Index

Aboriginal and Torres Strait Islanders (ATSI), 78
Academic Autism Spectrum Partnership in Research and Education (AAS-PIRE), 147
Adolescents, social skills programs, 68
African American autistics
  Aboriginal and Torres Strait Islanders (ATSI), 78
  Autism and Developmental Disabilities Monitoring (ADDM) Network, 75–77, 86
  autism awareness campaigns, 81
  Autism research community, 80–81
  Black and Hispanic autistics, 77
  ethnic diversity, 81
  ethnic minorities, 77–79, 81
  Focus on Autism and Other Developmental Disabilities (FOCUS), 78–79
  Interactive Autism Network (IAN), 77–78
  International Meeting For Autism Research (IMFAR), 80
  Journal of Autism and Developmental Disorders (JADD), 78–79
  race/ethnicity, 87–88, 91, 93–94
  racial disparities, 80–81
Alternative data collection methods, 126
American Psychiatric Association (APA), 2
American Statistical Association (ASA), 183
Asperger syndrome, 41–43
Assessment team, 107
Authenticity, 119–120
Autism advisory panel, 121
Autism and Developmental Disabilities Monitoring (ADDM) Network, 5, 53, 66, 75–77, 86
  advantages of, 54
  autism prevalence rates, 54
  data collection process steps, 55
  goals of, 53–54
  Surveillance Year, 54–62
Autism awareness campaigns, 81
Autism Diagnostic Observation Schedule Module 4 (ADOS Module 4), 29–30
Autism prevalence rates, 54
Autism research community, 80–81
Autism Science Foundation, 30–31
Autism spectrum
  academics, 6
  American Psychiatric Association (APA), 2
  Autism and Developmental Disabilities Monitoring (ADDM) Network, 5
  autistic females, increased recognition of, 2
  autistics, 6–7
  autistic seniors. *See* Autistic seniors
  category condition, 3
  Centers for Disease Control and Prevention (CDC), 5–6
  co-morbid conditions, 3
  Danish Psychiatric Register (DPR), 4
  developmental disorder, 3–4
  diagnosis, 108–109
  lifelong condition, 2–3
  parents, 7
  personal concerns, 13

- professionals, 7
- scholars, 12–13
- students, 7

Autism spectrum disorder (ASD), 29

Autism: The International Journal of Research and Practice, 28

Autistic adults, 101–102

Autistic characteristics, subtle presentation of, 30

Autistic diagnosis, 33–34

Autistic Disturbances of Affective Contact, 1

Autistic females, 215
- autism spectrum disorder (ASD), 29
- autistic characteristics, subtle presentation of, 30
- challenges, 32–33
- diagnosing females, 29
- female-specific barriers, 31
- healthcare system, 33–34
- increased recognition of, 2
- insensitive diagnostic instruments, 29–30
- literature about, 30–34
- males, 27–29
- medical professionals, 29
- recommendations, 32–33
- research, 27, 29, 32–33

Autistic patients, diagnosing
- assessment team, 107
- Autism Spectrum Diagnosis, 108–109
- autistic adults, 101–102
- diagnostic accuracy, improving, 103–104
- DSM-5 diagnostic criteria, 107–108
- ethnicity, 109
- families, 106–107
- healthcare system, 99–100
- health professionals, 104
- inconsistent/unorthodox diagnostic procedures, 100
- males and females, 105–106
- medical professionals, 102–103
- medical school training, 101
- parents of autistic children, 101
- problematic autistic diagnostic procedures consequences, 101–103
- race, 109
- research community, 103
- strategies, 103–110
- telehealth services, 110
- wait-time, 104–105

Autistic psychopathy, 1

Autistics, 6–7

Autistic samples, 62–63

Autistic seniors
- children with, 14–15
- cognitive abilities, 17–18
- diagnosing infants, 14–15
- employment, 18–19
- healthcare, 19
- mental health, 18
- nursing homes, 19–20
- palliative care, 19–20
- physical health, 16–17
- psychological well-being, 18
- public funding, 15–16
- research, 15–16
- transport usage, 19

Autistics proportion, 52–53, 66

Autistischen psychopathen, 1

Black and Hispanic autistics, 77

Breaks and quiet rooms, 126

Caregiver burden, 67

Centers for Disease Control and Prevention (CDC), 5–6

Cognitive abilities, 17–18

Community-based participatory research (CBPR), 147

Co-morbid conditions, 3

Consent process, 125–126

Cooperative Research Centre for Living With Autism (Autism CRC), 146–147

Danish Psychiatric Register (DPR), 4

Data collection, 126–134

- alternative data collection methods, 126
- breaks and quiet rooms, 126
- honorarium, 133–134
- interviews, 126–127, 133
- post-data collection considerations, 134
- process steps, 55

Developmental disorder, 3–4
Diagnosing females, 29
Diagnosing infants, 14–15
Diagnostic accuracy, improving, 103–104
DSM-5 diagnostic criteria, 107–108

Emotional distress, 134–140
Employment, 18–19
Ethnicity, 87–88, 91, 93–94, 109
- ethnic diversity, 81
- ethnic minorities, 77–79, 81

False assumptions, 120
Fathers raising autistic children
- examples, 41–44
- mothers, 39–40
- parental advocacy, 46
- parents' experiences of caring, 45–46
- paternal experiences, 40–44
- psychological and physical health, 44–45, 47
- raising experiences, 46–47
- research, paternal involvement in, 45
- strategies, 47–48

Fathers strategies, 47–48
Female-specific barriers, 31
Fletcher-Watson seminars, 119
Focus on Autism and Other Developmental Disabilities (FOCUS), 78–79

Griffiths Mental Development Scale – Extend Revised (GMDS-ER), 52

Healthcare system, 19, 33–34, 99–100
Healthcare utilisation, 69–70
Health professionals, 104
Honorarium, 133–134

Inconsistent/unorthodox diagnostic procedures, 100
Insensitive diagnostic instruments, 29–30
Intellectual disabilities
- Autism and Developmental Disabilities Monitoring (ADDM) network. *See* Autism and Developmental Disabilities Monitoring (ADDM) network
- autistic samples, 62–63
- autistics proportion, 52–53, 66
- caregiver burden, 67
- defining, 52
- goals of, 53–54
- Griffiths Mental Development Scale – Extend Revised (GMDS-ER), 52
- healthcare utilisation, 69–70
- intellectual quotient (IQ), 52, 58–59, 62
- mental health, 68
- potential participants small pool, 67
- prevalence of, 52–66
- relatives raising autistic children, 68–69
- social skills programs, adolescents, 68

Intellectual quotient (IQ), 52, 58–59, 62
Interactive Autism Network (IAN), 77–78
International Meeting For Autism Research (IMFAR), 12, 80
Intersectionality, 101
Interviews, 126–127, 133
Irreproducible research, financial costs of, 178–179

Journal of Autism and Developmental Disorders (JADD), 78–79

Low participant involvement, 144–145
Lucidity, 142

Medical professionals, 29, 102–103
Medical school training, 101
Mental health, 18, 68
Molecular Autism, 28
Mothers, autistic children, 39–40

Non-autistic researchers, 121
Nursing homes, 19–20

Palliative care, 19–20
Parents, 7
  autistic children, 101
  experiences of caring, 45–46
  parental advocacy, 46
Participant's confidentiality loss, 143–144
Participatory research practices
  authenticity, 119–120
  autism advisory panel, 121
  consent process, 125–126
  co-presenters of, 137–139
  cultivating, 118–119
  data collection. *See* Data collection
  defining, 117–121
  description, 118
  emotional distress, 134–140
  false assumptions, 120
  families, 135–136
  Fletcher-Watson seminars, 119
  funding in grants to, 140–141
  inconclusive/incomplete results, 145
  ineffective healthcare choices, 142–143
  low participant involvement, 144–145
  lucidity, 142
  maintaining respect, 118–119
  non-autistic researchers, 121
  participant's confidentiality loss, 143–144
  places, 124–125
  policies, 146–147
  pre-data collection considerations, 121–126
  promotional incentives, 145–146
  researcher misconceptions, 144
  research protocol, 149–150
  research's ignorance, 145
  stakeholder engagement, allocating funding for, 120–121
  stigma, 140
  study advertising, 124
  therapeutic misconceptions, 142
  time lag, 141
  uncertainty, 141
Paternal experiences, 40–44
Peer review process, 191–193
  consequences with, 191–192
  explanation of, 191
  improving, 192–193
  problems, 191–192
P-hacking, 182–186
  defining, 182
  solutions to, 182–186
Physical health, 16–17
Post-data collection considerations, 134
Potential participants small pool, 67
Pre-data collection considerations, 121–126
Predatory journals, 188–191
  impact of, 188
  overview, 188
  solutions to, 188–191
Problematic autistic diagnostic procedures consequences, 101–103
Professionals, 7
Promotional incentives, 145–146

Psychological and physical health, 44–45, 47
Psychological well-being, 18
Publication bias
  research, 180
  solutions to, 180–181
Public funding, 15–16

Qualitative research, 194

Race, 87–88, 91, 93–94, 109
  racial disparities, 80–81
Relatives raising autistic children, 68–69
Reproducibility crisis, 215
  consequences of, 178–179
  factors and solutions to, 179–194
  financial costs of irreproducible research, 178–179
  overview of, 177–178
  peer review process, 191–193
  P-hacking, 182–186
  predatory journals, 188–191
  publication bias, 180–181
  qualitative research, 194
  scientific discoveries, public's confidence in, 178
Research
  collaborations, 13, 146–147
  community, 103
  ignorance, 145
  misconceptions, 144
  protocol, 149–150

Scientific discoveries, public's confidence in, 178
Social skills programs, adolescents, 68
Stakeholder engagement, allocating funding for, 120–121
Stigma, 140
Stockholm Youth Cohort, 52
Students, 7
Surveillance Years, 54–62
  2000, 54–55
  2002, 55–56
  2004, 56–57
  2006, 57
  2008, 57–58
  2010, 58–59
  2012, 59–60
  2014, 60–61
  2016, 61–62

Telehealth services, 110
Time lag, 141
Transport usage, 19

Uncertainty, 141

Wait-time, 104–105