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**Abstract**

This chapter takes a critical psychology approach to reviewing research on psychological distress among people with variations of sex characteristics. The focus is on depathologizing emotional distress and developing affirming and empowering approaches to healthcare. Affirming approaches to psychosocial healthcare can be undertaken by health professionals who have enough knowledge about intersex, diverse sex development, or variations of sex characteristics to be able to support positive adaptation to bodily variation and facilitate non-stigmatizing talk about the experience of living with a diagnosis. There is room for significant development here, particularly research addressing psychosocial well-being in ways that are non-medicalized and culturally relevant in diverse global regions.

**Keywords**

Variations of sex characteristics, intersex, disorders of sex development, diverse sex development, mental health, psychosocial well-being, critical psychology

# Intersex Mental Health

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The topic of intersex or variations of sex characteristics (VSC) is fraught with contested terminology. The present chapter works across terms that we have chosen to respect the integrity of people living with VSC. The first part of this chapter introduces readers to medical and diagnostic terminology and describes shifts in medical intervention, activism, and human rights claims. We introduce a critical psychology framework that prioritizes a depathologizing approach. The main body of this chapter is a critical review of intersex mental health research with emphasis on affirmative healthcare. We situate intersex psychosocial well-being in the context of GLBTIQ+ mental health and related intersectional questions. This chapter concludes with consideration of research gaps and ways forward.

Intersex or VSC can be understood as an ordinary aspect of human diversity (Roen, 2015). Conversely, disorders of sex development (DSD) (as set out in Hughes, Houk, Ahmed, & Lee, 2006) or diverse sex development (dsd) are usually understood in terms of rare medical phenomena that, collectively, are present in approximately 1.7 percent of live births (Blackless et al., 2000). This framing of bodily variation as ordinary or as pathological underlies questions about the mental health and well-being of people living with VSC.

For the purpose of this chapter, we set out the scope of variations that could be relevant. The point here is to extend the focus beyond narrowly defined diagnoses of sex development. The bodily diversity relevant here includes that relating to chromosomal configurations other than XX or XY, such as Turner and Klinefelter syndrome; hormonal response, such as reduced sensitivity to androgens as in complete or partial androgen insensitivity syndrome (CAIS or PAIS); adrenal function as in congenital adrenal hyperplasia (CAH); gonadal development and location, such as gonads that are neither clearly ovaries nor clearly testes (gonadal dysgenesis), and testes that are not located in the scrotum; the size and appearance of the penis/clitoris (including chordee, micropenis, and clitoromegaly); the location of the urethral opening (hypospadias); the development of the vagina, uterus, and fallopian tubes (including vaginal agenesis and conditions such as Swyer syndrome and Mayer-Rokitansky-Küster-Hauser syndrome [MRKH]); the unexpected presence or absence of

menstrual bleeding; the timing of puberty, including puberty that is unusually early or late or does not happen spontaneously at all; and the occurrence of breast development, including that which occurs at any point in the life course of boys/men and that which does not occur as expected in girls/women.

In establishing this wide-ranging description, we are defining VSC in a way that is not limited to specific medical diagnoses, or to genital ambiguity, or to particular medical interventions. Instead, we highlight experiences of—and effects of—living with bodily difference coded as relating to “sex development,” where “sex” might be chromosomal, hormonal, or anatomical. Some common threads run through this experience from a psychosocial perspective, relating to the shame, stigma, and secrecy; the difficulty of finding words to talk comfortably about the difference; and the difficulty of finding frameworks of understanding that accommodate the difference. These common threads relate to the need for significant others (including parents and loved ones) and health professionals to have the capacity to be understanding and caring in the face of something that might be outside their usual field of experience. These common threads of experience relate to the psychosocial aspects of living with VSC and therefore have a bearing on emotional well-being and mental health.

## **Critical Psychology and Psychosocial Well-Being: A Way Forward**

We use critical psychology as a conceptual foundation because this offers a way to examine the insights from psychological research on “intersex mental health” while maintaining a careful distance from the pathologizing frameworks of understanding (Roen, 2019). Critical psychology provides a way to work strategically with psychological research, rethinking the subject of psychology (Henriques, Hollway, Urwin, Venn, & Walkerdine, 1984; Marecek et al., 2002) and drawing attention to power relations and social justice issues. Critical work within psychology opens up space for thinking about sex, gender, and sexuality as complex concepts that do not fit into the binary frameworks of male/female and normal/abnormal (Barker & Richards, 2015; Clarke & Peel, 2007).

Psychological research that investigates mental health and well-being among people with diagnoses of sex development typically takes one of three approaches: a psychiatric or psycho-pathologizing approach, an approach that focuses on quality of life and other psychometric measures, or an approach that is explicitly depathologizing or psychosocial. In the current chapter, we work with each of these approaches while privileging a depathologizing interpretation.

### **Challenges of Producing Evidence-Based Knowledge on Intersex Mental Health**

During the 1990s, the medical protocol suggested by Money et al. (Money & Ehrhardt, 1972; Money, Hampson, & Hampson, 1955) was criticized by stakeholders (Davis, 2015; Karkazis, 2008). One main criticism was that the recommended interventions were not evidence-based (Diamond & Sigmundson, 1997) but rested on normative assumptions that equated well-being with having a typically sexed body and having heterosexual penetrative sex (Kessler, 1998). Activists with lived experience of VSC also questioned the efficacy of the protocol. The Intersex Society of North America (ISNA) argued, for example, that interventions caused harm rather than promoting well-being. During the 1990s, it became clear that more research was needed in order to provide an evidence base that could inform more effective guidelines. In 2006, the first medical consensus statement was published, presenting as an international standard a biomedically driven approach to intersex healthcare (Lee, Houk, Ahmed, & Hughes, 2006). This statement influences medical practice and frames psycho-pathologizing approaches to intersex well-being.

Since the 1990s, commentators have continued to critically discuss whether the endeavor of evidence-based medicine will contribute to the well-being of people with VSC. Some suggest that research on psychological endpoints has focused heavily on hormonal effects (Stout, Litvak, Robbins, & Sandberg, 2010) and this has not helped people understand their variation or given them meaningful support in their everyday life (Lundberg, Lindström, Roen, & Hegarty, 2017; Stout et al., 2010). Researchers have also questioned how research recruitment is framed (Ansara, 2016), how aspects such as gender identity (Liao, Audi, Magritte, Meyer-Bahlburg, & Quigley, 2012; Schweizer, Brunner, Handford, & Richter-Appelt, 2014) as well as mental health (D'Alborton et al., 2015) are conceptualized, what statistical methods are used (Stout et al., 2010), and how

results should be interpreted (Lee et al., 2016). In a global update on DSD healthcare (Lee et al., 2016), the psychosocial section concluded that

Any causal link between a diagnosis and a single psychometric measure is flawed, since the effects of a diagnosis on wellbeing depend on a wide range of intrinsic and extrinsic factors across time . . . Wellbeing may be affected in highly specific ways at certain times, such as at the initial diagnosis, during the developmental stage, at symptom control, during fertility treatment or at the beginning and end of an important relationship. (p. 10)

When studies are done from a psychiatric or psycho-pathologizing perspective, social norms go unquestioned (Roen, 2019), including binary understandings of gender, heteronormative assumptions underpinning understandings of well-being, and the assumption that bodily variation might affect mental health negatively (Carpenter, 2016). Such concerns should be considered while reviewing studies on intersex mental health.

Commentators suggest that evidence-based knowledge needs to be complemented with person-centered and value-driven care (Liao & Simmonds, 2014; Lundberg, Roen, Hirschberg, & Frisén, 2016). This means showing patients respect, understanding and validating people's perspectives, and promoting self-determination as a driver of clinical practice. Some argue that qualitative research makes an important contribution here because of the diverse contextually shaped experiences and concerns that people with VSC might have (Guth, Witchel, Witchel, & Lee, 2006; Lundberg et al., 2016; Schönbucher et al., 2010; Stout et al., 2010). The idea of value-driven care (Liao & Simmonds, 2014) also acknowledges the ethical and human rights-related aspects of research and healthcare. Human rights advocates have, during the past two decades, raised important concerns as to what norms and values are driving healthcare, and whether these are ethical and in accordance with human rights principles (European Union Fundamental Rights Agency, 2015; Travis, 2015; United Nations Human Rights Council, 2013). For example, the United Nations (2013) has stated that elective surgery to “normalize” the appearance of genitals can be understood as inhumane treatment that violates physical integrity and bodily autonomy. Ethico-legal commentators have argued that current psychiatric or psycho-pathologizing frameworks might not ensure human rights such as the importance of self-determination, protection from discrimination, and access to justice and reparations (reviewed in, e.g., Carpenter, 2016; Monro, Crocetti, Yeadon-Lee, Garland, &

Travis, 2017). Much work remains to ensure that clinical practice and research on intersex mental health are driven by values based on human rights (Carpenter, 2016).

According to some, people with VSC have affinities with LGBTQ+ people in the sense that heteronormative and cisgenderist understandings have led similarly to the pathologization, stigmatization, and minoritization of these experiences in recent decades. However, there is a concern that adding “intersex” to create the acronym LGBTIQ risks focusing on challenges related to gender identity or sexual orientation only, rather than to sex characteristics (Carpenter, 2018; Cools et al., 2016). It is important that the specific challenges of people with VSC are not subsumed and made invisible.

### **Importance of a Depathologizing Framework**

Psychologists who undertake research on the mental health and well-being of LGBTIQ people must negotiate tensions that arise from the historical and ongoing pathologization, stigmatization, and minoritization that is woven through LGBTIQ lives (McDermott & Roen, 2016). There are specific points of negotiation to consider here. First, when a group of people has been explicitly pathologized—rendered diagnosable by medical science—it is no simple matter to assign further pathologizing terms, such as mental illness terms, to those people. It is ethically questionable to undertake research whose purpose is to psychiatrically diagnose LGBTIQ people without critically reflecting on the likelihood that this further stigmatizes an already stigmatized group. Second, when a group of people has been systematically stigmatized and minoritized over generations, it is never a straightforward question to ask about the mental health of that group. Such questions inevitably sit at a point of tension between possible interpretations: a pathologizing interpretation that positions the minority group as (perhaps inherently) mentally ill, and an alternative interpretation that postulates minoritization as a cause of (perhaps unavoidable) psychological distress. Each of these interpretations risks reinscribing minoritizing realities rather than benefiting those concerned. Each risks positioning the people concerned as inevitably mentally ill or perpetually on the edge of psychological distress (McDermott & Roen, 2016).

Some researchers write about psychological distress and well-being with a focus on empowerment-centered and LGBTIQ-friendly service provision (e.g., Harper & Singh, 2014; Roen & Groot, 2019). If we approach the

topic of intersex from this perspective, we would not ask how many people with a given diagnosis of sex development might also be psychiatrically diagnosable. Instead, we would ask: Given the ways that living with a VSC can be distressing (including distress that is caused within health services), how might attention best be directed toward promoting psychosocial health and well-being? Such a question would direct attention to a much broader conception of “mental health” than would usually be considered. It would direct attention to concepts such as experience: What kinds of experiences, within healthcare, families, and other relationships, are likely to foster well-being among people with VSC? It would also direct attention to concepts such as emotion: What is the role of emotion and emotional distress in the context of living with a VSC, and managing the healthcare and familial relationships? Such questions about experience and emotion direct attention away from psychopathology, allow for the possibility that emotional distress is sometimes to be expected, and draw respectful attention to the subjective perspectives of the people concerned. Some mental health professionals put concepts of emotion and experience at the center and take this affirming and non-pathologizing approach to the well-being of people with VSC (e.g., [Alderson, Madill, & Balen, 2004](#); [Carmichael & Alderson, 2004](#); [Chadwick, Smyth, & Liao, 2014](#); [Gough, Weyman, Alderson, Butler, & Stoner, 2008](#); [Liao, 2007, 2015](#)).

## Critical Review of Intersex Mental Health Research

A few researchers have undertaken reviews of intersex/dsd mental health literature (e.g., [Bohet et al., 2019](#); [Nordenström, 2015](#); [Schützmann, Brinkmann, Schacht, & Richter-Appelt, 2009](#)). For the purpose of this chapter, we draw principally on studies identified within the two reviews that jointly span 1956 to 2016. The first of these two papers was published in 2009 and reviews the eleven studies available at that time ([Schützmann et al., 2009](#)). The second of these papers was published in 2019 and reviews eighteen more recent studies ([Bohet et al., 2019](#)). In both reviews, the authors note that there is a very slim evidence base with sparse studies of variable quality.

Schützmann et al.’s literature review focuses on psychological distress across various DSD diagnoses, citing studies published between 1956 and 2005. The best-quality study they could find relating to children

included fifty-nine children and reported no psychological problems in 42 percent of the sample and mild psychological problems in 19 percent; a further 39 percent met diagnostic criteria in the fourth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (Slijper, Drop, Molenaar, & de Muinck Keizer-Schrama, 1998). Another study they consider of high quality focuses on fifty adults and two clinical comparison groups with unrelated diagnoses (Warne et al., 2005). According to this study, there were no differences between groups in mental health, depression, or current anxiety. There were differences, however, in relation to trait anxiety, self-esteem, and interpersonal problems, with the DSD group producing poorer scores than one of the comparison groups.

Schützmann et al. extracted findings from the literature they reviewed specifically in relation to people with CAH (total N = 268), noting consistent findings suggesting that people with CAH tend to be psychologically well adjusted and present psychological distress rates comparable to nonclinical reference groups. They speculate that this might be at least partially attributable to the tendency for researchers to recruit participants from hospitals, therefore excluding from study participants who are sufficiently traumatized to avoid hospitals and clinician-led research.

One paper they review offers a useful point of contrast. This study, by Diamond and Watson (2004), included fifty-seven adults with AIS and reported significant levels of distress, including shame, stigma, and identity problems in addition to suicidal thoughts (61 to 62 percent of the sample), and suicide attempts (17 to 23 percent of the sample). Schützmann et al. explain that these high levels of distress could be attributed to the fact that Diamond and Watson recruited participants from support groups.

The more recent review to examine the relationship between people with DSD and mental disorders does not problematize psycho-pathologization and does explicitly exclude qualitative studies (Bohet et al., 2019). The studies they identified were published between 2006 and 2016. These reviewers suggest that people with DSD face an increased risk of affective disorders, especially anxiety and depressive disorders and interpersonal difficulties. In addition, people with CAH exhibit an increased rate of alcohol consumption. Research with people with complete androgen insensitivity, however, suggested that there was not an increased rate of psychological distress in this group.

Schützmann et al.'s (2009) own empirical study is interesting in that it combines participants from clinical settings and nonclinical settings in an attempt to avoid the sampling issues that may have affected previous findings. They suggest that “psychological distress, especially interpersonal insecurities, suicidal tendencies, and self-harming behaviour, are more frequent in DSD than generally assumed” (p. 32). We suggest there are a few things to be wary of, and these are more or less indicated by Schützmann et al. The first is that not all studies use measures that are sensitive to the particular kinds of distress experienced by people with VSC. Quality-of-life (QOL) studies appear to be particularly poor at discerning the distresses related to VSC and treatment experiences for DSD. Second, as Schützmann et al. point out, clinical studies are unlikely to be able to recruit people who are sufficiently distressed to avoid clinical settings. In combination, these two issues plausibly lead to a significant overestimate of psychological well-being on the part of clinical researchers.

As the topic of intersex has gained wide currency, it has become increasingly possible for community-based and online surveys to be carried out, broadly assessing the well-being of people who identify as intersex or having different sex development. In recent years, this has produced nonacademic literature that can usefully feed into our understanding of intersex mental health. The U.K.-based organization *dsdfamilies* has published online a report based on research with 194 people in the United Kingdom, including children, young people, and families living with different sex development (*dsd families*, 2019). This report identifies key issues for the well-being of people with different sex development as including psychological and social issues that related to struggling to find people with similar experiences, struggles with self-acceptance, struggles to talk with others about the different sex development, and the desire for access to psychological support with these issues. Also in the United Kingdom, but focusing on a different kind of sample, the Government Equalities Office undertook a national survey of LGBT people that received responses from more than 100,000 people, 2 percent of whom identified as intersex (*Government Equalities Office*, 2018). Survey respondents were asked about their experiences of mental health services. Compared with other respondents, those who identified as intersex reported more difficulty in accessing mental health services. Thirteen percent of intersex respondents indicated that they had tried to access mental health services within the past twelve months and been unsuccessful. This compares with 8 percent of non-intersex (LGBT) respondents who reported being unsuccessful in accessing

mental health services over the same period. When they did manage to access mental health services, 27 percent of intersex respondents reported that the service was “mainly or completely negative.” This compares with 21 percent of non-intersex (LGBT) respondents who found the mental health service negative. These very high levels of negative experiences with mental health services deserve attention. It is imperative that mental health service providers develop the skills and knowledge needed to work well with people with VSC.

An Australian online survey posed similar questions about how intersex people experienced mental health services (Jones et al., 2016). Of the 117 participants who responded to a question about how well mental health service providers responded to their variation, 19 percent said “well or very well,” 30 percent selected “neutral or mixed,” and 23 percent indicated that service providers had responded “badly or very badly.” This rate of poor experiences in mental health services is strikingly similar across the U.K. and Australian studies, and the Australian study offers helpful details. Those who wrote comments about the difficulties they experienced with mental health service providers described scenarios where the health professional did not believe that the client had an intersex variation, the health professional lacked knowledge and seemed unwilling to learn about intersex, the health professional misunderstood intersex as something to do with sexual fetish or sexual disorder, and the health professional did not understand that having an intersex variation could impact psychosocial well-being and therefore was not willing to discuss the issues that were important. Those who wrote comments describing positive experiences with mental health services described professionals who were actively interested and willing to learn about intersex, professionals who saw their role as empowering and enabling clients to seek the healthcare they wanted, and professionals who helped clients come to terms with their own bodies. From this study, it seems clear that promoting intersex mental health means training a wide range of health professionals in ways of working that are sensitive to, and informed about, the realities of living with a VSC.

The Australian study participants (n = 272) were asked about any suicidal thoughts or actions, or self-harming behavior, they had experienced on the basis of issues related to living with a VSC. Twenty-six percent indicated having engaged in self-harm, 60 percent indicated they had thought about suicide, and 19 percent

indicated that they had attempted suicide (Jones et al., 2016). This compares with Australian population statistics where fewer than 3 percent of people report having considered or attempted suicide.

Participants in the Australian survey were asked whether health professionals had used counseling, training, or any form of pressure to act in a more feminine or more masculine way; 44 percent indicated that they had experienced this from health professionals (Jones et al., 2016). The many comments participants offered on this topic detail how being expected and coached to conform to gender-normative and heteronormative ways of being was at best misguided and unprofessional, did not lead to productive healthcare relationships, and did not contribute positively to the client's well-being. It has been clearly established within the trans healthcare literature that it is neither appropriate nor helpful to use methods aimed at gender conformity, yet there is little or no published critique of such practices within intersex healthcare. Promoting intersex mental health requires health professionals to understand that people with VSC are reasonably likely to inhabit or explore nonbinary gender possibilities (Schweizer, Brunner, Handford, & Richter-Appelt, 2014), and there is research evidence showing that pressure to conform to gender norms is not associated with psychological well-being (Egan & Perry, 2001; Langer & Martin, 2004). Being supported in the gender expression one is comfortable with, which may or may not be a binary gender expression, is associated with psychological well-being.

While these community-based surveys present a useful overview of well-being among large samples of people with VSC, much of the small body of research investigating intersex mental health is clinically based and takes a psycho-medical approach. Engberg et al. (2015) undertook a study of psychiatric diagnoses of girls and women with CAH based on Swedish national register data for people born between 1950 and 2010. This is the largest study of psychiatric morbidity of girls and women with CAH. Key findings were that those with CAH ( $n = 335$ ) were twice as likely as the control sample to have any psychiatric disorder, twice as likely to have stress-related and adjustment disorders, and almost three times more likely to have a record of alcohol misuse.

Engberg et al. seek to understand the levels of anxiety and substance misuse by focusing on genetic and biochemical factors and, in doing so, they do not consider the lifetime experiences that people with CAH go through in relation to the process of diagnosis, treatment, and ongoing management of health issues and stigma.

Rather than presuming genetic and biochemical explanations for their data, it would be relevant to consider how the experiences of illness and treatment might lead people to psychological distress that might well take the form of anxiety and might well lead to self-medication that gets classified as alcohol abuse or substance misuse. One risk of relying on a biomedical interpretation of mental health data is that this can lead to a failure to consider how life experiences affect how people feel. This is one example of what happens when a psychiatric and biomedical approach is taken and the researchers lose sight of concepts such as emotional well-being and life experience.

One Dutch study also took a biomedical approach, identifying 130 participants with DSD diagnoses and comparing them with a reference group of 372 people with fibromyalgia (de Neve–Enthoven et al., 2016). It is not clear how this particular comparison might be useful. The researchers used a variety of measures focusing on, for instance, subjective fatigue and self-esteem, QOL, and psychopathology. They concluded that participants “reported good psychosocial wellbeing; they generally reported a good HRQoL [health-related QOL], no serious emotional problems . . . compared to reference groups” (p. 60). The authors explain that clinical management in the Netherlands has included psychosocial expertise on DSD since the late 1970s. We might read this study to suggest that people with VSC in the Netherlands have enough psychosocial support that they tend not to experience serious emotional problems, or we might consider that the measurement tools and points of comparison do not help us to draw useful conclusions from the data.

One Turkish study focused on a clinical sample of 51 children seen by a Turkish multidisciplinary team (Özbaran et al., 2013). This study provides a striking example of how a psycho-pathologizing approach to research frames people with VSC. The participants in this study were aged between one and eighteen years, with 47 percent of them being in preschool. Despite the very young age of most participants, the researchers report with apparent confidence on their “sense of being male or female,” adding that “40 patients (78.4 percent) . . . did not have gender dysphoria; 9 of these patients had a psychiatric disorder” (p. 231). These clinicians focused on matching (binary) gender identity with karyotype, and used a psychiatric framework to evaluate people whose chromosomes and identities did not seem to match during these first years of life. These researchers reported that 54.9 percent “of the patients did not show any psychiatric symptoms,” but those who

did are described as having depression, anxiety disorder, attention-deficit/hyperactivity disorder, or adjustment disorder. This is an example of a study whose psychiatric framing makes it difficult to avoid pathologizing children with VSC and children who might come to question binary gender.

Krupp et al. (2014) present findings from fifty women with MRKH syndrome and eleven people with complete androgen insensitivity syndrome, focusing on QOL and psychological distress. Just over 54 percent of the sample was found to have a significant level of psychological distress, based on the Global Severity Index of the Brief Symptom Inventory, and the prevalence rates of suicide attempts were found to be significantly higher than national nonclinical population data. The reported rate of attempting suicide was slightly higher than that reported by Schützmann et al. (2009) and fell in the range that has previously been reported for people with mental health disorders such as major depressive episodes and panic disorder. The fact that QOL scores placed participants in an average range for the general population suggests that this is one of a number of studies where QOL scores do not accurately reflect the emotional distress experienced. By contrast, the Brief Symptom Inventory scores gave a more detailed picture of psychological distress. The authors of this article consider the diverse findings, across studies, and question what is happening when psychological distress is not reported. Such a line of questioning provides a platform for querying all clinical studies that treat mental health somewhat superficially, rely on measures that fail to reflect the particular distresses that can be associated with living with a VSC, and do not take into account the distress that is repeatedly reported by those who have undergone clinical interventions relating to DSD. Reviewing this literature through a critical psychology lens means questioning how intersex mental health is conceptualized.

## **Promoting Health and Well-Being via Lived Experience: Implications for Healthcare**

Some researchers argue that the *lived experience* of people with intersex variations needs to be a central focus in order to champion intersex mental health (Liao & Simmonds, 2014; Lundberg, 2017; Preves, 2003; Roen, 2019). These studies explore the everyday challenges people experience and how they navigate those

challenges. By drawing on such research, it is possible to develop interventions to improve the living conditions of people with VSC at a structural level, including interventions directed to specific individuals as well as communities (as suggested by, e.g., Meyer, 2015). The remainder of this chapter focuses on interventions that can promote individual mental health from a person-centered and value-based perspective (Liao & Simmonds, 2014), building on human rights values.

Research focusing on lived experience shows that important challenges include making sense of one's body, negotiating questions of identity, coming to understand and learning to talk about these experiences, and connecting with others (Alderson, Madill, & Balen, 2004; Danon, 2015; Davis, 2015; Ernst et al., 2016; Guntram, 2013, 2014; Karkazis, 2008; Lundberg et al., 2016; Preves, 2003; Sanders, Carter, & Lwin, 2015). While some people find strategies to navigate these challenges in everyday life on their own, others find community support and professional psychosocial input useful. Support can be provided by significant others, support or activist groups, or healthcare providers, including psychosocial professionals (Sani et al., 2019). Research exploring the themes taken up in professional psychosocial healthcare points to the importance of making sense of and accepting one's embodiment, talking about medical interventions, connecting with others, and talking about sexual health (Dessens et al., 2017). These psychosocial studies, like the community-based research showing that people have difficulty accessing appropriate professional psychosocial healthcare (dsd families, 2019; Government Equalities Office, 2018), highlight the need to develop affirmative psychosocial healthcare in order to promote psychosocial well-being.

## **Providing Affirmative Healthcare**

For decades, commentators have argued that intersex healthcare protocols build on problematic assumptions about normality and well-being (Kessler, 1990, 1998; Liao, 2015; Lundberg, 2017; Roen, 2008). First, well-being has historically been assumed to be possible only when a person's body, identity, and sexual practices conform to heterosexual and cisgender norms. Erasing and normalizing difference has thus been a priority in healthcare (Kessler, 1990, 1998; Roen, 2008). From an LGBTIQ-historical perspective, these normative assumptions are not new. Similar ideas have underpinned earlier psycho-pathological thinking on, for example,

reparative therapies for people experiencing same-sex attraction ([American Psychiatric Association, 2000](#)). In contrast to such pathologization, LGBTQ-affirmative psychosocial practices have grown since the 1980s ([Harrison, 2000](#)). Such affirmative approaches highlight the need to counteract any negative effects of sociocultural norms and pressures ([Johnson, 2012](#)). Affirmative practice builds on the understanding that the person seeking support must be able to trust the psychosocial professional. Being able to build rapport and a therapeutic alliance involves having professional skills, having enough understanding and knowledge to be able to validate the patient's experiences, and being able to work with the client to affirm and, when appropriate, to celebrate difference ([Johnson, 2012](#); [King, Semlyen, Killaspy, Nazareth, & Osborn, 2007](#)).

Psychosocial commentators suggest that health providers should stop regarding normalizing surgical and hormonal interventions that erase difference as standard intersex healthcare ([Danon, 2015](#); [Preves, 2003](#); [Roen, 2019](#)). Instead, health professionals should offer psychosocial care that affirms difference. Such healthcare could also be understood as “normalizing” in the sense that it involves normalizing the experience of being different as very common. It is “normal” to be different in one way or another ([Guntram, 2013](#)), and coming to understand this is a significant step on the path to addressing stigma and shame. Data from the report of the [Government Equalities Office \(2018\)](#) further support this understanding. Survey respondents reported positive healthcare experiences with mental health professionals who saw their role as empowering and enabling clients, and supporting clients to come to terms with their body. This is very much in line with an affirmative approach.

Many commentators have critiqued the assumption that bodily differences can be erased through medical intervention, and that this will avert emotional suffering ([Liao, 2015](#); [Roen, 2019](#)). We follow Liao's reasoning that medical interventions cannot “bypass emotional suffering” and are not “without emotional cost” (2015, p. 63). Instead of trying to avoid negative feelings, emotions should be addressed and worked with respectfully. LGBTIQ-affirmative psychosocial approaches recognize that affirming difference, instead of trying to erase it, is not necessarily easier and does not simply avert distress. However, the sources of distress and ways of dealing with distress are understood from a different perspective that builds on human rights-based values of self-determination and bodily integrity. Providing affirmative care is not a matter of imposing a certain kind of affirmative agenda on the client ([Johnson, 2012](#)). Rather, it is about taking a person-centered approach where

the client's specific way of living with a VSC is addressed, and where that person is able to explore what helps them to make sense of themselves and find ways of relating and communicating with others that are useful in their everyday life (Liao, 2012; Lundberg, Hegarty, & Roen, 2018). In order to make sense of and come to terms with one's body, a person might usefully explore different ways of talking about bodily characteristics and experiences. In other words, reaching for self-determination and exploring terminology might go hand in hand.

## Self-Determination and Terminology

Taking an affirmative and person-centered approach means de-emphasizing the terminology that reflects professionals' ideas of what is important, and finding out what terminology has day-to-day relevance for people with VSC (Lundberg et al., 2018). Continuing to privilege medical terminology has been described in terms of "hermeneutical injustice" (Carpenter, 2016, p. 79).

While representatives of the medical perspective often use the term *DSD* in research and practice (Pasterski, Prentice, & Hughes, 2010), some argue that "differences" should be used instead of "disorders" (Ahmed et al., 2015) or that the specific diagnostic term might better be used (Cools et al., 2018) when communicating with clients and their families. Studies examining the language preferences of people with VSC suggest that only a minority of participants prefer the term *DSD* (Bennecke & De Vries, 2016; Davis, 2015; Johnson et al., 2017; Jones et al., 2016; Lin-Su, Lekarev, Poppas, & Vogiatzi, 2015; Lundberg et al., 2018; Monro et al., 2017). These studies also show that many prefer to use *intersex* (Jones et al., 2016), while others also think *intersex* is a problematic term (Lundberg et al., 2018). In the study by Johnson et al. (2017), participants preferred *Intersex* or *differences* or *variations* of sex development/characteristics. In one of our studies (Lundberg et al., 2018), participants preferred descriptive language that explained how their body had developed or looked.

Promoting self-determination and providing person-centered and affirmative healthcare could mean supporting the person to explore the diverse ways of understanding VSC and exploring different ways of

making sense and talking about these experiences (Lundberg et al., 2018). Having diverse ways of understanding one's body might help a person to know their body as well as talk and connect with others.

## Identifying Research Gaps and Looking Forward

In conclusion, we identify areas of research that have not yet been addressed, and we point to conceptual frameworks that might inform researchers wanting to address these gaps. Intersectional thinking has been a key conceptual development within humanities and social sciences in recent decades, stemming from the work of scholars and others concerned with the social injustices that fail to be addressed at the intersections of gender and race inequalities (Crenshaw, 1989). Researchers concerned with LGBTIQ and psychosocial well-being also highlight the importance of considering intersecting identities and social positions (Zeeman et al., 2019) and acknowledging the heterogeneity of people with VSC (Carpenter, 2018). Further work is needed to ensure that intersex research informs understanding about psychosocial well-being across age groups, geographic locations, and sociocultural and economic contexts.

People with VSC are likely to have substantially different experiences according to their age because healthcare protocols for informing people about their variation have changed substantially from not disclosing information (Natarajan, 1996) to giving full age-appropriate information (Lee et al., 2006). Those who were children during the era of secrecy are more likely to have been excluded from conversations about their own healthcare, and to have been unable to ask for support or find similar others.

Culture and geographic location are intersectional considerations that are mostly absent from existing research. Most studies cited in this chapter are done in Europe, the United States, and Australia, and do not offer insights into cultural differences. However, there is a growing body of work in Asian and South American countries, for example (see, e.g., Dessens et al., 2018; Gilban, Junior, & Beserra, 2014; Zainuddin, Grover, Shamsuddin, & Mahdy, 2013), and there appears to be a tendency for these studies to take a psycho-pathologizing approach. One example is a study with Indonesian participants, where Dessens et al. (2018) concluded that adults with VSC experienced more negative emotions compared to controls and that these

findings are similar to results found in China and in Western countries. However, they also point out that the Indonesian participants had received minimal medical care and that this had a negative effect on their bodily development as well as their understanding of their body. These researchers conclude that the participants experienced stigma in culturally specific ways. However, they do not elaborate on how these unique lived challenges faced by the participants are understood to have influenced the research results. Further, they also used a generic QoL measure that was not developed in an Indonesian context. Clearly, producing research that informs the psychosocial well-being of people in non-Western countries means developing research tools and approaches appropriate to each cultural context.

In Western countries, there are currently two competing stories, or ways of making sense of VSC: one from a social or human rights–based perspective and one from a biomedical or pathologizing perspective (Monro et al., 2017). It is not clear how or whether (Western) biomedically focused approaches contribute insights on how to promote psychosocial well-being for people with VSC in Indonesia. The authors conclude that what is needed in Indonesia is the same medical model used across various Western countries (Dessens et al., 2018). However, Wieringa (2015), a social science scholar connected to this research project, critically discusses the biomedical agenda it prioritizes. As a supporter of a social understanding of why people with VSC might experience psychosocial distress, Wieringa (2015) proposes that stories designed to reduce stigma could help people make sense of their variation better than biomedical explanations.

A postcolonial critique would suggest that, regardless of attempts to improve research knowledge and healthcare provision, no real change has occurred in how Western researchers engage with the Global South. An exoticizing and othering perspective in anthropological intersex case studies has been replaced by a biomedical approach that effectively colonizes by imposing Western understandings on people with VSC (Kraus, 2013). We know from human rights literature that advocating for LGBTQ rights globally is not a project that escapes postcolonial critique (Ali, 2017; Kollman & Waites, 2009). Both perspectives on VSC, the social or human rights–focused and the biomedical psycho-pathological perspective, need to be critically examined and discussed in terms of their colonizing effects (Rubin, 2015).

In conclusion, research could focus on community-based interventions that promote well-being rather than endorsing hospital-based interventions that can add to shame, stigma, and disempowerment. Working with diverse stakeholders, support groups, organizations, and communities is important for building an evidence base that might foster psychosocial well-being and promote human rights for people with VSC.

Finally, commentators suggest that we also need more research on lay people's understandings of VSC (Liao & Simmonds, 2014; Lundberg, Dønåsen, Hegarty, & Roen, 2019). As Liao and Simmonds note, "[i]t is peculiar that academics, journalists and programme makers alike should assume that the only way to understand DSD is via research on affected people. It is as if the non-DSD world had nothing to do with how DSD is experienced" (2014, p. 96). Some research on lay people has been done in this topic area in recent years (Hegarty, Bogan-Carey, & Smith, 2019; Lundberg et al., 2019; Streuli, Vayena, Cavicchia-Balmer, & Huber, 2013). However, we share the view of Liao and Simmonds (2014) that popular understandings circulating in the general public play an important role in framing the lived experience of people with VSC. In order to foster intersex psychosocial well-being, we need to know more about shifting the understanding of the public in general, to encourage supportive rather than stigmatizing responses, and to promote human rights.

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