

Index

- 5 α -reductase type 2 deficiency (5 α R2D), 16–17, 23, 217
- 17 β -hydroxysteroid dehydrogenase-3 deficiency (17 β HSD3D), 23–24
- 46,XX DSD, 16, 21, 388.140. *See also* congenital adrenal hyperplasia; Mayer-Rokitansky-Küster-Hauser syndrome; ovotesticular DSD
- 46,XXY DSD. *See* Klinefelter syndrome
- 46,XY DSD, 16, 21, 23, 73, 192, 196, 309.30. *See also* androgen insensitivity syndrome; 5 α -reductase type 2 deficiency (5 α R2D); 17 β -hydroxysteroid dehydrogenase-3 deficiency; Swyer syndrome
- activism. *See also* advocacy/advocacy groups; support groups
- in Australia and New Zealand, 74
 - in Germany, 73–74
 - for healthcare reform, 76–79
 - intersex activism, 12, 27, 34, 50, 60, 66–71, 74
 - in Malta, 74
 - in Switzerland, 69, 74
- adolescents/adolescence
- androgen insensitivity syndrome in, 23
 - congenital adrenal hyperplasia in, 51
 - diagnosing sex variations in, 32, 35
 - global increase in gender services for, 195
 - identification as lesbian, gay, bisexual, queer, pansexual, bicurious, 194–195
 - medical communications overload for, 90
 - need for psychological safety, 145
 - post-surgical follow-ups, 59
 - reactions to infertility, 256
 - self-protection strategies of, 90
- adoption, 259
- adults. *See also* adults, outcome of childhood genital surgery; adults, self-disclosure research/findings; caretakers; family (families/households); parents
- demands for healthcare reforms, 32
 - disclosure research/findings, 210–213
 - distress at pediatric management, 36
 - experiences of intrusion, 35
 - medical communications overload for, 90
 - memories of degrading/shaming childhood experiences, 36
 - psychological adaptation, 153
 - self-protection strategies of, 90
- adults, outcome of childhood genital surgery, 46–59
- feminizing surgery, studies/findings, 50–52, 57–59
 - masculinizing surgery, 53–56
- adults, self-disclosure research/findings, 210–213
- AIS study with women, 210
 - degrees of sharing/withholding based on type or relationship, 211–212
 - difficulties talking with family members, 211
 - dsdfamilies advocacy group survey on concealment, 212–213
 - MRKHS study, with women, 210–211
 - opportunities presented by disclosure, 214
 - physical intimacy related and non-disclosure, 210–211
 - positive message to caretakers, 214
 - preoccupation with thoughts of disclosure, 212
 - variability in disclosure, 211–212
- advocacy/advocacy groups. *See also* human rights activism
- advocacy, defined, 60
 - global advocacy movements, 32
 - global human rights efforts, 73–76
 - goals of, 61
 - patient's rights and, 61–62
 - peer support as a form of, 60
 - present day activities of, 80
 - role of the mass media, 60, 71–73
 - UK groups, 60
 - US groups, 60

- US survey/findings data, 28
 YOUTH & I advocacy publication, 206
- AIS. *See* androgen insensitivity syndrome
- ambiguous genitalia, 38–39, 167
- androgen insensitivity syndrome (AIS)
A.L.I.A.S. booklet (Androgen Insensitivity Syndrome Support Group, UK), 60, 63
 complete AIS study, 210
 concealment, 33
 concealment of diagnosis, 33
 description, 23
 diagnosis/being lied to about, 33
 infertility as an aspect of, 168
 parental concerns, 168
 partial androgen insensitivity syndrome, 17, 213
 peer groups for, 63
 research study with women, 210
 role of caretakers in informing children, 209
 study/findings of parents with daughters with, 168
 support groups for, xii, 60, 63, 76–77, 213–214
 testes removal, 33–34
- assisted reproductive technology (ART), 252–259
 advances in male fertility treatment, 260
 criticism of commodification, 258–259
 crytopreservation, 147
 donor egg IVF, 258
 gestational surrogacy and, 258–259
 heterosexual male infertility and, 257–258
 psychological burdens of, 258
 reproductive tourism and, 258
 successful outcomes in LGBT communities, 263–264
 surrogacy, possibility with MRKHS, 253
- bladder exstrophy-epispadias complex (BEEC), 26
- brain gender / brain organization theory
 animal experimentation and findings, 190
 boys/girls, gender-stereotyped choices, 191
Brain Gender (Melissa Hines), 190
Brain Storm (Rebecca Jordan-Young), 193
 comparison/similarities to biomedicine, 192–193
 human observations/psychometric testing, 190
 needs for theoretical development, 193–194
 research focus on chromosomal and social females with CAH, 191–193
 role in understanding gender development, 145
- CAH. *See* congenital adrenal hyperplasia
- care documents (DSD). *See also* *Clinical Guideline for the Management of Disorders of Sex Development*
 evidence-/experienced-based/common sense, 119–120
 holistic care, 81
 medical framing, 90–94
 minoritization-informed care, 94–95
 multidisciplinary teams (MDTs), 81, 85–88
 need for translational work by psychosocial experts, 140
 patient-centered care (PCC), 82–94
 psychosocial presence, 88–90
 caretakers/parents, 325.130. *See also* caretakers, self-disclosure, research/findings; grief/grieving of caretakers and adolescents, 215
 caretaker–child attachment, 174
 changing advice on revealing intersex diagnosis to the child, 207
 compliance with medical procedures, 35–36, 90
 concerns about child with variations, 168
 conflicts over child's right to privacy, 207–210
 confusion over terminology, 26–27, 92
 consequences of giving false hope, 167
 conviction that surgery is in child's best interest, 46, 150
 disability studies and findings, 172–173
 emotional needs of, 169
 grief and growth of, 166–187
 impact of emotional arousal on decision-making, 154
 need for maximizing psychological safety for, 37
 negotiation of relationships by, 175
 parental influences, 152, 169–170, 173–174
 parental demand for childhood genital surgery, 92–93
 post-surgery regrets of, 55, 57
 processing losses, 168, 170–173
 research and findings with, 28, 102, 167–169
 restoration-oriented coping by, 172
 role of PCPs in enabling caretaker to communicate with the child, 208–209
 sourcing of socially inclusive stories by, 135
 stressfulness of gender assignment, 188, 196
 strong emotions, 167, 170, 207
 UN Convention on the Rights of the Child on the roles and duties of, 76
 willingness of CAH caretakers to talk to the child, 208
 care users. *See also* advocacy/advocacy groups
 beliefs about the healthcare process, 34, 91–92

- care users. (cont.)
 concealment of biological variation from, 11–12
 concealment of sex variation from, 34
 difficulties/pressures in choosing interventions, 151–153
 displeasure with post-surgery genital appearance, 52
 evaluation of goals of, 139
 fear/dread in talking about sexual intimacy, 235
 feelings of anger/betrayal of, 35
 goals of initial psychological assessment with, 163, 180, 220, 246
 impact of emotional arousal on, 154
 increasing role of service user involvement, 61
 issues in determining timing for disclosure, 212
 lack of longitudinal research data from, 56–57
 minoritization of, 94
 narratives of first person accounts of traumatic medical encounters, 36
 need for maximizing psychological safety of, 37
 ongoing sexual anxiety, communication difficulties, 57
 preference for indirect naming, 29
 PTMF-informed psychological conversations, 110–111, 117
 research findings on post-surgery genital appearance, 52
 response of medicine to dissent by, 11
 role in healthcare reform, 76–79
 role of PCPs in engagement of, 116, 127, 165, 205
 service experiences of, 21, 45, 77, 124, 129–130, 151
 struggles in talking about sex variations, 227
 use of peer support/self-help groups, 62
- Carpenter, Morgan, 70–71, 74
 Chase, Cheryl, 76–77
 Chicago consensus. *See Consensus Statement on Management of Intersex Disorders*
- childfree lives
 attitudes toward women, 263
 childfreedom *vs.* childlessness, 262
 pronatalism and, 253, 263
 research/findings on, 262–264
- childhood genital surgery
 continuation of, 36–37, 47, 91–94, 149
 debates about, 12–13, 46–47
 feminizing surgery, 47–50
 informed consent for, 13, 79
 masculinizing surgery, 53–56
 need for ethical/methodological follow-up, 59
 practice vignette, 157–165
- children. *See also* childhood genital surgery;
 family (families/households)
 with bladder exstrophy-epispadias complex, 26
 clinical visits, 216
 diagnosing sex variations at birth, 35
 genital masculinization of XX children with CAH, 43–44
 global increase in gender services for, 195
 initial psychological evaluation period for, 88
 need for psychological safety, 145
 negative experiences of physical examinations, 36
 phallus size related gender assignment at birth, 32
 post-surgical follow-ups, 59
 reasons for concealment of information by caretakers to, 210
 role of caretakers in informing of AIS conditions to, 209
 telling the truth to, 40
 vaginoplasty, 41
 choosing “normalizing” genital surgery in adulthood, 147–165
 disadvantage/influence factors in choosing, 147–148, 151–153
 informed consent and, 148, 154–157
 societal pressures and, 152–153
- chromosomal sex characteristics, 15
 cloacal anomalies, 26
 Colombia, intersex activism, 70
 complete androgen insensitivity syndrome (CAIS), 210
 concealment of information (lying), 33–35
 ethical/legal implications of, 35
 medical paternalism and, 33–34
 women with AIS case history, 33
- congenital adrenal hyperplasia (CAH)
 assessment of genital masculinization of XX children with, 43–44
 classification/taxonomy debate, 17, 30
 conception rates, classical/non-classical CAH, 255–256
 description/characteristics, 22–23
 fertility in women with, 253–254
 genital masculinization in XX children, 43–44
 glucocorticoid treatment, 254
 Hugh Hampton Young, 19
 influence on puberty, 23
 Lawson Wilkins, 38
 parental support for children with, 5
 parents of female children with, 4–5, 152
 pediatric psychology recommendation regarding, 6
 peer groups for, 63
 practice vignette, 157–165

- pros/cons of adult surgery, 5
 research focus on chromosomal and social females with, 191–193
 research with women with, 27–28, 36, 102, 185, 192, 229
 study of parents consenting to clitoral reduction on daughters with, 149–150
 study of the therapist-patient alliance, 126–127
 support groups for, 5
 talking to children about, 208
 vaginal construction surgery in, 48–49
 Warne's book on, 62
- Consensus Statement on Management of Intersex Disorders*, 20–21
 calls for an update, 29
 description/achievements of, 77–79
 lack of acknowledgment of risks of surgery, 152
 naming dispute, 26–27
 recommendation for psychological contributions, 152
- Cull, Melissa, 178
- D'Alberton, Franco, 35
 Davis, Georgiann, 36
 Devore, Howard, 69
- diagnosis
 of 5 α R2D, 23
 of AIS/lies about diagnosis of AIS, 33
 being lied to, 12
 concealment of, 34
 of congenital adrenal hyperplasia, 5
 delayed diagnosis, 15
 of differences in sex development, 21
 of infant intersex variations, 42
 of MRKHS, in adolescents, 22
 of ovotesticular DSD, 24
 prenatal, of DSD, 31
 of Swyer syndrome, 7
 of Turner syndrome, 24
 uncertainties of, 21
- differences in sex development (DSD), ix, 23, 180. *See also* specific conditions
- categories/term derivation, 21
 damage-centered research and findings, 104
 DSD services, ix, 4
 genetic diagnosis possibilities for, 21
 impact of the new classification scheme, 31
 knowledge requirement for psychological practitioners, 21
 naming convention issues, 26–29
 need for minoritization-informed services, 126
 overwhelming communications about, 90
- prevalence/inclusion issues, 29–31
 psychological concepts in DSD care documents, 119–120
 reproductive sex characteristics, 15–16
 sex reversal, term-related issues, 26–27
 survey of parents of children with, 27–28
 variations in urogenital differentiation, 15–16, 88
- dimorphic sex development, 15–16
 disclosure, 350.20. *See also* adults, self-disclosure research/findings; caretakers, self-disclosure, research/findings
 absence of, 34
 consequences of not receiving, 35
 contested knowing and talking, 213–216
 degrees of, in different social contexts, 202, 206
 difficulties/challenges of, 145
 ISNA recommendations for, 68
 Money/Hampsons' advice on, 40
 opportunities presented by, 214
 practice vignette example, 164–165
 professional endorsement of, 77–78
 videos related to, 206
 vocabulary for, 213–216
- Downing, Lisa, 37
 Dreger, Alice, 69, 109
 DSD. *See* differences in sex development
- dstdfamilies* (UK-based peer advocacy group), 21, 164
The Handbook for Parents, 215
 Making it Fun (Top Tips for Dilation) program, 230
Sex Development Stories booklet, 214
- estrogen, 7
 estrogen cream, 234
 estrogen patch, 243
 estrogen replacement, 234
- European Network for Psychosocial Studies in Intersex/Diverse Sex Development (EuroPSI), 96
- exstrophy conditions
 bladder exstrophy-epispadias complex (BEEC), 26
 psychosocial study and findings, 103–104
- external genitalia. *See also* female genitalia (external); male genitalia
 female-typical development, 16
 female-typical/male-typical spectrum, 15
 male-typical development, 16
 prevalence of associated conditions, 30–31
 testosterone's conversion to DHT, 16
- external genitalia score (EGS), 43–44
 external masculinization score (EMS), 43

- family (families/households)
 assessment for mental health history, 161
 challenges of communications, 60, 166, 211
 child's gender issues, 169
 confiding in close others, 215
 daily tasks faced by, 176
 diversity of families/family life, 252
 emotion-centered care for, 169
 family consultations, 126, 176
 family therapy, 134, 160
 goals of evaluation for, 139
 grief and adaptation, 171
 mapping out family structure, 132
 need for questioning gender-based stereotypes, 216
 patient-centered care (PCC) approach, 83
 PCP's role in discussing types of support for, 197
 psychosocial screening tools for maladaptive coping, 78, 89–94
 reactions to intersex variations, 34, 136–139
 related multidisciplinary team discussions with, 125
 relationship to help and, 126
 support group participation, 5, 178
 syndrome-specific peer support, 62, 72
 threats to family scripts, 135
 UK care guidance document for, 176
 use of mindfulness practices, 138
- fear of intimacy, 236
- Feder, Ellen, 36, 69
- female embodiment, 112–113, 168
- female genital cutting, 233–234
- female genitalia (external)
 cloacal exstrophy influence on development, 26
 female-typical external genitalia, 15
 influence of androgen insensitivity syndrome on development, 23
 influence of CAH on development, 23
 influence of Swyer syndrome on development, 24
 variability in “normal” genitalia, 48
- female pseudohermaphroditism, 18–19, 42
- feminizing surgery
 for addressing genital variations, 4–5, 32, 47–50, 69
 clitoral reduction/recession surgery, 4–5, 32, 47–48
 debates on techniques, 48–52
 European survey on self-reported reduction in surgery, 93
 one-stage feminizing genitoplasty, 30, 48–49, 113, 115
- post-gonadectomy life-long hormone replacement, 49
- practice vignette, 152, 157–165
- projected social harm of bigger clitoris, 47
- research with adults, 52
- variability in “normal” genitalia, 48
- fertility. *See also* assisted reproductive technology; infertility
- congenital adrenal hyperplasia and, 253–254
- experimental preservation of gonads, 200
- male factor infertility and treatment, 15, 260
- Mayer-Rokitansky-Küster-Hauser syndrome and, 22
- potential prospects for, 41
- proximal hypospadias and, 54
- psychological support, 260–262
- Swyer syndrome and, 24, 254
- Turner syndrome and, 25
- variations in sex development and, 253–256
- gender, definitions, 188–192
- gender assignment, 188–205
 assessment tools, 43–44
 brain organization theory and, 189
 caretakers' flexibility, 196
 Chicago consensus recommendation, 189
 congenital adrenal hyperplasia and, 30
 contributions by PCPs in, 197
 gender-genitals alignment, 12
 gender plasticity, 38, 40
 gender reassignment surgery, 46
 gender-stereotyped choices, 191
 genital size consideration, 32, 44
 goals of, 66–67, 189–190, 195–196
 immediacy at birth, 42
 increased male gender assignments, 231
 Money on the role of parents, 39
 ratio of female *vs.* male assignment, 43
 social-surgical female sex assignment, 43
 stress factors for caretakers, 188
 working with limitations, 195–197
- gender identity
 congenital adrenal hyperplasia and, 30
 endorsement of minority sex/gender identities by Western young people, 194–195
 gender diversity, 195
 gender uncertainties, 194–195
 multiple dimensions of, 193–194
- genital assessment, negative experiences of, 36, 43–44
- genital morphology
 5 α R2 enzyme and, 23
 role of assessment in diagnosing sex variations, 35
- terminology, 21

- Germany, intersex activism, 70
- gonads
 classification scheme, 20
 experimental preservation of, 255
 germ cell tumors, 24
 non-consensual gonadectomy, 255
- Great Wall of Vagina, sculpture (McCarthy), 165
- grief and growth of caretakers, 166–187
 call for emotion-focused care for families, 169
 cognitive scientists' understanding of, 171–172
 at diagnosis of a child, 60
 dimensions of, 169–170
 disability studies and findings, 172–173
 expectations and adaptations, 169–170, 173–174
 mourning for what might have been, 166–167, 170
 reciprocal attachment (attachment and bonding), 173–174
 restoration-oriented coping, 172
 social differences in loss and grieving, 170–171
 supportive role of psychosocial practitioners, 79–80
- growth hormone treatment, 147, 153, 181, 185
- Hampson, Joan and John, 39–41
- Handbook for Parents, 214–215
- The Handbook for Parents*, 215
- healthcare reform, 133.150. *See also* advocacy/advocacy groups
 conversations at medical conventions, symposiums, 76–77
 implications for psychological practice, 95–96
 medical response to challenges for, 76
 social model of health care, 95
- Hermaphrodites with Attitude* (ISNA), 60, 66–68
- hermaphroditism, 16–18
 dropping of term usage, 21
 female pseudohermaphroditism, 18–19
 feminizing surgery for, 48
 historical understanding of, 17
 interchangeability with intersexuality, 19
 male pseudohermaphrodites, 18
 terminology issues, 26–27
 true hermaphrodites, 18
- hormone replacement treatment (HRT), 33, 254
- hypospadias, 2–4
 challenges of medical management, 55
 description, 25–26
 distal hypospadias, 53–56
 masculinizing surgery for, 53–56
 proximal hypospadias, 53–55
 regional differences in incidence, 25
- regret in giving proxy consent for childhood surgery, 55–56
 review of surgical techniques for, 53, 55
- Iceland, intersex activism, 70
- infertility, 285.240. *See also* fertility
 adoption, 259
 in androgen insensitivity syndrome, 168
 cultural, social, psychological factors, 257
 definition/prevalence, 256
 impact on heterosexual men, 258
 influential lifestyle factors, 256–257
 intra-cytoplasmic sperm injection (ICSI), 254
 Klinefelter syndrome (KS) and, 25
 pronatalist ideology and, 146
 psychological impact of treatment, 257
 psychological barriers to, 256–257, 262
 in Turner syndrome, 185
 in vitro fertilization (IVF), 258
- informed consent
 complexities in obtaining, 144
 example guide for, 155–156
 intersex activism for, 13
 patient's rights and, 61
 psychological barriers to, 154–157
 related Australian legislation, 79
 variabilities in seeking, 148
- Intersex Society of North America (ISNA), 43–44, 60, 66–67
- ISNA. *See* Intersex Society of North America
- Jordan-Young, Rebecca, 193
- Karkazisz, Katrina, 82
- Kessler, Suzanne, 68, 82, 150–152
- Klebs, Theodor Albrecht Edwin, 18
- Klinefelter syndrome (KS), 25, 113
 peer groups for, 63
 practice vignette, heterosexual couple, one with KS diagnosis, 146, 264–268
 success in having children with, 255
 testicular sperm extraction and, 254–255
 use of ART, 256
- Koyama, Emi, 189
- Lawson Wilkins Pediatric Endocrine Society, 76–77
- LGBTQ+ (lesbian, gay, bisexual, transgender, queer+)
 clients/services, 129–130
 sexual identity choice and, 71
 successful ART/parenthood outcomes, 263–264

- LGBTQ+ (lesbian, gay, bisexual, transgender, queer+) (cont.)
therapist self-disclosure (TSD) and, 129, 244
- male genitalia
cloacal exstrophy influence on development, 26
hypospadias and, 25–26
male-typical external genitalia, 15
- Malta, intersex activism, 70, 74
- masculinizing surgery
caretaker/parental regret in giving proxy consent for surgery, 55
complication rates, 53–55
focus on hypospadias, 53–56
medical management of hypospadias, 55
need for multiple operations, 54
surgical trade-offs, mild hypospadias, 56
variety of techniques/modifications, 53
- mass media, 71–73
Golden Boy novel, 73
Growing Up Intersex tv broadcast (Winfrey), 72
Hermaphrodites Speak! documentary, 72
How Do Intersex People Navigate Life and the Medical System?, 72
Interface Project, interviews, 72
Intersexion film, 72
Me, My Sex, and I, BBC documentary, 72
Middlesex novel, 73
Orchids, My Intersex Adventure online videos, visual art, 72
XY Women, BBC documentary, 72
- Mayer-Rokitansky-Küster-Hauser syndrome (MRKHS), 22, 63
fertility and, 253
non-surgical vaginal construction studies, 229–230
research study, with women, 210
sexual function and, 229–230
- medicalization of intersex
demedicalization, xi
medical framing, 82, 90–94, 196
- menopause, 185
- Meoded Danmon, Limor, 88
- minoritization
minoritized communities, 109, 129
need for minoritization-informed care, 94–95, 126
- Mitchell, Mani, 72
- Money, John
emphasis on role of parents in gender assignment, 39
on gender plasticity, 40
on the harm of genital examinations, 41
influence on medical specialists, 45
optimal-gender policy, 38–42
psychoneuroendocrinology, 193
psychosexual differentiation theory, 38
on telling caretakers/children the truth, 40–41
on transsexual men, 41
writings/lectures/theories of, 37–38
- Moreno, Angela, 69
- Morland, Iain, 37, 84–93
- MRKHS. *See* Mayer-Rokitansky-Küster-Hauser syndrome
- Müllerian and Wolffian ducts, 15–16
- multidisciplinary teams (MDTs), 81, 85–88
absence of mention, in DSD publications, 86
accountability of, 86, 88
childhood genital surgery and, 78
description, 86
need to redevelop, 87, 89, 94–95
origins/emergence of, xii
role in optimal clinical management by, 77
role of psychological practitioners in, 85–89
whole person care and, 90
- orgasm
absence of, in studies of CAH women, 50–51, 229
female genital cutting and, 233–234
impairment of in clitoral surgery, 79
in men with 1-6 genital operations, 231
reduced in MRKHS women, 229–230
as a seeming requirement, obligation, responsibility, 233
study/findings of men with a “micropenis,” 43
- ovotesticular DSD, 21, 24, 73
- Pagonis, Pidgeon, 240
- partial androgen insensitivity syndrome (PAIS), 17, 213
- patient-centered care, 82–94
definition/DSD publications, 84–85
definition/Stewart, 83–84
demands for/principles of, 83
need to redevelop MDT processes, 94
patients’ rights and, 61–62
- PCPs. *See* psychological care providers
- Pediatric Endocrine Society. *See* Lawson Wilkins Pediatric Endocrine Society
- peer support. *See also* advocacy/advocacy groups; support groups
for androgen insensitivity syndrome, 63, 178
for congenital adrenal hyperplasia, 63
facilitation of connections with peers, 178–179

- for intersex, 34, 50
- for Klinefelter syndrome, 63
- move toward generic DSD/VSC groups, 66
- research findings, 178
- social risks/emotional costs of, 178–179
- syndrome-specific peer support, 62, 72
- for Turner syndrome, 63
- pelvic examinations
 - need for care protocols for, 37
 - negative experiences of, 37
- phallus
 - decision to designate as a penis, or designate as a clitoris, 42
 - medical phallocentrism, 43–44
 - phalloplasty, 41, 43
 - size/ gender assignment, 32
- Portugal, intersex activism, 70
- Power Threat Meaning Framework (PTMF), 101, 110–111, 114, 132
 - definitions of power, 109
 - ideological power, 109–111, 114
 - proximal mediation of, 109–110
 - standard and PTMF-informed psychological conversations, 115
 - usefulness of, 133–134
 - variations in sex development and, 112–115
- Prader scale, 43–44
- Preves, Sharon, 65, 69
- principles of service provision for caretakers, 175–179
 - emotionally competent consultation, 176–177
 - facilitating connections with peers, 178–179
 - safeness/containment, 175–176
- pronatalism, 253, 263
- psychological assessment, 123, 130–133, 139
 - example template, 130–131
 - practice vignette, female couple, one with partial AIS, 244
 - practice vignette, feminizing surgery, 158
 - practice vignette, talking about variations in sex development, 217
 - practice vignette, work with parents of unborn child with Turner Syndrome, 179–187
- psychological care providers (PCPs)
 - ability to juxtapose contradictory ideas in consultations, 124
 - call for emotion-focused care for families, 169
 - face-to-face discussions with parents, 88
 - help for caretakers/parents, 216
 - illness orientation, deficit orientation, growth orientation of, 134
 - job/role of, 128
 - judgement of, by patients, 127
 - needs assessment by, 130–133
 - role in enabling communication, 208–209
 - scientific credibility of, 174
 - theoretical tools used by, 101
 - types of discourse elicited by, 125
 - unique styles/preferences of, 134
 - use of the Power Threat Meaning Framework, 110–111, 117, 132
 - working with teams in DSD services, 176
- psychological interventions, 134–140
 - behavioral models/behavior therapy, 136
 - cognitive-behavioral therapy (CBT), 1, 113, 136–139, 165, 237, 243, 262
 - dialectical approaches, 136–137
 - dialogical approaches, 135
 - evaluation of, 139–140
 - existential psychotherapy, 134
 - family consultation, 126, 134, 160, 176
 - formulation/sense-making, 133–134
 - mindfulness-based approaches, 137–138
 - narrative therapy, 134
 - practitioner qualities, 126–130
 - psychoanalytic therapy, 105
 - psychological concepts in DSD care
 - documents, 119–120
 - relationship to help, 124–126, 130
 - signposting, liaising, triaging, 138–139
 - story repair, story telling, 134–135
 - stress and anxiety management, 113, 137
- psychological theories, 104–106
 - anti-oppressive practice, 115–117
 - biopsychosocial model and critique of, 101, 106–108
 - epistemological concerns in intersex research, 102–104
 - ideological power, 116
 - Power Threat Meaning Framework, 101
 - psychosomatic causality framework, 103
 - recognizing epistemic assumptions in research and practice, 102–104
 - stimulus-appraisal-response framework and, 105–106
- relationship to help, 124–126
 - initial assessment, 124, 130
 - psychological care providers and, 124–126
 - usefulness/benefits of, 126
- Sandberg, David, 191
- self-disclosure
 - research/findings, with adults, 210–213
 - research/findings, with caretakers, 207–217
 - therapists self-disclosures, 128–130
- SENS, European project, 82, 91
- sensate focus, in sex therapy, 241
- sex
 - coital imperative, 231–233

- sex (cont.)
- hormonal treatments (testosterone, estrogen)
 - for, 234–235
 - medicalization of, 234–235
 - orgasmic imperative, 233–234
 - sex chromosome DSD, 21, 24–25. *See also*
 - Klinefelter syndrome; Turner syndrome
 - sex therapy, 120, 133–134, 239–243
 - BDSM, 240, 242
 - body shame, 236
 - cognitive and behavioral techniques, 243
 - genital aversion, 136, 236, 248
 - goals of, 241
 - limits to, 240
 - mindfulness-based, 242–243
 - new demands on therapists, 240
 - pleasure talk prompts, in sex therapy, 242
 - practice vignette, 248–251
 - programs, 240
 - reducing body shame, 241
 - sensate focus, 241
 - sexual dysfunction, 229–233, 235, 238, 242
 - sexual intimacy concerns, 228–251
 - absence of pleasure talk, 235–236
 - digital sexual encounters/teledildonics sex, 232
 - erection, orgasm, ejaculatory concerns, 231
 - fear of sexual encounters, 235–236
 - lifetime variations in sex-related interests, 228
 - objectification, aversion, shame, 236–237
 - older people and, 228
 - physical health considerations, 237–239
 - self-spectatoring, 237
 - Simmonds, Margaret, xii, 178
 - Sullivan, Nikki, 37
 - support groups
 - for androgen insensitivity syndrome, xii, 63
 - for congenital adrenal hyperplasia, 5, 63
 - dsdamilies* (UK), 164, 208
 - goals of, 61
 - impact of the emergence of, 50–51
 - for intersex, 62, 65–66
 - for Klinefelter Syndrome, 63
 - for Mayer-Rokitansky-Kuster-Hauser Syndrome, 63
 - newsletters/information booklets of, 62
 - origins/descriptions of, 63
 - patient's rights and, 61–62
 - peer groups, 5, 28, 60, 63
 - Preves's research and findings, 65
 - for Turner Syndrome, 63
 - use of 'sketches' at, 41
 - surgery. *See also* adults, outcome of childhood
 - genital surgery; childhood genital surgery;
 - choosing "normalizing" genital surgery
 - clitoral reduction surgery, 4–5, 32
 - comments on, 41, 46–47, 92–93
 - critics of childhood surgery, 46–47
 - development at Johns Hopkins University, 38
 - disadvantage factors, 151–153
 - evolving goal of, 19
 - factors in decisionmaking, 37
 - feminizing surgery, 47–52
 - gender normalization surgery, 32
 - for hypospadias, 2
 - informed consent for, 13
 - justification for "normalizing" surgery, 32
 - masculinizing surgery, 53–56
 - need for ethical/methodological follow-up, 59
 - parents' concerns about, 92–93
 - potential complications/outcomes, 4
 - psychological preparation for, 6
 - reassignment surgery, 46
 - reconstructive genital surgery, 46
 - review of techniques for proximal hypospadias, 55
 - technical/emotional complexities of, 46
 - Swyer syndrome (XY complete gonadal dysgenesis)
 - description, 24
 - fertility in women with, 254
 - pregnancy and, 24
 - presence of a uterus with, 253
 - testes removal/gonadectomy, 33–34
 - testicular sperm extraction (TESE) with intra-cytoplasmic sperm injection (ICSI) (TESE-ICSI), 254–255, 266–267
 - testosterone
 - conversion to DHT, 23
 - role in male-typical development, 16, 23, 25
 - study of social influences on, 193
 - testosterone patches, 234
 - Tiefer, Leonore, 235
 - Turner syndrome (TS), 24–25, 114
 - fertility and, 185, 253–254
 - peer groups for, 63
 - practice vignette, work with parents of unborn child with TS, 144, 179–187
 - United Nations Convention on the Rights of the Child (Article 5), 76
 - United Nations Human Rights Council, 74–75
 - vaginoplasty
 - childhood vaginoplasty, 41, 150
 - factors in choosing, 164, 200
 - gut vaginoplasty, 49
 - introitus/introitoplasty, 157, 159

Index

305

- MRKHS/non-surgical vaginal construction studies, 229–230
physical and psychological complications, 52, 150, 235
risk reduction through psychosexual education with non-surgical dilation, 230
variations in sex characteristics (VSC), ix, 30
VSC. *See* variations in sex characteristics
- womb transplantation, 253
XY complete gonadal dysgenesis. *See* Swyer syndrome (XY complete gonadal dysgenesis)
Young, Hugh Hampton, 19, 47