did the job that terminology should do in the topic area, the underlying concerns driving a change of the nomenclature seem to have differed between stakeholders.

**Arguments supporting DSD.** One main argument against using the term intersex had been that it was not specific enough to be medically relevant. Some commentators have written that the purpose of the new nomenclature was to provide a descriptive term overarching a classificatory system of more specific diagnoses, of which many "can be traced to gene mutations causing pathophysiological consequences" that "abnormally affect physiology, whether by disrupting steroidogenesis or blocking receptor functioning" (Pasterski et al., 2010a: 189). In the consensus statement the importance of a descriptive term was highlighted that could "reflect genetic etiology when available and accommodate the spectrum of phenotypic variation. Clinicians and scientists must value the nomenclature's use, and it must be understandable to patients and their families" (Lee et al., 2006, p. e489). The use of an overarching term like DSD to classify a vast array of different diagnoses is also in line with the structure of classificatory systems, such as the ICD-10, where symptoms, underlying processes, and reasons for seeking health care are understood in relation to diagnostic criteria (World Health Organization, 2015). As such, a friendly reading of these motives could interpret the aim of DSD as providing language that works in biomedical

research and health care institutions to facilitate opportunities to detect and treat any bodily processes that might be dangerous to a person's health.

The knowing underpinning these concerns build on epistemological realism, which assumes that reality, in this situation bodily processes, can be uncovered by biomedical research and that language used corresponds to the objects under study (Willig, 2013). Such approaches understand that language can be *merely descriptive*, even though some terms are considered more descriptive than others. Drawing on this perspective, some commentators in the area seem to promote the use of DSD because it is understood to correspond to reality.

In contrast, other stakeholders who also supported DSD did not seem to understand that terminology is merely descriptive. Instead, their driving motives to change the nomenclature seem to have built on the view that a change in language would elicit change in clinical practice. Some academics supported the term because they thought that DSD would promote an understanding of these conditions as "disorder[s] like many others", by moving the focus from identity and genitals to genetic and endocrinological functioning (Feder, 2009b: 134). Others suggested that in order for health professionals to agree on practice, they had to agree on terminology (Dreger & Herndon, 2009). Activists supporting the new nomenclature also raised the point that DSD was more familiar to the medical discipline and could elicit the best of medicine's humanistic project by promoting more appropriate responses. However, intersex could be used at the same time as DSD, because they refer to different things (Chase, 2006). The knowing underpinning these ideas emphasises that terms are never descriptive but performative, doing specific work. Some suggest, however, that the work that DSD has done in the topic area has not been in the direction that these academics and advocates hoped for; rather it has made medicalization even stronger (Davis, 2015).

**Arguments against DSD.** The main argument against DSD has been that the term is stigmatizing, pathologizing people's lives, and gives the medical community disproportionate power in defining people's embodiment and needs (Clune-Taylor, 2010; Davis, 2014; Holmes, 2011; Reis, 2007; Topp, 2013). From a critical psychosocial perspective, such medicalization is understood to frame people's understandings of themselves in ways that might impede wellbeing (Clune-Taylor, 2010). Several less-pathologizing terms have been suggested as alternatives to DSD; variations of sex development (Diamond & Beh, 2006), variations in reproductive development (Simmonds, 2007), divergence of sex development (Reis, 2007), differences of sex development (Tamar-Mattis, Baratz, Baratz Dalke, & Karkazis, 2014; Topp, 2013) and diverse sex development (Liao & Simmonds, 2014).

I argue that complicating factors in these discussions of terminology are the diverse epistemological perspectives underpinning each suggestion. This also relates to how the role of language as well as the role of medicine is conceptualised. As discussed above, if language is understood to be performative rather than merely descriptive, terms must be thoroughly and continuously reviewed in order to examine if they serve their intended purposes. If language is understood as performative there is especially a need to review medical diagnoses and discuss the role of medicine in classifying bodies (Dreger, 1998a; Garland, 2016).

One main criticism raised against medical diagnostic terms is that they confuse normative assumptions about bodies, gender and functionality with bodily processes where medical intervention might be needed for survival or physical wellbeing. This means that diagnostic terms typically include bodily states or processes signifying a need of health care and “atypicality” where a need of medical interventions is not needed. This is evident in, for example, ICD-10 where symptoms (i.e. of bodily processes) as well as reasons for seeking health care (i.e. not liking your body) are understood in relation to diagnostic criteria. Disability activists and academics have effectively deconstructed these assumptions and many commentators on intersex/DSD have argued that we need to learn from this important work (Holmes, 2011; Kon, 2015; Koyama, 2006; Reis, 2007).

Using the arguments presented by representatives of biomedical frameworks that a descriptive term is needed in order to point to such bodily processes where medical intervention is needed, DSD might still be considered to be no more descriptive than intersex, because it still confuses bodily variation beyond norms with bodily processes that might signal a need for health care (Clune-Taylor, 2010). I argue that if health professionals need an umbrella term to cover specific conditions that are understood to affect sex development in order to identify instances when medical care is needed (in order to save lives or promote physical wellbeing) then why not use a term like *conditions* or *diagnoses classified as affecting sex development*? This, however, builds on an assumption that the role of medicine is to promote physical health, not generally label or describe bodily variations.

Finally, some authors further suggest that while using diagnostic criteria in order to develop knowing in relation to medical aspects, many psychosocial challenges are shared across diverse conditions. In contrast to the medical ideal to study separate diagnostic groups on a range of variables, a “non-categorical” approach can be more useful in developing psychosocial knowing (Sandberg & Mazur, 2014). The development of such knowing is considered in the next chapter.

#### **4. MAKING SENSE OF EXPERIENCES: Drawing on the body of psychosocial knowledge**

While it was suggested in the consensus statement that professionals drawing on psychosocial knowing are important parts in the MDT to assist decision-making and promote adjustment for the family and the patient (Lee et al., 2006), authors of the global update addressed that psychological interests are much broader in this area (Lee et al., 2016). In the global update it was also argued that the term “psychosocial” needs conceptual clarity (Lee et al., 2016). Several commentators have tried to summarize the kind of psychosocial research that is needed in relation to intersex/DSD. Most of these conclude that research on brain organization theories dominates the area and that there are several other issues where psychosocial knowing is needed (Liao & Roen, 2014; Roen & Pasterski, 2014; Sandberg, Gardner, & Cohen-Kettenis, 2012; Stout, Litvak, Robbins, & Sandberg, 2010). For example, psychosocial adaption of the patient, including stable gender identity, self-esteem and/or having a good life, have historically been articulated as goals of medical treatment (Kessler, 1998). Also today some suggest that “[m]edical management decisions in DSD are often based on promoting psychological adaptation and well-being rather than a physical health need *per se*” (Brain et al., 2010, p. 342).

The emphasis on psychosocial perspectives has encouraged researchers, with diverse underlying theoretical perspectives, to engage in the area since the consensus (Liao & Roen, 2014). While some work in accordance with dominant medical knowing described in chapter 3, others explicitly draw on critical perspectives that seek to challenge taken-for-granted understandings about bodies, identity, gender and children. As mentioned in chapter 2, these critical approaches have, historically, focused less on interventions or bodies *per se*, but rather on *experiences* of medicalization, embodiment and related issues of shame and secrecy. Below, I interrogate some post-consensus developments of psychosocial research.

##### **Moving from information and decision-making to sense-making**

The consensus statement highlighted the value of psychosocial knowing in relation to aspects such as information management, coping and decision-making (Lee et al., 2006). In recent years, the importance of full disclosure of medical information to patients and parents has been emphasised (Allen, 2009; Garrett & Kirkman, 2009; Guth, Witchel, Witchel, & Lee, 2006; Liao, Green, Creighton, Crouch, & Conway, 2010) and various authors have proposed age-appropriate ways of sharing information with children (Allen, 2009; Wisniewski, Chernausek, & Kropp, 2012).

Research suggests that younger people now have more knowing about their conditions compared to those patients who were subject to previous decades' non-disclosure practices. However, the rate at which young people know about their condition is far from a hundred percent (Liao et al., 2010; Migeon et al., 2002; Simmonds, 2012; Tamar-Mattis et al., 2014), and some explanations for this lack of knowing have been proposed (Liao et al., 2010; Sanders & Carter, 2015). Possible explanations include that the main responsibility for information giving is attributed to parents instead of medical doctors (Liao et al., 2010; Simmonds, 2012). Some studies imply that parents think it is important to share information with their children (Dayner, Lee, & Houk, 2004), but that some find it challenging to do so (Freda, Dicé, Auricchio, Salerno, & Valerio, 2014). These studies suggest that a pragmatic focus on disclosure need to consider these challenges in order to assist parents and young people in developing knowing about intersex/DSD.

Research also shows that the way information about intersex/DSD is being presented to families during assessment is important for parental coping (Boyse, Gardner, Marvicsin, & Sandberg, 2014; Duguid et al., 2007; Freda et al., 2014; Jürgensen, Hampel, Hiort, & Thyen, 2006; Pasterski, Mastroyannopoulou, Wright, Zucker, & Hughes, 2014; Zeiler & Wickstrom, 2009). Some of these studies suggest that parents' coping is affected by health professionals' understandings of sex and their ability to communicate that a decision on a certain gender assignment is difficult (Crissman et al., 2011; Freda et al., 2014; Gough, Weyman, Alderson, Butler, & Stoner, 2008; Sanders, Carter, & Goodacre, 2008, 2011). Again, these findings suggest that providing families with knowing seems to be more than just presenting descriptions of bodily states or processes. Rather, it seems to be about engaging with the taken-for-granted ideas about bodies and gender that underpin medicine as well as most people's everyday understandings.

Another important psychosocial concern is the involvement of parents and patients in medical decision-making (Asciutto et al., 2011; Karkazis, 2008b; Roen, 2009). Studies have shown how parents have experienced decision-making with regards of gender assignment and surgery. These results suggest that some parents put their trust in the recommendations given by medical experts, without questioning it (Crissman et al., 2011; Karkazis, 2008b; Kessler, 1998; Zeiler & Wickstrom, 2009). Some studies have also shown that gender assignment usually is understood to imply early genital surgery and that parents might need support to disentangle these two different aspects (Sanders et al., 2008; Zeiler & Wickstrom, 2009). Results also show that surgery has been done, sometimes without a decision-making process, because parents have wanted it (Crissman et al., 2011) or because health professionals have

recommended it (Dayner et al., 2004; Sanders et al., 2008; Zeiler & Wickstrom, 2009). Studies with laypeople without personal experience of intersex/DSD further inform how information impacts decision-making. Streuli, Vayena, Cavicchia-Balmer and Huber (2013) showed that participants made different treatment choices depending on what kind of information they received. Participants, who were asked to imagine themselves being a parent with a newborn child with genital features considered atypical, opted for surgery to a significantly larger extent if they were presented a video with medicalized information compared to those who were presented a video that highlighted resilience.

Even though many clinicians and support groups advocate for full patient involvement in medical decision-making (Tamar-Mattis et al., 2014), the results from these studies suggest that such involvement can be challenging. Some commentators argue that in order to address these complicated situations, research need to move beyond the underlying ideas that good decision-making happens because correct medical information has been given by health professionals to families (Karkazis, 2008a). In literature on patient education in chronic conditions it is further suggested that information is not enough to support patients and families (see e.g., Canam, 1993; Hartzler & Pratt, 2011). Instead, processes of sense-making should be supported as well as the acquirement of a range of skills in order for patients and families to develop the kinds of knowing that are useful in everyday life (Pols, 2013). I argue that these critical perspectives, which move from information to emphasise sense-making and knowing, is important to develop the psychosocial body of knowledge in intersex/DSD.

### **Moving beyond a sole focus on gender identity and (re)assignment**

The dilemmas of gender assignment identified in the medical literature have led commentators to suggest that psychosocial research plays an important role in relation to aspects such as gender identity and gender (re)assignment (Lee et al., 2006; Lee et al., 2016). One of the primary psychosocial concerns stated in the medical literature is how to predict later gender identity (Lee et al., 2006; Lee et al., 2016). These documents share the ambition of neuro-scientific research to find one or several variables that could help clinicians determine a child's "true sex" or later gender identification (Dreger, 1998b). Such theories have been extensively researched in recent years (Jordan-Young, 2012; Stout et al., 2010).

The knowing underpinned by realist epistemologies evident in these research efforts has been questioned by critical psychosocial commentators. Roen (2008) has drawn attention to the risk of medical professionals dictating the kind of research input that psychosocial commentators should have in intersex/DSD. This puts psychosocial

professionals in danger of being complicit with a medical model of care instead of using psychosocial expertise to promote wellbeing. I argue, from a transformative and pragmatic stance, that psychosocial knowing need to include ideas on gender that moves beyond theories on prenatal hormones in order to be helpful in people's everyday life.

Several commentators acknowledge that there are numerous important factors that contribute to gendered behaviour (Hines, 2011; Liao, Audi, Magritte, Meyer-Bahlburg, & Quigley, 2012; Steensma, Kreukels, de Vries, & Cohen-Kettenis, 2013). Alternative models include multidimensional theories of gender identity, such as the one suggested by Egan and Perry (2001). Others have emphasised how societal understandings of gender as binary or non-binary, as well as legal possibilities in different countries, affect the possibilities for identifications that are available for people (Meyer-Bahlburg et al., 2016; Schweizer, Brunner, Handford, & Richter-Appelt, 2014). Commentators have also suggested that instead of focusing on gender identity outcomes alone, research need to be complemented with studies that could improve clinical practice and, in turn, promote wellbeing for patients and families more directly (Liao & Simmonds, 2014; Stout et al., 2010). Similar concerns have also been raised by support group representatives (Magritte, 2012).

### **Moving from quality of life to a focus on experiences and human rights**

The consensus statement (Lee et al., 2006) and global update (Lee et al., 2016) did emphasise the importance of promoting wellbeing and, in order to be able to do so, called for better measures to address patient outcomes. Prompted by this call, research on patient adjustment and wellbeing, in quantitative studies usually operationalized as *Quality of Life (QoL)*, has grown extensively in recent years (Alpern, Gardner, Kogan, Sandberg, & Quittner, 2016; Sandberg et al., 2011). The results of some of these QoL-studies were reviewed in a paper by Nordenstrom (2015). While some articles indicated a good general health or no impairment in psychological adjustment, a majority of the studies indicated mildly impaired to impaired QoL or other psychosocially relevant difficulties. Later studies also show variable outcomes in relation to QoL (e.g. Amaral et al., 2015). While the participants in an Italian study on XY-women did well in education and professional life and had good QoL, they did score higher on scales measuring mental health problems compared to controls (D'Alberton et al., 2015). QoL-measures have also been developed to address more specific subdimensions of health, such as Sexual QoL (SexQoL). A review paper on SexQoL in 46,XY DSD showed participants' overall ratings indicated impaired sexual function and satisfaction, but many

studies have methodological issues (Schönbucher et al., 2010). Later studies have, however, confirmed these results (Callens et al., 2012).

As shown by the examples above, the findings on QoL are variable and, even from a realist epistemological stance, might be hard to interpret in order to suggest improvements. This is due to problems such as: differences between QoL-scores and results on other psychological measures as showed in D'Alborton (2015); results being highly dependent on the terms being used to recruit participants (e.g. if “intersex” or “DSD” is used); and difficulties to establish cause-effect relationships between, for example, surgery and wellbeing. Some authors in the global update are sceptical that QoL-scores can be used as indicators of clinical care or patient wellbeing, because “[a]ny causal link between a diagnosis and a single psychometric measure is flawed [...] Wellbeing may be affected in highly specific ways at certain times” due to a range of reasons (Lee et al., 2016, p. 10).

Similar concerns have been raised by other commentators. Prutkin and Feinstein (2002) conclude that there are a vast range of problems with QoL-measures that can be attributed to the fact that these instruments are developed within the social sciences *and* in medicine. The underpinning theories and traditions within these two streams are very different and none of them seem to have generated an approach that would be able to adress a specific person’s complex and changing ideas about their own quality of life by using standard indexes. As a solution to this problem they suggest a “return to an old clinical approach, which directly asks patients to indicate what they feel” (Prutkin & Feinstein, 2002, p. 89).

From a transformative and pragmatic point of view, it is questionable how knowing about QoL on a group level could be used to promote wellbeing for a specific person. While commentators highlight a need to develop evidence-based guidelines in order to champion effective psychosocial support and counselling to people with personal experience of intersex/DSD (Ahmed et al., 2015; Cohen-Kettenis, 2010; Liao, 2008, 2012; Liao & Simmonds, 2014; Roen, 2015; Sandberg et al., 2012), some also point to the inherently problematic aspects of such knowing (Liao & Simmonds, 2014). Because evidence-based guidelines typically rely on large-scale data and produce results that are relevant on a group level, these do not give voice to peoples’ actual experiences and, thus, give little guidance on how to support a specific person with distinct experiences of intersex/DSD. In addition to large-scale studies prioritized in the area (Sandberg, Callens, & Wisniewski, 2015), several commentators call for more qualitative research that could contribute with better in-depth understandings of people’s everyday lives (Guth et al., 2006; Schönbucher et al., 2010; Stout et al., 2010).

Some also argue that an evidence-based care needs to be complemented by value-driven intentions (Liao & Simmonds, 2014). The latter would require health professionals and researchers "to be explicit about the theories and values that define their professional priorities, methods, transactions and goals, as they actively navigate conflicting agendas and embedded assumptions" (Liao & Simmonds, 2014, p. 96). Liao and Simmonds suggest that championing emotional safety, dignity and wellbeing within health care will only be possible by engaging critically with the theories and values that are underpinning clinical practice. This also requires health professionals to engage with human rights-issues and of ethics (Liao, 2008; Liao & Roen, 2014; Roen, 2015). Drawing on human rights-perspectives, several commentators have also raised the point that what needs to change is society, not people's bodies (Reis, 2007), and that this can be achieved by working with affirmative approaches to intersex/DSD and by raising awareness in the general population (Roen, 2015). Such ideas underpin this transformative project and are further highlighted in the next chapter.

## **5. MAKING SENSE OF POLITICS: Drawing on bodies of human rights and ethics**

Ethics and human rights concerns about medical practice have been put forward by activists and academics since the 90s (Dreger & Herndon, 2009) and is increasingly being attended to by international bodies such as the UN (United Nations Human Rights Council, 2013) and the EU (The European Union Fundamental Rights Agency, 2015). While some activists and support groups have collaborated with or supported health professionals to develop new guidelines, other groups have been critical of these models (Davis, 2015). Instead of organizing themselves around DSD or a specific condition, groups such as Intersex UK and OII have an explicit focus on promoting human rights in the area. These groups have, together with others, played an essential role in making bodies, such as the UN, aware of the human rights situation related to intersex/DSD. The focus on human rights can be interpreted as representing a body of knowledge that creates an alternative ground for knowing in the area that is not medical. By using the legitimacy invested in ethics and human rights, this body of knowledge aims at curtailing harmful medical practices.

### **Some human rights and legal responses to clinical dilemmas**

Human rights related to intersex/DSD have been highlighted in relation to several legal processes and important legislative changes since 2005 (Garland, 2016). Such approaches understand people with experiences of intersex/DSD to be entitled to human rights and protection against discrimination. In some countries these rights are understood to be covered in existing sex discrimination acts, while in other countries new acts have been proposed (The Council of Europe Commissioner for Human Rights, 2015; The European Union Fundamental Rights Agency, 2015; Travis, 2015). In Malta, for example, the new legislation includes discrimination on the grounds of sex characteristics (Malta, 2015).

The consequences of the construction of sex as binary have also increasingly been challenged (United Nations Human Rights Council, 2013). This critique includes the impact that sociocultural constructions of sex have on *gender assignment* and *early surgery*. It has been argued, for example, that no one can make a certain decision about gender assignment for any child (Garland, 2016) and that efforts need to be made to ensure the protection of the child's right to mental integrity and free development of personality (The Council of Europe Commissioner for Human Rights, 2015). Some countries, such as Germany (German Ethics Council, 2013) and Australia (Australian Government Attorney-General's Department, 2015), now recognize a third legal gender category. Such legal recognition opens up new

possibilities in relation to gender assignment, because it does not force parents to make decisions about a gender for their child (The Council of Europe Commissioner for Human Rights, 2015; The European Union Fundamental Rights Agency, 2015). Some critics have argued, however, that a third legal category to use when a child is born where intersex/DSD is evident is problematic of several reasons, including the risk of making medicalization stronger and issues of stigmatization even worse (Travis, 2015).

Several commentators also argue that irreversible early surgery is underpinned by the demand of gender assignment and that parents might feel persuaded or unable not to consent to such interventions (Tamar-Mattis, 2013; The Council of Europe Commissioner for Human Rights, 2015). However, not all children (irrespective of sex development) grow up to identify with the gender they were assigned. Thus, irreversible surgery is problematic because it might remove tissue that a child would have wanted or needed later. Medically unnecessary early surgery, done without free and informed consent, is, also being condemned by several bodies because: it violates the right to bodily integrity and individual autonomy; risks inflicting pain; refuses people their rights to health (including sexual and reproductive rights); and can be seen as torture or degrading interventions (Tamar-Mattis, 2013; The Council of Europe Commissioner for Human Rights, 2015; The European Union Fundamental Rights Agency, 2015; United Nations Human Rights Council, 2013).

Finally, these human rights documents highlight the importance of the right to *full information*, access to medical notes as well as the need for the individuals to be fully involved in medical decision-making (Tamar-Mattis, 2013; The European Union Fundamental Rights Agency, 2015). While many highlight the importance of self-determination, parental possibilities to consent is protected by privacy rights, for example in the US (Tamar-Mattis, 2013). In Europe, it is unclear how to best involve children in decision-making as well as to handle situations where children and parents might disagree (The European Union Fundamental Rights Agency, 2015).

### **Ethical and human rights concerns addressed in medical literature**

Human rights and ethical concerns are mentioned in some medical literature, however usually as an add-on. The consensus statement included an appendix with legal issues relating to DSD care, including aspects such as informed consent, the right to medical information and also parental rights and responsibilities (Lee et al., 2006). A section focusing on ethics and human rights was also included in the Global Update (Lee et al., 2016).

Many of the principles highlighted in human rights documents have also been included

in ethical guidelines to be used in medical treatment of children experiencing intersex/DSD. The importance of fostering wellbeing (Wiesemann et al., 2010), by minimising physical and psychosocial risks, preserving fertility and promoting capacity for sexual relationships (Gillam, Hewitt, & Warne, 2010), has been suggested. Wiesemann et al. (2010) state that if there are any doubts as to why a certain intervention should be done, the psychological and social support of the family and child should be considered more important than, for example, physical normalcy. Several commentators have also argued for a principle of delaying all treatments that can wait, and leaving the future as open as possible (Gillam et al., 2010; Kon, 2015), in order to make sure that children are involved in decision-making and have the chance to identify with the gender they feel comfortable with (Kon, 2015; Wiesemann et al., 2010). Some also suggest respecting the wishes and beliefs of parent (Gillam et al., 2010) or respecting the family and the parent-child relationship (Wiesemann et al., 2010). In addition to these ethical guidelines, several national ethics councils have addressed the ethical concerns inherent in medical practice (ETENE, 2016; German Ethics Council, 2013; Helsedirektoratet, 2016; Swedish National Council on Medical Ethics, 2015; Swiss National Advisory Commission on Biomedical Ethics, 2012),

### **(In)compatible underlying perspectives in medicine and human rights?**

Even though some medical literature mention ethics and human rights it is unclear if the frameworks of ethical knowing inform medical practice, or if these writings are just added to the literature without any further engagement. Even though medical practice is governed by medical law and professional ethics, such frameworks of knowing are very different to medical knowing (Alm, 2006). Diverse perspectives and values underpin these differences, including the way intersex/DSD is perceived. As mentioned, the medical term DSD suggests that it should be understood as a disorder (Lee et al., 2006), implying a malfunction or malformation. In human rights contexts, however, intersex is used suggesting it should be perceived as a human variation in sexed embodiment. Some advocates have recently suggested a post-medicine definition of intersex as "the lived experience of the socio-cultural consequences of being born with a body that does not fit the normative social constructions of male and female" (van der Have, 2016). I argue that these differences create an inevitable gap between understandings in health care and legislation that needs to be addressed in order for knowing in ethics and human rights to work as transformative resources changing medical practice.

## **6. POSITIONING THIS BODY OF KNOWLEDGE: Drawing on the body of social studies of science**

As I demonstrated in the previous chapters, what is considered to be historical and current knowing in the area of intersex/DSD is promoted by diverse bodies of knowledge that are underpinned by different epistemological understandings connoting power in diverse and complex ways. While promoting wellbeing or a good life for people with experiences of intersex/DSD seems to be an agreed priority (Davis, 2015; Lee et al., 2016; Wiesemann et al., 2010), perspectives differ on how this can be achieved. Authors of medical guidelines suggest that more research needs to be done to provide evidence-based protocols and resolve persistent clinical dilemmas. They also suggest that better genetic understandings of specific diagnoses and condition-specific outcome studies will reduce uncertainty about optimal treatment (Lee et al., 2016). Several current international research collaborations have been formed working from this understanding (Sandberg et al., 2015). In policy oriented contexts, however, ethicists and human rights advocates argue for the importance of legislation to curtail medical intervention and promote human rights protection along with other minorities (The European Union Fundamental Rights Agency, 2015). These parallel developments seem to be happening without a shared nomenclature or agenda.

So where could a research project usefully sit in this complex scene where diverse bodies of knowledge claim to present solutions to resolve the dilemmas inherent in the field? In order to better understand the complex environment of knowing characterizing the topic area, I utilize theories from social studies of science.

### **Two waves of knowing and expertise**

Scientific expertise has been interrogated by social studies of science, however from different perspectives. Collins and Evans (2002) have outlined “three waves” of how expertise has been conceptualized. During the first wave, dated to the 50s and 60s, an expert in one field was positioned as *the* authority having *the* knowing in the area and also in unrelated fields. Experts were understood to share their knowing with laypeople in a ‘top-down’ fashion. These representations of experts by science studies scholars also reified the idea of the progression of science and the authority of scientists.

With the questioning of positivism and the postmodern critique of science, a new wave of perspectives on expertise emerged during the 70s. Research was increasingly being conceptualised as a social activity where factors “outside” of the scientific activities *per se* were given more attention. This involved what kind of research that was funded, how certain

groups of researchers, but not others, were given legitimacy as well as how scientific knowing was used by institutions in society in relation to policy making, education and in courtrooms. Collins and Evans (2002) argue that these developments in science studies deconstructed the notion of ‘expertise’ by showing that the matter of who is considered to have expertise is a negotiable one, as is determining who is understood to be knowledgeable – all of which changes in different contexts and times.

These two understandings of expertise are applicable in making sense of the developments in the field of intersex/DSD. The uncontested nature of the optimal gender policy is understandable in light of the first wave of expertise, in which doctors are positioned as “knowing best” and people trust the judgements made by professionals and researchers. However, this notion of expertise was destabilized by the lived experiences brought forward by activists during the 90s. By showing that interventions grounded in medical expertise in the topic area did not work as intended, people with personal experience claimed knowing over what was best for themselves and their bodies. In accordance with the second wave of making sense of expertise, the understanding of *who* was considered to be in a position to have essential knowing was, thus, deconstructed in the area of intersex/DSD.

Collins and Evans (2002) argue that the second wave of understanding expertise has functioned well to highlight the complexities of knowing. This also destabilized the notion of authority and introduced more egalitarian principles, such as democracy and human rights, relevant in understanding expertise. From this perspective, people without formal scientific training were given agency in questions that were related to them, even though they did not have specific training or scientific knowledge about the topic. However, they argue that there are problems with the second wave of understanding expertise as well. The authors call it “the problem of extension” (Collins & Evans, 2002, p. 235f), defined as the problem how, and to what extent, participation of different stakeholders, with scientific or other kinds of expertise, should influence the recommendations or decisions when it comes to specific issues.

### **A third wave of knowing and expertise**

To solve the problems with earlier understandings, Collins and Evans (2002) proposed a third wave of conceptualising expertise. If wave one concentrated on authority and wave two on egalitarian principles, they suggest that researchers should focus on expertise and knowing *per se*, and try to work out how to use expertise in constructive ways. While the first wave divided the population in two, where a small top of authorities held ‘the truth’ and were clearly separated from the ‘laity’, this thick boundary was deconstructed during the second

wave. As a suggested third wave, Collins and Evans (2002) emphasized the boundary again. However, this line is not used to separate authorities from the public, but rather, the certified specialists in a specific academic field from other scientists without specific knowledge. Included in the group with expertise are also uncertified experts from the public that have important and specific experiences related to the area of interest.

They suggested that scientific training might be important to become an expert, but it is not enough. They also introduced the term “experience-based expertise” and made clear that “it may be necessary to have experience in order to have experience-based expertise, but it is not sufficient” (Collins & Evans, 2002, p. 251). A person living with a specific condition might have expertise that could contribute to the general field of research of that condition. However, a person might not be considered to have expertise if it is judged that anyone could master this situation without practice; some kind of skill must have been acquired.

Expertise can also be conceptualised as to exist on different “levels”. Those with no expertise are usually unable to contribute to a specific issue in constructive ways. However, non-experts are able to have an opinion on what kinds of knowing that seems plausible in a certain situation and what experts they find credible. Another level of expertise is interactional, which means enough understanding to interact with different experts in a constructive way and also translate knowing to non-experts. Closely related is referred expertise, which denotes a situation where knowing from one field can be used in another. Finally, a level of contributory expertise involves someone with enough expertise to contribute to the same extent as the core set of scientists in the area. These levels are not to be seen as static or even ‘real’, but as useful frameworks in order to make sense of the role people with different expertise can play in relation to knowing in a specific area. Collins and Evans (2002) suggested that in research where there are several parties of contributory expertise, the interactional expertise becomes essential in order to create constructive outcomes by communicating with different groups to make sure that knowing is combined.

### **Applying theories of knowing and expertise on intersex/DSD**

It might be argued that by using the third wave of understanding expertise to interrogate the current state of knowing in relation to intersex/DSD, the diverse bodies of knowledge presented in earlier chapters can be seen as diverse bodies of contributory knowing. Lacking in the literature is, however, knowing that resembles what Collins and Evans (2002) called interactional expertise.

There are some efforts in the subject area of combining different contributory bodies of

knowledge. As an example, ethical knowing is used to improve medicine in the ethical guidelines presented in chapter 5. Many also argue that human rights and policy should not only be used to curtail potentially harmful medical interventions, but also to strengthen the right to access patient-centred care, when needed (Asciutto et al., 2011; Liao & Simmonds, 2014). Patient-centred care can be interpreted as an attempt to integrate egalitarian principles in medical practice. As such, some commentators suggest that patient-centred care has shifted medicine from a perspective where the medical doctor is seen as *the* expert, to a framework where the expertise of the patient is recognised as well (Bensing, 2000).

At the same time as the importance of patient-centred care is increasingly being emphasised in medicine, numbers of consensus statements building on evidence-based medicine are being produced (Bensing, 2000); a development also evident in intersex/DSD (Lee et al., 2006; Lee et al., 2016). The original idea of evidence-based medicine focused “on determining the best research evidence relevant to a clinical problem or decision and applying that evidence to resolve the issue” (Haynes, Devereaux, & Guyatt, 2002, p. 36). Some commentators argue that there is no conflict between evidence-based medicine and patient-centred care, and that the latter can easily be incorporated within the evidence-based medicine paradigm, as done in later definitions (Epstein & Street, 2011; Haynes et al., 2002). Others, however, think there are challenges in combining these two values in practice (Bensing, 2000; S. Oliver, 2009). One crucial difference relates to the underlying understandings of each framework. Some argue that while patient-centred care puts the specific person at the centre of attention, evidence-based medicine, on the other hand, is disease- and clinician-focused, making these two approaches “separate worlds” (Bensing, 2000). Providing an evidence base could also be understood to lend particular health professionals the power and authority of a joint scientific community. Instead of moving towards a third wave of making sense of expertise, evidence-based medicine could be interpreted as a new way to restore authority of medicine. A similar interpretation of why DSD was suggested and now consistently used in medicine is offered by Davis (2015).

To summarize, there is now a situation of knowing in relation to intersex/DSD where the egalitarian understanding of expertise (similar to the second wave) is put forward by policy-makers and human rights advocates, as well as by those who promote patient-centred care. And at the same time, the authority of evidence-based medical guidelines (similar to the first wave), building on large international scientific collaborations, is suggested to solve the dilemmas inherent in intersex/DSD. This is further complicated by the use of separate nomenclature, underpinned by different epistemological frameworks. I argue that in order to

transform the knowing in this topic area to work to promote wellbeing and social justice for people with lived experience of intersex/DSD, there are important challenges to find perspectives, theories and language that could identify aspects of these different contexts that could serve as interactional knowing in the area.

### **Developing interactional knowing in intersex/DSD**

This project is an attempt to develop interactional knowing, by interrogating the possible contributory knowing provided by different bodies of knowledge in intersex/DSD. From a social constructionist or discursive point of view, these different bodies of knowledge build on different ontological and epistemological understandings. The performative aspects of the knowing presented by different bodies of knowledge work in different ways, opening up some possibilities and closing down others. Therefore, they are not considered to contribute in equal ways to a shared goal. From a pragmatic perspective, however, the diverse bodies of knowledge reviewed in the previous chapters can be considered as contributing, in different ways, with certain expertise to the topic area *as long as* they promote wellbeing and social justice. Drawing on discursive perspectives, these need to be carefully and continuously interrogated and reviewed, especially against the needs expressed by the people affected by such knowing (Hacking, 2002). Activists, patient and support groups are crucial in addressing such needs. Commentators suggest, however, that also researchers should address the knowing that people develop and use in their everyday lives in systematic manners (Pols, 2013). The experience-based expertise that people with personal experiences of intersex/DSD have developed is, thus, understood as an additional body of contributory knowing and explored in the empirical part of this project. I argue that such knowing cannot be studied solemnly by measuring variables, but by carrying out qualitative in-depth investigations.

Finally, in order to develop interactional expertise, the kinds of knowing that non-experts, without any formal training or personal experiences, might bring to the area is explored. Several commentators have suggested that a useful way of developing knowing in the area would be to engage with non-affected populations (Liao & Simmonds, 2014). Such suggestions are built on the fact that most people who find themselves in a situation where intersex/DSD becomes a lived reality, usually do not have any prior knowledge of the topic. More empirical data on the understandings that people bring to these situations could inform how support can be tailored in clinics and in other settings where information about intersex/DSD is shared. Studies on non-experts have contributed with such useful input on, for example, medical decision-making in intersex/DSD (Kessler, 1998; Streuli et al., 2013).

## 7. BUILDING THIS BODY OF KNOWLEDGE: Presenting methods and participants

In order to study experience-based knowing in detail, I chose a mixed-methods design, with a primary focus on qualitative methodologies. Qualitative projects typically describe the context-dependent nature of processes or experiences by engaging with specificity as well as diversity (Magnusson & Marecek, 2010). Kvale (1997) has pointed out that qualitative data-generating activities “are not progressive or repressive in their own right; the value of the knowledge produced is dependent on the context where this knowledge is situated and how it is used” (p. 71). However, Kvale has also argued that qualitative researchers, traditionally, are more open to discuss the political aspects of their work. Qualitative methods have also been used in transformative research for decades (Mertens, 2009). As such, such methods were considered appropriate in addressing the research questions in this project. In this chapter, I present the data-generating activities, ethical permissions, participants and analytical methods.

### Data-generating activities

**Interviews.** When describing interviews, Kvale (1997) refers to the French word *entrevue*, meaning between two views or perspectives. By using interviews, the researcher aims to understand the world as experienced by the interviewee. Kvale suggests that doing interviews is not a matter of collecting data, but rather an activity of generating, or co-creating, data in dialogue with the participant. Informed by this understanding, I understand interviews in this project to be an activity in co-creating knowing.

A semi-structured interview typically assists the researcher to stay focused on the phenomena of interest, while allowing the participants to freely develop their thoughts or individually frame their responses (Kvale, 1997; Willig, 2013). This makes the method open and flexible. However, it also requires the researcher to know the research field and the underpinning theoretical perspectives framing the project well in order to generate useful data. The interviewer should be structured, sensitive and open about the aim and purpose of the study, in order to involve the participant as much as possible (Kvale, 1997). These ideals have guided the interview processes in this project.

**Focus groups.** Focus groups are usually defined as group interviews focusing on the content of the issues being discussed as well as on the social interaction of the group (Freeman, 2006; Redmond & Curtis, 2009). Stewart, Rook, and Shamdasani (2007) suggest that focus groups are especially appropriate when conducting in-depth explorations of a particular situation or issue. Focus groups are able to reveal how “points of view[s] are

constructed and expressed” (Barbour & Kitzinger, 1999, p. 5). Participants also “obtain immediate feedback on their own views and constructions of reality, as their stories are challenged, corroborated or marginalized by their peers” (Green & Hart, 1999, p. 24). This makes an analytical focus on context as well as “different repertoires of knowledge” (Green & Hart, 1999, p. 34) important in the interpretation of focus group data.

Stewart et al. (2007) also highlight that focus group participants should be understood as meaning-making subjects that are framed by their context and interaction with others. In order to address these aspects, the researcher should use a semi-structured approach that makes interaction possible. However, in contrast to semi-structured individual interviews, the number of focus group-participants shifts the power balance between the participants and the researcher. This challenges the understanding of who is the essential agent in generating the knowing that becomes evident in the research setting (Barbour & Kitzinger, 1999).

**Transforming qualitative to quantitative data.** Even though many writers on methodology make a sharp distinction between quantitative and qualitative methods, such separations have been criticised in the growing literature on mixed methods (Johnson & Onwuegbuzie, 2004). Arguing from a pragmatic perspective, proponents of mixed methods suggest that methodologies should be appropriate in relation to the issues or phenomena that are to be studied. Thus, even though the data were generated with qualitative methods in this research, some were analysed quantitatively. This part of the data was usually identified during the first steps of thematic analysis. The assumptions underpinning these results are, however, also based on the understanding that data is socially constructed. Even though the results can be seen to illustratively point to important processes that might be evident also for other people, the numbers presented are not to be understood as automatically representative of opinions expressed in a larger population.

### **Ethics and ethical permissions**

This research project is informed by the idea that ethics are part of the whole research process. Throughout the project, I have tried to be transparent about the frameworks and understandings that I have used and the rationale behind the choices that I have done. Reflections of such “macro-ethics” (Brinkmann & Kvale, 2008) are included throughout this thesis. However, the ethical considerations understood as “micro-ethics” are highlighted here.

This research is informed by literature examining ethical issues raised by doing research with young people on sensitive issues (Caskey & Rosenthal, 2005), for example by ensuring that the consent process was negotiated with research participants in an interactive

way, with the understanding that giving consent is not a one-off event. I have also used literature highlighting the importance of engaging stakeholders in the process (Jordan, Gust, & Scheman, 2005). User groups were consulted consistently throughout the research process and their input on how this project was carried out was considered. Some groups were AISSG UK, dsdfamilies and CAH organizations in Sweden and the UK. Such groups have also received updates on the development of the project via a newsletter that have been distributed twice a year. In addition, the project was informed by important documents by organizations such as OII Europe (Ghattas, 2015) and Intersex Initiative Portland (Koyama, 2003).

Ethical permissions were sought for all data generating activities and the permissions for each part of the project were sought and approved as follows: (a) Interviews with young people and parents, recruited and interviewed in the UK: The National Research Ethics Services: NRES Committee London/West London (REC: 11/LL/0385); The Joint Research Office at University College London Hospitals (R&D Project ID: 11/0143) and; The Ethics Committee at the University of Surrey (EC/2012/52/FAHS); (b) The interviews with young people, recruited and interviewed in Sweden: the Regional Ethics Committee in Stockholm (2008/1671-31/3); (c) The interviews with parents, recruited and interviewed in Sweden: the Norwegian Social Science Data Services (32055/3/MAS); (d) The focus groups in Sweden and the UK: Ethics Committee at the University of Surrey (EC/2013/86/FAHS); (e) The focus groups in Norway: the Norwegian Social Science Data Services (35028/3/KH).

### **Interviews with young people**

In order to access the experiences of young people, an age limit of 15-26 years was set. Ten young women (aged 18-26 years) who were already part of a larger research project at Karolinska were approached and informed about the study. Nine participants chose to be part of the study and 1 person declined. In addition, 1 young person was recruited after receiving information about the study from a support group in Sweden. In the UK, 23 young people (aged 15-26 years), attending the DSD-clinic at UCLH during September and October 2014, were approached and informed about the study. Of these, 10 young people accepted to be in the study and 13 declined the offer. Reported reasons why people did not want to be in the study were that they did not want to talk about their experiences or that they did not have time to be in an interview. In addition, two young people were recruited after having heard about the study via one support group in the UK.

The 22 participants who agreed to be part of the study were aged 15-26 years ( $M = 21.6$ ) and all were assigned female at birth. Three participants stated explicitly, however, that

they did not (only) identify as women. The reported diagnoses represented among participants were gonadal dysgenesis (7 participants), AIS (6 participants), CAH (5 participants) or other related diagnoses such as chromosomal mosaicism or Mayer Rokitansky Küster Hauser Syndrome, (MRKH; 4 participants). Of the participants, 12 were students, 8 were employed and 2 unemployed at the time of the interview. While 6 participants said that they had a relationship at the time of the interview, 14 said they were single or did not indicate their relationship status. Nineteen participants reported living in an urban area and 3 in a rural area.

One-to-one, in depth, semi-structured interviews were carried out with all participants, except one. This interview was conducted with the young person and the parent at the same time, in accordance with their wishes. Participants were able to choose when and where to meet. Most interviews were done at Karolinska, UCLH, at University campuses or in the home of the interviewer. Before the interview, each participant was guided through the information sheet by the interviewer. The interviewer also presented each item on the consent form before the participant signed it. The interview guide prompted the participants to talk about their life in general, the process that led up to the diagnosis, their experiences and thoughts of health care and treatment and their thoughts about the future. Follow-up questions were used to highlight issues that the young people found most challenging in their everyday lives as well as how they had understood interventions, treatments and recommendations and their level of satisfaction with any treatments that had been offered. The young people were also asked what terms or words they used if they had to talk about their condition and what they thought of the terms *intersex* and *DSD* (presented in English to all participants).

In addition, 13 young people were also presented three theories on gender and gender identity and asked what they thought of them. The theories presented were; (i) the brain organisation theory as described in Hines (2011), called *the hormonal theory*; (ii) the multidimensional theory on gender identity as described in Egan and Perry (2001), called *the psychological theory*, and (iii) *a cultural theory*: where gender was described to participants as arbitrary and dependent on cultural rules, discourses and legal contexts (Morris, 1995; Nanda, 2014). This data was later transformed to a quantitative scale where the theory considered most important was rated as number 1, the second most important as number 2 and the least important theory as number 3. These preferences were coded because the interviewee made the preference explicit during the interview.

Interviews lasted for 31-113 minutes ( $M = 64$ ) and were audio-recorded. Participants were given a gift card of approximately £15 as a token of appreciation.

## **Interviews with parents**

Parents were recruited via support groups in Sweden and the UK (26 participants), snowball sampling (i.e. parents recruited by their partner; 5 parents) as well as via the clinic at UCLH (2 participants). An additional five parents were asked to participate or showed an initial interest in taking part of the study, but declined or never contacted the researcher again. The 33 parents (24 mothers and 9 fathers) who participated came from 25 families. Twenty participants were recruited in the UK and 13 in Sweden. They were parents of 32 children (25 children reared as girls and 7 children reared as boys), aged 6 months-24 years ( $M = 9.9$  years), who had been diagnosed with CAH (22 children), AIS (5 children) or another diagnosis such as gonadal dysgenesis or 5 $\alpha$ -reductase (5 children).

Semi-structured face-to-face interviews were conducted with all participants but one. As described above, this interview was conducted with the young person and the parent at the same time. Participants were able to choose when and where to meet and most interviews were done in the home of the participant. Before the interview, each participant was guided through the information sheet and each item on the consent form before they were asked to sign it. The interview guide used in the parent interviews was similar to the one used with young people. It prompted parents to give a general description of their child, and talk about the process that led up to the child receiving the diagnosis, their experiences and thoughts of health care, treatment, and the future. In addition, parents were asked what they think the child feels about their development. Parents were also asked what terms or words they used if they had to talk about their children's condition and what they thought of the terms *intersex* and *DSD* (presented in English to all participants). Interviews lasted for 26-118 minutes ( $M = 72.5$ ) and were audio-recorded. Parents were also given a 15£ gift card.

## **Focus groups**

Focus group participants were recruited via universities in Norway, the UK and Sweden, or via advertisements in social media. A total of 82 participants showed interest to be part of the study. They were carefully screened with a questionnaire assessing their previous experience and knowledge of intersex/DSD and excluded if they indicated any knowledge. This happened in 9 cases. An additional 32 people who were interested did not attend, changed their mind or were unavailable to come on the dates that were suggested.

Ten focus groups (3-5 persons in each) with a total of 41 participants (31 identifying as women and 10 as men) were conducted in Norway (4 groups), England (4 groups) and Sweden (2 groups). Six groups included university students (aged 19-39 years,  $M = 21.9$ ), 2

groups included clinical psychologists in training (aged 22-33 years,  $M = 28.5$ ) and 2 groups included parents (aged 32-47 years,  $M = 36.4$ ). The author moderated the groups in England and Sweden and Ingrid Dønåsen led the groups in Norway. Focus group sessions lasted 80-121 minutes ( $M = 98.5$ ). Each participant was given a gift card of approximately £10.

The focus group guide was prepared to maximise active dialogue between participants. The session started with a presentation of the project. The first question asked participants to discuss what they thought clinicians do (and should do) when a child is born with atypical sex features (discussion 1). Next, two vignettes that highlight different clinical dilemmas were presented. During the first vignette participants were invited to discuss what they would do in situation where a child was born with a clitoris considered larger than average, and in which health professionals offered hormonal and surgical treatment. Half of the groups were prompted to imagine that they were the parent of this child. The other groups were prompted to imagine that this had happened to them when they were born (discussion 2). The second vignette dealt with disclosure of medical information to young people. Participants were invited to imagine a teenage girl that had not started having periods yet. Her parents had taken her to the doctor, who had done lots of tests. The health professionals had contacted the parents to tell them that the girl had XY-chromosomes, testicles instead of ovaries and no uterus. Half of the groups were prompted to imagine that they were the parent of the girl and if, and how, they would tell their daughter about this. The other half of the groups were supposed to imagine themselves being this girl and asked if they would like to know this information, and in that case, how they would like to receive it (where, when and by whom; discussion 3). Next, participants were asked to discuss what they thought about the terms *intersex* and *Disorders of Sex Development (DSD)* (presented in English to all groups) and to suggest alternative terms to describe atypical sex development (discussion 4). Finally, they were asked to individually rate the importance of the *hormonal*, *psychological* or *cultural theory* on gender and gender identity (described above) when talking to a young person with experience of atypical sex development in order to help that person make sense of the situation. The ratings were made on paper where the most important theory was rated as number 1, the second most important as number 2 and the least important theory as number 3. They were later asked to discuss their ratings of these theories (discussion 5).

### **Preparation of data**

The 55 interviews and 10 focus groups were transcribed verbatim and anonymized. In the process of anonymization participants included in paper II were given a pseudonym.

Participants in paper I, III and IV were given a code. Young people were given a number (e.g. YP1), and this principle was also used for parents (e.g. P2). Focus group participants were given a code (e.g. P3FG4) consisting of a participant number (P3) and the number of the focus group (FG4). The process of anonymization also involved the removal of potentially identifying information (i.e. names of hospitals, consultants, country or hometown).

The data was coded in NVivo software (version 10 for Windows, by QSR International), which was also used to facilitate qualitative analytical procedures. SPSS Statistics Software (version 23.0 for Mac, by IBM) was used for the quantitative analyses.

### **Analytical approaches**

Below, the main analytical approaches utilized to interpret the meaning of the data are presented. However, the underlying understanding of what an analysis ‘is’, has been informed by the ideas presented by Kvale (1997). He suggested that the analysis happens on several different levels, continuously during the research process. During the interview, the participant might reinterpret and find new meanings with their experience. The researcher also responds by interpreting and summarizing what the interviewee says. By doing this, the researcher’s interpretation is validated or refused by the participant during the interview. In the final step, interpretations are done by analysing transcriptions from interviews. This process usually starts with structuring the material in a comprehensive way and further clarification of data, by separating important and unimportant parts and taking away unnecessary information, follows. Finally the analysis of meaning in the data starts, which is the step that is traditionally considered the time when *analysis* happens. The methods used in this last part of the ‘analytical chain’ of the project were thematic analysis, narrative analysis as well as discursive approaches.

**Thematic analysis.** Braun and Clarke (2006) have suggested that thematic analysis aims to find patterns of meaning while searching across data. They provide a six-step guide how to approach the data. The first step involves reading and getting to know your data by transcribing the material and noting spontaneous ideas. The researcher also starts to think about potential codes, to be used in step 2. During the third step, the researcher sorts all codes into potential themes that “captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 82). In step 4, the researcher reviews these potential themes by checking that a theme has enough data to support it; that themes are separate enough; and that themes are on the same level. If these themes seem to work, the researcher moves on to step

5, which involves finding the “essence” of each theme. The final step involves writing up the story by presenting themes consistently and logically, providing the reader with examples from the data that support the interpretations done.

All interviews were ‘indexed’ with thematic analysis, consistent with step 1-4 described above. Thematic analysis as a whole was used in paper I, together with a quantitative analysis. In the other papers, more analytically informed approaches were used to develop the analysis further. This involved using theory-driven questions to focus on some aspects of the data rather than others (Braun & Clarke, 2006; Kvale, 1997; Mason, 2002). While some analyses (in paper II and IV) were driven by other qualitative frameworks, such as narrative and discourse analysis (presented below), the analysis in paper III was also led by a specific theoretical framework of “kinds of knowing” (Pols, 2013).

**Narrative analysis.** Qualitative approaches focusing on narratives have successfully been used in earlier research to highlight experiences of health and illness (Charmaz, 1999; Frank, 1993; Garrett & Kirkman, 2009; Sanders et al., 2008, 2011). The main objective of this technique is to address how people bring order to, understand and make sense of a significant or challenging event or a series of events (Murray, 2008; Willig, 2013). While many qualitative methodologies break data down into themes or categories, this type of analysis is trying to take whole narratives into account (Murray, 2008) These narratives are usually ordered within a time-dimension with a beginning, a middle part and an end (Willig, 2013). The focus on narratives highlights how people interpret what happens to them and points to how people understand themselves and their life (Murray, 2008; Willig, 2013).

This project used the two-step approach outlined by Murray (2008), with an emphasis on the first descriptive phase. This included summarizing narratives in each interview. In paper I, it involved identifying how the participant talked about the time before the consultation when the diagnosis was disclosed (the beginning), during the consultation (the middle) and after the consultation (the end). In paper III it involved identifying themes evident during different parts of the child’s life: making sense of the situation when the diagnosis was made (the beginning), attending to medical needs during the child’s life (the middle) and building independence for the child (the end). After narratives had been identified in each interview, all data were read together and key issues and linkages were explored. During the second interpretative step, narratives are typically put in relation to theoretical literature in order to further analyse the stories that have emerged during step one. In this project, the second phase was used to explore what kinds of implications the emerging

narratives from step one could have for clinical practice in paper II; and how different “kinds of knowing” were evident during different parts of the child’s life in paper III.

**Discourse analysis.** The discursive approach used in this project is informed by Foucauldian theory (also called Foucauldian discourse analysis, FDA). Within this approach, discourses are understood as cultural patterns of meaning or collective ways of understanding a certain phenomenon in a particular group or culture (Magnusson & Marecek, 2010). Individuals are seen as producers of interactions and talk, as well as framed and produced by discourses. Researchers using this approach are interested in how a particular discourse frames people’s understandings of themselves and the world. This involves identifying what makes (no) sense to say within a particular context.

In this project, discursive approaches with an emphasis on *ideological dilemmas* (Billig et al., 1988) were used in paper IV. Billig (1991) states that everyday thinking and talking can be understood as processes of ideology, because of their rhetorical and argumentative nature. He refers to the concept of “common sense” as cultural products that are closely related to complex and conflicting ideologies and values. When conflicting common sense values become evident in talk, *ideological dilemmas* occur. Exploring these inconsistencies in everyday talk is an important task for discursive researchers interested in questioning taken-for-granted common sense understandings.

## **8. MAKING SENSE OF THIS BODY OF KNOWLEDGE: Presenting the results**

This chapter offers a suggestion of how each specific paper contributes to the thesis as a whole. I also summarize the results of each paper.

### **Summary of paper I**

Language and nomenclature can be understood to ground knowing. It frames how phenomena are understood, what kind of knowing is possible and what is considered as (un)intelligible. Diverse preferences for terms as well as underlying understandings of sex and gender are evident in relation to intersex/DSD. While many tend to agree that language has important functions in the topic area, commentators differ on what kind of assumptions and values they think should frame discussions on terminology and theory.

The purpose of paper I was to study how laypeople, with and without personal experience of intersex/DSD, made sense of terms and theories currently used in the area. We explored how their sense-making overlapped with, and differed from, expert opinion. All data types generated as part of the project were used in this paper, including interviews with 33 parents, 22 young people and 10 focus groups. Using a mixed-methods approach we studied what terms young people and parents preferred to use when they needed to talk about their, or their child's, sex development. We also asked what they thought of the terms *intersex* and *Disorders of Sex Development*. The latter question was presented to focus group participants as well, who were also asked to suggest any alternative terms they could think of to describe sex development that do not fit binary categorisations. In addition, 41 focus group participants and 13 young people were asked to rate and discuss the importance of three theories (one hormonal, one psychological and one cultural theory on gender) in the situation where a young person might need to make sense of their sex development.

The results showed that focus group participants identified a need for different language in different contexts, as did parents and young people. However, while almost half of the young people and parents found intersex problematic, a majority of focus group participants supported the term. In contrast, young people and parents preferred descriptive language. Most participants across groups agreed, however, that DSD was a problematic term. Focus group participants preferred the psychological theory over the cultural theory to a significant degree. However, young people did not show any preferences for a specific theory. The opinions raised by laypeople in this study resonated with many of the arguments presented in the literature on terms and theories. Those who supported hormonal theories and DSD

terminology understood these as descriptive and correct, in accordance with biomedical perspectives. In contrast, the majority who supported intersex and descriptive language as well as the psychological (and cultural) theories highlighted the ideas such as variation in how people experience embodiment and how they identify, and emphasised rights, coping, agency, and ability to live an everyday life.

We concluded that a person-centred and pragmatic approach to language that works in everyday life, and to theories, has been largely overshadowed by a medically-centred wish to find language that works within medical practice and biomedical science. We further suggested that if health professionals and researchers are serious about promoting agency and wellbeing, as suggested in the literature, further discussions on terminology and theories should start from, and stay focused on, the everyday needs of those affected by such language and theorizing.

## **Summary of paper II**

There is current consensus among health professionals as well as human rights advocates that all patients have the right to full disclosure of medical information (Lee et al., 2016). Research has shown, however, that this does not routinely happen: not all young people with experiences of intersex/DSD have adequate knowing about their embodiment and/or their diagnosis (e.g., Liao et al., 2010).

The purpose of paper II was to explore the experiences of receiving a diagnosis related to intersex/DSD among young people, in order to better understand the processes that young people go through in developing knowing about their bodies. In this paper, data generated from interviews with the 9 young people recruited in Sweden were used. Applying a narrative methodology, we explored participants' pre-diagnostic life experiences, as well as the processes that led up to the consultation when the diagnosis was given (the beginning), the consultation when they received the diagnosis (the middle), and the time after the consultation (the end). The analysis suggested that earlier general life experiences of participants, as well as the experiences of the process that led up to receiving the diagnosis, framed how participants made sense of the situation.

All participants said that they had been given a diagnosis and information about their embodiment at the consultation, however some did not remember what they had been told. Some said that the diagnostic terms were not something they used very often and others that most of the details of their condition was not something they attended to in their everyday life. While some participants were relieved by the information they were given, others felt bad

about themselves or became worried when they heard words such as "cancer". Such diverse experiences were also evident in relation to how participants responded to health professionals' approaches. While some appreciated that professionals addressed general issues, such as infertility, and tried to normalize the situation, others did not feel that these issues applied to them or that normalization helped them cope. As a consequence, rather than feeling supported some felt even worse about themselves. Finally, many participants said that they needed time to make sense of what they had been told. They had questions about the future that involved psychological, social and philosophical issues. Even though the consultation was over, these participants described how they had to do intellectual and emotional work on their own, in order to make sense of their situation.

The main conclusion made from this study highlights the importance of exploring the unique life experiences of each patient. This is needed in order to assist the sense-making processes that can help young people with diverse needs and experiences to develop knowing about their bodies and requires health professionals to use an exploratory and flexible approach. Such strategies add a new dimension to promote knowing compared to the general guidelines for disclosure outlined in the literature. In order to equip health professionals to do such exploration effectively, future research should not only focus on establishing guidelines by generating group-level data on typical scenarios or common issues, but also explore the varieties of people's experiences.

### **Summary of paper III**

According to the consensus statement, CAH is categorised as a DSD when the person with the condition also has 46,XX chromosomes (Lee et al., 2006). While most psychological studies done on CAH focus on generating knowledge on gender roles, gender identity and sexual orientation (Stout et al., 2010), other studies highlight the importance of providing early high-quality information in order to support parents' coping and promote wellbeing. The main purpose of paper III was to expand this focus on information by investigating the different kinds of knowing (a framework suggested by Pols, 2013) that parents find useful in everyday life when caring for their children with CAH.

In this paper, data generated from interviews with 20 parents (of 22 children with CAH) were used. We used a narrative methodology as well as a theoretically driven thematic analysis to analyze the data and ended up with three specific time periods during the child's life involving specific challenges where different kinds of knowing were needed in order to handle the issues that were evident.

The first time period, described by parents, was when the child was born. Before and after the diagnosis had been established the parents needed to *make sense of the situation*. During this time period, parents reported that they needed support in *knowing what* CAH is as well as *knowing how* to cope with this situation. While some said they had felt supported in regards of both of these aspects, others felt that health professionals could have attended to their needs and worries in a better way. Finally, some parents found it challenging to talk to others about their child, especially in those cases where somatic sex development was affected. This led some parents to develop strategies and skills in order to access support by others, without telling them too much about the child's condition. These strategies required the parent to do things on the fly and improvise what they said and how they said it in each new unique situation. The skills that some of the parents described that they had developed were interpreted as a sense of *knowing now*.

The second time period involving challenges of *attending to medical needs* started when the family came home from the hospital. Several parents described that they felt badly equipped in *knowing what* medication to give to their child and *knowing how* to give medication. This was especially evident in relation to the need of giving infants sodium. Many parents spent hours giving each dose and had to come up with their own strategies for handling these situations. Finally, many parents also talked about negative experiences of seeking medical care at emergency care units when the child was ill or had had an accident. This led some parents to avoid emergency care units at any cost. This required their constant *knowing now*, by attending to the child's medication, activity level and general state of being.

Finally, as the child grew, parents talked about the importance of helping their child *build independence* by inculcating knowing what, how and now in their children. Several parents said that they needed health professionals to help them *knowing what* support, other than medical, that their child might need. They also needed support in *knowing how* to provide this support. One important aspect mentioned where parents wanted more support by health professionals was *knowing how* to talk to a child about CAH, medicine as well as genitals and surgery. While many had talked about medication, some found talking about genitals, sex and potential surgery as more challenging. Finally, many children were uninterested to learn more about their condition. In order for parents to still assist their children to build independence, some parents used *knowing now* to take advantage of those concrete situations where their child's interest to learn more was evident.

The main conclusion drawn from this paper is that parents experience challenges and needs of knowing that are addressed neither by health care nor by research. It also shows that

parents have developed a considerable amount of "everyday expertise" that should be surveyed in order to support families in the future. These results suggest that health care professionals need to develop their services in order to address the everyday challenges that families face. While the study showed that there are specific issues related to sex development, these are also intertwined with other challenges that the family experiences in everyday life. If health professionals want to promote wellbeing for children experiencing intersex/DSD, such contextual aspects need to be taken into consideration in health care as well as in research.

### **Summary of paper IV**

In recent medical literature, authors conclude that there are persistent dilemmas that need to be addressed in relation to intersex/DSD (Lee et al., 2016). The most important dilemmas identified by the consensus statement relate to issues of *gender assignment*, *early surgery* and *full disclosure* (Lee et al., 2006). While health professionals suggest that these dilemmas can be handled by developing knowing by doing better research as well as involving parents and patients in decision-making, some human rights advocates propose changes in legislation and policy in order to give some principles, such as self-determination and bodily integrity, precedence over others. Even though human rights advocates and medical representatives might agree on what principles to give precedence, research suggest that the principles for care do not always affect what actually happens in medical practice.

The main purpose of paper IV was to explore how laypeople, without personal experiences of intersex/DSD, make sense of and understand the clinical dilemmas mentioned above. Most people who find themselves in a situation where they face information related to intersex/DSD, such as being given a medical diagnosis, do not have any specific knowing about the topic. We wanted to better understand the types of knowing that laypeople take with them to such situations and how this knowing would frame how they understood and responded to these dilemmas. By using the theoretical framework of ideological dilemmas (Billig et al., 1988), the analysis revealed how underlying understandings of how people are *making sense of sex and gender*, how they are *dealing with difference*, and who is understood to be in a position of *making decisions* are all important, affecting how these dilemmas are approached and responded to.

The analysis showed that the perception of the dilemma of early gender assignment seem to be underpinned by different understandings of sex and gender; as *binary or non-binary*, as a *biological or personal identity* and as *in need of assistance or simply unfolding*

*from within* over time. Drawing on some of these understandings, rather than others, seemed to affect what was considered optimal responses to the dilemma and opened up for some actions but also closed down others. For example, some who argued that gender assignment should be done early also thought that this should be confirmed with medical interventions, such as early surgery. While the idea of promoting wellbeing as the most important aspect in relation to the dilemma of early surgery was suggested, different understandings on *whether difference is problematic or not* and whether to *erase or affirm difference* were evident during the discussion. These different ideas, in turn, made some responses to the dilemma more intelligible than others. When erasing difference was voiced, the idea to do early surgery was also suggested, in order to protect the child from remembering the surgery. Finally, responses to the dilemma of full disclosure, as well as the other dilemmas, varied depending on which party was understood to be in the best position, or have the right, to *make decisions*. Responses to the dilemma were underpinned by ideas where the expertise of *health professionals* were contrasted against *parents' responsibilities*, where *parental rights and responsibilities* were discussed against *the rights of the individual* and finally, how to position *the individual in relation to health professionals*

In accordance with Billig et al. (1988), we argue that prioritising one principle does not make the de-prioritised principles disappear and does not solve dilemmas. Instead, our results suggested that such strategies would only provide shallow solutions to the dilemmas discussed. In a clinical situation where early genital surgery is discussed, the principle of bodily integrity might be considered a priority. However, for an individual who (also) values normality, or understand gender identity development as requiring assistance, prioritizing bodily integrity does not engage with their perspectives and, therefore, may not help them to feel closure with decisions made. We conclude that engaging with dilemmas by addressing values and understandings that may be overlooked by focusing on particular principles is important for empowering people and families in the context of medical decision-making.

## **9. CLOSING THE SCENE: Discussing this body of knowledge**

Building on theories developed within science studies (Collins & Evans, 2002), I have tried to present interactional knowing by reviewing how different contributory bodies of knowledge could promote wellbeing and social justice for people with experiences of intersex/DSD. The thesis I have proposed is that what is conventionally considered knowing in this area builds on diverse but certain kinds of knowing and expertise. Therefore, I set out to explore how laypeople, with and without personal experience of intersex/DSD, use and trouble the different kinds of knowing that are highlighted in the literature in the area. Based on the results in this thesis, I argue that the use of the conventionally recognized kinds of knowing creates gaps in research and clinical practice, that in turn, has consequences for people's everyday lives, and, consequently, their wellbeing. In order to address this gap, I have sought to explore other kinds of knowing that people with personal experience might benefit from, including kinds of knowing that are not evident in the current literature. Several important kinds of knowing were identified. These are reviewed below in relation to other specific bodies of knowledge in the topic area.

### **The contributory body of experiential knowing**

The findings in this thesis suggest that people with personal experience develop specific kinds of knowing that go beyond what is presented in the medical, psychosocial or human rights literature in the area. We show in paper II that the knowing that young people develop about their embodiment is dependent on their pre-diagnostic life experiences as well as processes of sense-making after the diagnosis has been given. The latter included practical as well as philosophical issues that these young people had to deal with themselves. Paper I and III further contribute to the area by showing how people with personal experience develop knowing that works, pragmatically, in everyday life. In both papers, several participants with personal experience described, for example, how they had developed different ways of talking about sex development that make everyday life work. In paper III, it was obvious that this kind of knowing went beyond what had been offered by health professionals.

Finally, I argue that it is not only people with personal experiences that can contribute with experiential knowing to this topic area. The results from paper IV suggest that generally available common sense understandings affect the way intersex/DSD is understood and how people respond to clinical dilemmas evident in the area. The underlying understandings and values voiced by laypeople without personal experience of intersex/DSD are not significantly

different from the understandings and values presented in the expert literature in the subject area. The general contribution of paper IV highlights that the dilemmas in the area might not be just an issue for science to solve, but rather a question of values that touches the very core of being an embodied human. The results from this paper suggest that these underlying values need to be addressed if stakeholders want to improve and/or change clinical practice.

### **Contributions to the body of medical knowledge**

In current medical literature the importance of establishing large-scale research projects is put forward in order to develop evidence-based guidelines to address persistent clinical dilemmas. These perspectives build on the assumptions that better genetic understandings of diagnoses, described with medical nomenclature, can promote better health care and, consequently, wellbeing in people with personal experiences of intersex/DSD. Some participants in this research expressed issues where medical knowing can be useful. One example is to identify and develop effective treatment in relation to medical needs that might be associated with certain variations in embodiment (highlighted by some in paper I, II and III). However, drawing on the analytical framework used in this thesis, current medical knowing in intersex/DSD can be interpreted to build on an authoritative ideal, and it is still unclear, judging from the medical literature, how the ideal of patient-centred care, including ethics and human rights-concerns, is being addressed in practice and research.

Some commentators have suggested that the medical knowing in the subject area would benefit from input from other disciplines, such as gender studies (see e.g., Simmonds, 2012), in order to better address patient concerns. Such arguments are supported by the data in this thesis. Paper I suggests that the new nomenclature of DSD is understandable as an effort to find language that works within medical practice and biomedical science. As shown in paper I, II and III, several participants also find medical language and theories helpful. However, results in paper I also show that the medically-centred language might have overshadowed the need of a person-centred and pragmatic approach to language that works for people in their everyday life. Results in paper II and III further suggest that the knowing provided by health professionals (i.e. medical information) is not enough to promote coping. Employing other epistemological frameworks, readily used in other disciplines, to address language and knowing could enable such patient concerns to be more successfully taken into consideration.

In paper I, it is suggested that the discussion on terminology could be further informed by speech-act theorists (Austin, 1962). These theories show how language acts on us, instead of being merely descriptive, because it produces particular kinds of realities. Such

understandings of terminology expand debates about the value of language beyond consideration of what is biomedically correct, to consider what is ethically sound and empowers people who are affected by such language. These findings point to the merits of postmodern epistemologies, in which theories and knowledge are understood as different perspectives on reality that provide certain opportunities for action but also close down others (Burr, 2003). By taking a step back and reviewing the possibilities and the shortcomings of biomedical frameworks from such a perspective might enable health professionals and medical research to highlight other bodies of knowledge as contributory knowing in the area. Paper IV provides an example of how this can be done with a discursive framework such as ideological dilemmas. By understanding dilemmas inherent in the area as unresolvable, medical frameworks are seen as one, but not the only or the correct, way to respond to such situations. By interrogating the positive as well as the limiting aspects of biomedical understandings, as well as other suggestions from for example human rights advocates, might put researchers and clinicians in a better position to develop medical practice where collaboration with patients and their families can be done with integrity.

This would require medical professionals and researchers to move from a realist epistemology, which usually underpin biomedical science, to a pragmatic and transformative stance informed by postmodern and social constructionist theories. This is impossible as long as biomedical understandings (or other disciplines building on the same epistemological understandings) are seen as the only credible source of knowing in the area.

### **Contributions to the body of psychosocial knowledge**

Psychosocial academics have contributed with a vast array of research underpinned by different perspectives to intersex/DSD. As psychosocial professionals are becoming increasingly involved in the health care provided by MDTs, it is important to continue to review and discuss what 'the psychosocial' should constitute in the topic area. Some commentators have warned that the psychosocial might become a "tap on" to medicine, where psychosocial perspectives are used in order to justify medical interventions that lack scientific evidence (Liao & Simmonds, 2014). Psychosocial research can also easily be pushed to certain epistemological frameworks in order to be compatible with, and also be acknowledged by, the biomedical body of knowledge in the area. Human rights advocates have further warned that taking a critical stance and adequately addressing the counselling needs of patients as a psychosocial researcher or professional seems to be a bad career move, because these types of perspectives are underfunded (van der Have, 2016).

It is important that psychosocial professionals and researchers themselves actively define what the input from this contributory body of knowledge should be. Building on the critical psychosocial research done before and after the consensus in 2006, this thesis is an attempt to develop such critical psychosocial knowing in the area by providing contributory knowing as well as working as an interactional body of knowledge. I urge psychosocial researchers and professionals to continue to engage with the complex, contextual and dilemmatic aspects of being an embodied human being, and I argue that this is what I have been trying to do in paper I, II, III and IV.

### **Contributions to bodies of human rights and ethics**

Advocates for human rights and ethics provide alternative, non-medical, kinds of knowing to respond to the dilemmas identified in the subject area. Such approaches highlight egalitarian principles that respect the dignity and rights of people with experiences of intersex/DSD. The underlying values of these perspectives are easy to combine with patient-centred approaches as well as pragmatic and transformative epistemological understandings. However, the results in this thesis also challenge some claims to knowing presented by bodies of human rights and ethics.

First, there are risks associated with an unproblematised use of the term intersex in policy and legislation. In paper I, it is evident that some participants with personal experience of intersex/DSD do not know that the term intersex refers to their development. In addition, several participants with personal experience find the term problematic and unhelpful in their everyday life. The same critique raised against medical nomenclature can, therefore, also be raised against using the term intersex; that it does not automatically empower people who are affected by such language. Some human rights advocates suggest that in order to develop protective legislation, language should focus on the grounds for discrimination, for example on the basis of ‘sex characteristics’, instead of a group label such as intersex (Anderson, 2016). Drawing on the results from paper I, such attempts should be accompanied by efforts to develop language that works in everyday life.

Second, paper IV should complicate the strategy promoted by human rights advocates to solve the dilemmas inherent in the area by emphasising some ethical principles over others. The results in this paper suggests that even though a principle of protecting bodily integrity would be prioritized in legislation prohibiting early genital surgery, the other understandings and values underpinning the de-prioritized principles, such as valuing normality, will not automatically disappear. These understandings and values will still affect people in their

everyday life and continue to frame decisions made in health care and everyday life. These complex dynamics of principles need to be considered by human rights advocates.

### **Questions for future research**

I conclude that this research leaves more questions unanswered than answered. Some major issues still refer to how to develop respectful and useful language in the area. Commentators have argued that any suggested term will fail to address the diverse concerns raised by different parties with different interests (Davis, 2014; Liao & Roen, 2014). Reis (2007) suggests, however, that finding language is a matter of prioritizing some perspectives over others to be able to decide what term to give precedence. Drawing on the results from this thesis, a pragmatic perspective seems promising, but needs to be reviewed further.

There are also important questions about the goals that diverse bodies of knowledge are working towards. If medicine, psychosocial understandings, human rights and experiential bodies of knowledge are seen as holding diverse but potentially contributory kinds of knowing - against what values, or on what grounds, should these be reviewed? This also includes this transformative project and concerns issues such as “what constitutes social justice in practice” and “how should wellbeing be conceptualised”? Even though some results in this thesis suggest that it seems important for people with personal experiences to have support to manage their everyday life, questions about how to promote wellbeing (beyond conceptualisations such as quality of life) need to be addressed in future research.

### **Methodological discussion**

As with any methodology, the one used in this thesis has its challenges, strengths and weaknesses. One of the most challenging dilemmas in this study has been to juggle the diverse, sometimes incompatible, underlying understandings, language and opinions in the area; embodied in the literature and expressed by research participants. With the transformative aim of giving people with personal experience voice, several problems have occurred. Kitzinger and Wilkinson (1997) discuss the tensions between validating versus questioning participants' lived experience. Validating gives the participant recognition and a sense of being understood, but might also maintain oppressive structures. Questioning participants' experiences might, on the other hand, invalidate the experiences of a participant, but also point to how societal structures may change. The importance of questioning oppressive norms as suggested by transformative research ideals should be recognized, but also handled appropriately. In this project this has been handled by trying to make evident the

diversity of kinds of knowing expressed by participants. This has required a constant reflexive stance where the pragmatic question “what difference does this make?” has been the guiding principle in the decisions done throughout this project.

The value of semi-structured interviews has also been debated. One issue that has been addressed is that many researchers using semi-structured interviews do not consider contextual factors, such as the interactive aspects of the interview, and only take such data at face value (Willig, 2013). From a social constructionist perspective, interviews are seen as a site of a collaborative meaning-making process where knowing is constructed together with the participant, not as an event to objectively access the participant’s inner world or reality. The data provided by such an interaction must be understood as one version, of several possible ones, of this meaning-making process. The thesis presented here should be understood as one version of several possible and further research will have an important function to assess and review the arguments underpinned by the results of this project.

The theoretical framework employed in this thesis can also be criticised from several perspectives. From a social constructionist or discursive point of view, the different bodies of knowledge presented do not sit neatly or comfortably next to each other and are not easily integrated. They are frameworks of knowing underpinned by ontological and epistemological assumptions with differing ideas about truth, that can be contested or seem undisputed. These bodies are steeped in value systems presenting contradictory norms and ideals. By presenting these as contributory bodies of knowing, they might appear as equivalent which, in turn, underestimate the unequal and complex dynamics of power and legitimacy (in)vested in these different kinds of knowing. Presenting them as separate bodies of knowledge is also a simplification, underestimating how understandings can work together in powerful ways. Such power dynamics should be considered in further studies.

Finally, results presented here are not “representative” of parents and young people with experiences of intersex/DSD in a realist epistemological sense. Rather, broad findings should be read and reviewed because of their transferability (Andenæs, 2000; Willig, 2013). This means they should be recognised by their ability to provide knowing that can be used in other situations or settings. In this thesis, I claim to have addressed knowing and dilemmas evident in the current literature and how laypeople make sense of, use and trouble such knowing. I also address how people with personal experiences of intersex/DSD develop knowing that goes beyond the kinds provided in the literature. As such, I argue that this thesis innovatively highlights how people engage with diverse kinds of knowing in this subject area.

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