

VARIATIONS IN SEX DEVELOPMENT

LIH-MEI LIAO is a licensed psychologist, independent scholar and trainer/supervisor for health professionals in the UK.

A compassionate, insightful, and necessary book from a foremost psychologist on intersex. A long-time advocate for improving care, Dr. Liao expertly guides readers through one of the most contested areas of medicine. With lucidity, urgency, and a unique blend of science and storytelling, *Variations in Sex Development* nimbly navigates complex debates that deepen our appreciation of what constitutes good care.

– Katrina Karkazis, Professor of Sexuality, Women’s, and Gender Studies, and author, *Fixing Sex: Intersex, Medical Authority and Lived Experience*.

This book will revolutionise psychological practice in the field. No other psychologist in the history of Intersex/differences in sex development (DSD) has forged and maintained such fruitful working relationships across the terrain of international professional and peer experts. EVERY psychologist in this field of practice should own this book and use it as a primer, guide and backbone for their clinical practice and professional development.

– Julie Alderson, Consultant Clinical Psychologist, and Chair, Paediatric Psychology Network DSD Special Interest Group, UK.

“Dr. Liao’s extensive experience in working with, alongside, and on behalf of people with variations in sex development makes her especially equipped to write this text. The inclusion of practice vignettes will enhance readers’ skills in taking an intersectional, anti-oppressive approach to therapeutic work. This book promises to be the first to explain to mental health providers how to compassionately and ethically work with intersex people and their loved ones.”

– Lourdes Dolores Follins, psychotherapist, author, and co-editor, *Black LGBT Health in The United States: The Intersection of Race, Gender, and Sexual Orientation*.

This subject matter of this book should always make us think with an open mind. I thoroughly enjoyed reading this wonderful and thought-provoking book. You may agree or disagree with the author at times, but you will benefit from engaging with the challenges that the book poses.

– Dan Wood, Professor of Urology, and senior editor, *Journal of Pediatric Urology*.

Dr Liao has distilled decades of knowledge and experience in a MUST READ for every care provider in differences in sex development (DSD). Away from dogmatic interpretations, the book portrays the evolution of DSD management and spells out what open-minded and holistic care may actually look like, so that it can be a compass for the future.

– Lina Michala, Assistant Professor in Paediatric and Adolescent Gynaecology, University of Athens.

An insightful, compassionate and nuanced analysis of care needs, controversies and advocacy, with a long awaited focus on psychosocial concerns of individuals and families. A distillation of decades of expertise, this book is indispensable reading for peer workers and health, social care and education professionals.

– Morgan Carpenter, Executive Director of Intersex Human Rights Australia.

VARIATIONS IN SEX
DEVELOPMENT

Medicine, Culture and Psychological Practice

LIH-MEI LIAO



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For SheHan, memories of SangMin, Antonia, Jordana

Contents

<i>Preface</i>	<i>page</i> ix
<i>List of Abbreviations</i>	xv
SECTION 1 ORDINARY LIVES	
1 Circles and Squares	1
SECTION 2 MEDICALIZATION AND RESISTANCE	
Introductory Notes	
2 Evolving Terms and Definitions	15
3 Medical and Psychological Controversies	32
4 Adult Outcome of Childhood Genital Surgery	46
5 Advocacy, Public Engagement and Healthcare Reform	60
6 The New Care Standard	81
SECTION 3 PSYCHOLOGICAL THEORIES AND APPLICATIONS	
Introductory Notes	
7 Psychological Practice: Epistemic Considerations	101
8 Psychological Practice: Process Considerations	118

SECTION 4 WORKING PSYCHOLOGICALLY

Introductory Notes

9	Choosing “Normalizing” Genital Surgery	147
10	Caretakers’ Grief and Growth	166
11	Assigning Legal Gender	188
12	Disclosure	206
13	Sexual Intimacy	228
14	Childfreedom	252
	<i>References</i>	269
	<i>Index</i>	296

Colour Plates section to be found between pp. 94 and 95

Preface

This book is about psychological practice for people and families impacted by a wide range of developmental presentations whereby the sex chromosomes, reproductive anatomy and urogenital characteristics – in combination – do not map clearly onto the social categories of female or male. The book goes some way to explain why this is a contested healthcare field and to visualize ethical psychological practices.

Irreconcilable Differences in Language

In the past, medical doctors and scientists referred to atypical biological sex as *intersex*. Today, the presentations are grouped under the collective term *differences in sex development* (DSD). Meanwhile, the term *variations in sex characteristics* (VSC) has been introduced as a less stigmatizing term than intersex and DSD. The irreconcilable debate on terminology is understandable. It is a contest about who gets to name whom. Therefore, it is unlikely that any one term will receive broad acceptance by those whom it describes.

Under the collective term(s) are highly variable bodily presentations. In medicine, diagnostic workup is triggered either by visible genital variations in an infant or by atypical or absent pubertal development in an adolescent. People who are born with the said physical variations are as different from one another as people without variations in terms of identity, sexuality and all human attributes. While many people with lived experience have reclaimed intersex as a personal/political identity, many more consider themselves as gender-normative with a bodily variation that does not define them.

The evolving terms and changing criteria make it important to emphasize that this book is about psychological practice in the field of intersex/DSD/VSC, by which I mean nonsexually dimorphic combinations of genetic, reproductive and urogenital characteristics, as described in Chapter 2. As this is a healthcare book, it has to be in dialogue with the clinical literature. This means engaging with medical terminology when referencing medical publications. For example, I refer to *intersex medicine* when discussing past medical practices and to *DSD services* when discussing current medical practices. Otherwise, I use vocabularies such as

variations in sex development, genital variations or just variations – descriptively. Furthermore, in this book, psychological service users are not just “patients” with variations but also caretakers, families and partners who are impacted by sex variations.

Why This Book?

This book is an attempt to bring social science research and critical analyses into interpersonal work with service users. Like many psychological care providers (PCPs), I inhabit both coalface and ivory tower with limited resource to digest the voluminous publications on the topic across disciplinary corridors. This book condenses several literatures to provide a background to enhance PCPs’ understanding of the current debates, as a preparation for rigorous and ethical interpersonal work with service users.

Many physicians and nurses tell me that they wish to be more psychologically informed in order to engage more confidently with service users about uncertainty, stigma, loss, identity, marginalization, relationships and sex. Furthermore, medical providers who work in other regions of the world tell me that, without access to formally trained PCPs, they often double up as counselors for patients and families. Despite its Western focus, I hope that some of the content of this book is useful to them.

This book discusses healthcare for intersex/DSD/VSC as a lifelong concern. Lifelong care requires contributions from communities where people work, play, learn, worship, socialize, fall in love, grow up and grow old. Community-based providers such as family doctors, nursery nurses, teachers, sex educators and spiritual care providers have much to offer individuals and families. The problem is that people impacted by variations are often misunderstood outside specialist services. This book is a resource to orientate the nonspecialist to the field so that their capacity for care contributions can be realized.

Finally, the book is also for researchers new to sex development or new to critical psychology. My critical interpretation of psychosocial research in the field reflects my personal journey that criss-crossed paradigms. By paradigm I mean a philosophical framework that guides me to examine my values, assumptions, methods and interpretations. Experimental psychology was my strong point at the beginning of that journey, and I am grateful for the immersion. It has helped me to answer some questions but also opened my eyes to the arbitrariness of probabilistic computations. The formulaic nature of positivist research is reassuring but, in the interpersonal space that I occupy as a therapist, the way that feelings and intentions

unfold is much more aptly captured by qualitative research. The privileging of intersubjective influences of language, values and power relationships in discursive research, which positions all researchers as already politically engaged, speaks most directly to my clinical practice, where talk is by nature dynamic and elusive yet context-bound. I hope that this book will stimulate debate about the future of psychosocial research, which can materially affect lives and carries social responsibilities.

How is the Book Structured?

Biogenetics is the dominant discourse of variations in sex characteristics. In a book that uniquely privileges psychosocial practice, it feels more appropriate to begin with stories of people, places, relationships, feelings and choices rather than body compounds like genes and enzymes. Therefore, in Chapter 1, I literally tell a story. Entitled “Circles and Squares,” the story enables me to introduce salient psychological themes, which are addressed in different parts of the book. Thereafter, the book is split into three sections.

Psychological practice broadly involves the steps of familiarizing oneself with the service context, identifying the problem to be addressed, using explicit frameworks to contextualize the problems and working with clients towards agreed goals. The structure of this book approximates these steps. The introductory notes at the beginning of each section are there to orientate readers to the focus of the section.

The section “Medicalization and Resistance” is a portrayal of an evolving service context. It addresses medical understandings past and present and gives context to the call to demedicalize intersex. Demedicalization does not mean denying the materiality of genes, hormones and anatomy or negating the benefits of new technology. Rather, it halts the framing of psychosocial concerns as medical problems and argues for a social model of understanding lived experience and interpreting care needs.

The section “Psychological Theories and Applications” is, as the title suggests, a conversation about knowledge frameworks in healthcare psychology and their strengths and weaknesses in informing remedial interpersonal work. This section lays the ground for working with the clinical themes in subsequent chapters.

The final section, “Working Psychologically,” is the practice area of the book. It comprises Chapters 9–14, which address six overlapping themes. In a researcher-practitioner spirit, each chapter begins with a narrative summary of relevant research and ends with a practice vignette. The vignettes are

not recipes to follow. Quite the opposite; they are constructed to show that interpersonal work is by nature contingent and open to challenge. I hope that in future, more PCPs render their interpersonal work transparent in the interests of peer learning and practice improvement.

Whom to Thank?

Sarah Creighton and Gerry Conway have been the most important people on the journey that led me to this book. When we first gathered at University College London Hospitals (UCLH) in the UK in the mid-1990s, we did not anticipate the long and organic growth of our project. It began when we met Margaret Simmonds in 1995 at a Royal Society of Medicine symposium, *Management of Intersex into Adult Life*, at which she and another member of the Androgen Insensitivity Syndrome Support Group (AISSG) UK had been invited to speak. The 1990s was a time when the UK was without a service strategy for adults with sex variations. The idea of a multidisciplinary service for adults emerged in 1997 in conversations with Margaret and other AISSG UK members. Out of these early discussions grew the world's first known adult clinic that combined expertise in endocrinology, gynecology and clinical psychology and enabled service users to see specialists in any or all of these disciplines in the course of a single clinic visit.

Between the late 1990s and mid-2000s, our service quickly grew from once a month to three times a week. A person whose dedication was pivotal to coordinate this growth before she retired was a nurse specialist called Maligaye Bikoo. We were also supported by exceptional colleagues in urology, imaging and genetics and were so fortunate as to attract a continuous stream of outstanding trainees and fellows in medicine, nursing and psychology to keep us inspired. I had much to learn from colleagues not very far away from UCLH, at the pediatric DSD service at Great Ormond Street Hospital for Children. The geographical closeness meant that early on, service users had the chance to access the kind of lifespan care that is so talked about today.

The postmodern therapist has been likened to an *accidental ethnographer* who comes into the system from a position of not fixing. With neither lived experience nor professional guidance for working in the field, the analogy worked for me, if up to a point. While I knew neither what nor how to fix, I was already a feminist and critical psychologist and made sense of my experiences in a particular way. But it is true that for some years, my existence in intersex medicine was something akin to that of an

ethnographer, though I did not know it at the time. Such a venture would not have been possible without the generosity and kindness of people who are too numerous to thank individually.

Among clinical experts, I need to thank the many medical and psychological professionals who invited me to meet with their teams in France, Italy, Sweden, Germany, the UK and the USA. My gratitude also goes to the many academic hosts who involved me in teaching and learning. I could not but be impressed by the progress made in the field in a very short time and humbled by the dedication and passion to improve care.

A person who offered me new dialogue in the early days was Iain Morland. When we met in 2002, I had no idea how much I was to profit from his unrivalled intellect and humor. Among other people who have also raised my game are Katrina Roen and Peter Hegarty, with whom I have enjoyed numerous projects. Franco D'Alberton's clinical acumen and camaraderie made me realize the importance of peer support for myself. I salute the dozens of contributors to the former European Network for Psychosocial Studies in Intersex (EuroPSI). The network was relaunched as Psychosocial Studies in Intersex International (PSI-I) in 2021. The enthusiasm to champion the fledgling efforts of this evolving network speaks volumes of the value that psychosocial researchers and practitioners place on mutual learning and support.

Working with peer advocacy groups has been inspirational. As well as the AISSG UK, it has been my deepest honor to connect with the following people and organizations: Magda Rakita, Anick Soni and Interconnected UK, Ellie Magritte and dsdfamilies, Arlene Smyth and the Turner Syndrome Support Society UK, Alison Bridges, Paul Dutton and the Klinefelter Syndrome Association UK, AISIA in Italy and grApSIA in Spain. Further afield, I thank pioneering intersex advocates Bo Laurent, Arlene Baratz and their colleagues in the USA for their friendship and collaboration.

Many people have provided me with helpful conversations and feedback regarding specific aspects of the book. Among those not already named are Julie Alderson, Mary Boyle, Morgan Carpenter and Dan Wood, whose expert advice has been indispensable. Jackie Doyle and Jackie Hughes' unconditional support for the book was an intellectual and spiritual well that kept me going.

My gratitude goes, of course, also to the hundreds of service users who shared their stories with me and to the dedicated supervisees, trainees, students and interns not just in DSD but across specialties – from perinatal to palliative care – for the time spent in thinking together about

intrapersonal and interpersonal human concerns and the relevance and limitations of psychological approaches.

Writing is selfish and excluding and a risk to relationships. My family and friends have remained loving without the quality attention due to them.

Thank you all.

Abbreviations

5 α R2D-5	alpha reductase 2 deficiency
17 β HSD3D-17	beta hydroxysteroid dehydrogenase 3 deficiency
AI5	androgen insensitivity syndrome
ART	assisted reproductive technology
BPSM	biopsychosocial model
CAH	congenital adrenal hyperplasia
DSD	differences in sex development
ISNA	Intersex Society of North America
KS	Klinefelter syndrome
MDT	multidisciplinary team
MRKHS	Mayer-Rokitansky-Küster-Hauser syndrome
PCC	patient-centered care
PCP	psychological care provider
PTMF	Power Threat Meaning Framework
TS	Turner syndrome
UN	United Nations
VSC	variations in sex characteristics
WHO	World Health Organization

SECTION I
Ordinary Lives

