

# Index

- A-Z Reference Book of Syndromes and Inherited Disorders (Gilbert), 28
- ability to testify, 61–62
- Absolute Discharge, 152
- Accessible Cause-Outcome Representation and Notation System (ACORNS), 130
- Accessible Information Standard, 48
- Accreditation for Inpatient Mental Health Services (AIMS), 209
- Acute Care Hospitals, 196
- Acute Hospital Trusts, 199
- adaptive behaviour
- challenging behaviour and, 175
  - defined, 1–2, 3
  - dementia and, 95, 138
  - influence of, 2
  - introduction to, 1–2, 3
  - tools for assessing, 90, 95, 139
- Adaptive Behaviour Dementia Questionnaire (ABDQ), 139
- adults with intellectual disability
- accurate diagnosis, 127–128
  - aetiology, 130–131
  - assessment, 128–129
  - epidemiology, 125–127
  - interventions, 131
  - introduction to, 125
  - prognosis, 132
  - psychiatric symptoms and classification, 129–130
- aetiology of intellectual disability, 5–6
- affective disorder, 7, 31, 58, 132, 204, 215
- age at death, 107
- age-related cognitive impairment, 95
- Alzheimer's disease, 6, 29, 67
- Alzheimer's Society, 166
- American Association on Intellectual and Developmental Disabilities' manual (AAIDD), 2, 6
- American Psychiatric Association, 2, 55
- Angelman syndrome (AS), 17, 18, 30
- anger management, 165, 172–174
- Annual Review of Competence Progression (ARCP), 251–252
- Antecedent, Behaviour and Consequence (ABC) charts, 169–170
- antidementia drugs, 140
- antidepressant medication, 141, 179
- antiepileptic medication, 142
- antipsychotic medication, 140–141, 179
- antisocial behaviour, 28
- anxiety/anxiety disorders
- assessment of, 120
  - autism and, 59, 122
  - in children, 122–123
  - Glasgow Anxiety Scale, 208
  - incidence of, 132, 204
  - medication for, 122–123, 220
  - psychological interventions for, 172
  - social anxiety, 31, 32–33, 123
- APP gene and dementia, 137
- Applied Behaviour Analysis conceptual framework, 171
- Asperger, Hans, 53
- Asperger syndrome, 53
- assessment. *See also*
- biopsychosocial approach to assessment;
  - instruments of screening
- adults with intellectual disability, 128–129
- anxiety/anxiety disorders, 120
- attention deficit and hyperactivity disorder, 120
- behaviour with epilepsy, 74
- biopsychosocial approach to, 86, 89–96
- cognitive skills
- assessment, 90
- depression, 120, 139
- developmental history
- assessment, 90
- difficulty accessing, 104
- engaging with carers, 89
- engaging with physical health colleagues, 87–89
- epilepsy, 72, 74, 91
- forensic psychiatric patients, 154–155
- improvements to, 85–89
- learning disability, 175
- least restrictive principle in, 86–87
- motor skills assessment, 90
- normalisation in, 86–87
- person centred approach to, 86
- reasonable adjustments in, 86
- respiratory conditions
- assessment, 93
  - vision assessment, 94
- Association of Director of Social Care (ADASS), 209
- attention deficit and hyperactivity disorder (ADHD)
- assessment of, 120
  - autism, 58
  - Cornelia de Lange syndrome, 31
  - fragile X syndrome, 33
  - lack of screening tool, 121
  - mental health legislation, 215–216
  - sex aneuploidy, 34
- Atypical Autism, 53
- atypical mood disorders, 123
- atypical psychosis, 31
- auditory memory, 47

- autism spectrum disorders (ASD)  
ability to testify, 61–62  
aetiology of, 56–57  
anxiety and, 122  
child-specific concerns, 116, 120–121  
comorbidity, 29, 58–60  
Cornelia de Lange syndrome, 31  
decision making and mental capacity, 62  
differential diagnosis, 168  
epidemiology of, 57–60  
evolving concepts, 53–54  
foetal valproate syndrome, 31  
fragile X syndrome, 33  
genetic risk factors, 13  
identification and screening, 54–56  
instruments for, 55  
interviews, 56  
introduction to, 7  
management of, 60–61  
mental health legislation, 215–216  
offending behaviour, 61  
prevalence of, 57–58  
questionnaires, 55  
summary of, 62
- autosomal dominant disorders, 16
- avoidant learning style, 29
- Bach, Richard, 223
- barriers to involvement in clinical research, 236–237
- basal ganglia, 49
- behavioural phenotypes  
Angelman syndrome, 30  
Cornelia de Lange syndrome, 31  
defined, 28  
Down syndrome, 29  
foetal alcohol syndrome, 31–32  
foetal valproate syndrome, 31  
fragile X syndrome, 32–33  
hypothyroidism, 35, 36–38*t*  
introduction to, 28–29, 130  
Lesch-Nyhan syndrome, 33  
phenylketonuria, 35, 36–38*t*  
physical health, 29
- Prader-Willi syndrome, 30–31
- Rett syndrome, 33
- sex aneuploidy, 33–34
- Smith-Magenis syndrome, 34  
summary of, 39
- tuberous sclerosis complex, 34–35
- William syndrome, 35
- Belmont Report on Ethical Principles and Guidelines for the Protection of Human Subjects of Research, 232
- bezos concerns, 92
- biomarkers in genetics, 240
- biopsychosocial approach to assessment  
age-related cognitive impairment, 95  
cardiac conditions, 93  
description of cognitive/motor skills, 90  
developmental history, 90  
eating and choking symptoms, 92  
endocrine system, 93  
epilepsy, 91  
gastrointestinal system, 91–92  
health promotion/living, 95  
healthcare management, 95–96  
hearing and vision, 94  
in hospital setting, 96–97  
introduction to, 86, 89  
life events, 90  
medications, 94  
mental illness symptoms, 94  
musculoskeletal system, 93  
overview of, 89–96  
pain, 91  
physical/mental health issues, 95  
psychiatric review of, 96  
respiratory conditions, 93  
usual behaviour, 90–91
- bipolar disorder and autism, 59–60
- borderline intellectual functioning, 3, 153
- borderline learning disability, 153
- Bradley Report, 150
- Brief Psychotic Disorder, 59
- British Psychological Society, 138, 142, 161
- Broca's area of the brain, 49
- Building the Right Support, 152
- capacity legislation, 218–220, 235–236
- cardiac conditions  
assessment, 93
- Care and Treatment Review (CTR), 207
- Care Quality Commission, 199
- carers and dementia, 143
- catatonia and autism, 59–60
- Catholic identity, 195
- cause of death. *See also*  
mortality  
age-related, 102, 103  
choking, 92  
intellectual disability and, 7–8, 105  
overview of, 108
- Cause of Death certificate, 105
- cause-specific mortality, 108, 109
- celiac disease, 92
- Center for Disease Control and Prevention (CDC), 57
- central coherence, 56
- cerebral palsy, 33, 67, 92, 93, 103, 109, 153
- Certificate of Completion of Training (CCT), 251
- challenging behaviour and pharmacology  
conceptual framework for understanding, 180  
formulation informed intervention plans, 180–183, 182*f*  
good prescribing practices, 183–185, 184*f*, 186–187*t*, 187*f*  
harm to others, 185  
harm to self, 185  
introduction to, 179  
summary of, 185
- challenging behaviour and psychotherapy  
achieving/maintaining change, 174  
anger management, 165, 172–174  
case study, 160

- differential diagnosis and diagnostic overshadowing, 166–168  
 differential reinforcement, 172*t*  
 functional analysis, 168–170  
 interventions, 170  
 introduction to, 165–166  
 measuring outcomes, 174–175  
 Positive Behaviour Support, 170–171  
 summary of, 175  
 Child and Adolescent Mental Health Services (CAMHS), 115, 119  
 child-environment transactions, 130  
 childhood Obsessive Compulsive Disorder, 57  
 Childhood Schizophrenia, 53  
 children with intellectual disability  
 anxiety, 122–123  
 atypical mood disorders, 123  
 autism and, 116, 120–121  
 common problems, 120–123  
 depression, 121  
 epilepsy and, 121  
 family issues, 117–118  
 introduction to, 115–116  
 multidisciplinary teams, 119–120  
 psychosis, 123  
 school issues, 118–119  
 self-talk, 123  
 sleep disorders, 120  
 summary of, 124  
 Tourette's syndrome, 121  
 transitioning from school, 119  
 choking symptoms, 92  
 Clinical Commissioning Groups, 209  
 clinical criterion of intellectual disability, 1  
 Clinical Global Impression Scale (CGI), 208  
 Clinical Practice Research Database, 107, 109  
 clinical research/trials  
 barriers to involvement, 236–237  
 consent for inclusive research, 235–236  
 ethical codes for medical experimentation, 232–233  
 ethical review process, 233  
 future directions, 240  
 historical overview of ethics, 231–232  
 introduction to, 231  
 overcoming barriers to involvement, 237, 239*f*  
 summary, 239–241  
 Clinical Trial Authorisation (CTA), 235  
 Clinical Trial of an Investigational Medicinal Product (CTIMP), 233, 235  
*clobazam* medication, 77  
 close-knit peer support, 88  
 clumsiness and autism, 58  
 Cochrane Collaboration reviews, 140  
 cognitive behaviour therapy (CBT), 121, 131, 165, 170, 172  
 cognitive skills assessment, 90  
 cognitive treatment, 154  
 Commissioning for Quality and Innovation (CQUINs), 209  
 communicable disease, 1  
 communicating skills in leadership and management, 224  
 communication with intellectual disability  
 auditory memory, 47  
 during clinical appointment, 51–52*t*  
 easy read information, 48  
 expressive language use, 44–47  
 inclusive/total communication, 47  
 introduction to, 42  
 language difficulties, 43,  
 language neurology, 48–49  
 management of disorders, 60  
 motor system for speech, 49–50, 50*t*  
 psychotherapy and, 159  
 real objects in, 46, 47*t*  
 receptive language, 47  
 signing systems, 45  
 speech difficulties, 42, 43*t*  
 speech neurology, 49  
 spoken output, 44  
 symbols, pictures and photographs, 45–46, 46*t*  
 written language, 44  
 community care, 199*t*, 200*t*, 201  
 community disposal of forensic patients, 152  
 Community Forensic Intellectual Disability teams, 152  
 comorbidity, 29, 58–60, 61, 141  
 complex interventions, 238  
 concomitant neurodevelopmental disorders, 128  
 Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD), 104, 107, 110*t*, 111, 224  
 Confidentiality Advisory Group (CAG), 236  
 consent for inclusive research, 235–236  
 consent-to-treatment procedures, 183  
 constipation concerns, 92  
 copy-number variants (CNVs), 214–221, 240  
 Cornelia de Lange syndrome (CdLS), 31  
 Court Diversion Schemes, 150  
 court reports for forensic patients, 154  
 Cri-du-chat syndrome, 16  
 criminal justice system (CJS), 147, 148, 149–151  
 Criminal Procedure rule (2005), 150  
 Cygnet program, 117  
 cytogenetic abnormalities, 13–16  
 cytogenetic technique, 13  
 cytokines, 130  
 Danish Civil Registration System, 5  
 Data Protection Act, 236  
 Database of Genomic Variants (DGV), 19  
*de novo* mutations (DNMs), 13, 21  
*Death by Indifference* (Mencap report), 103, 104  
 Death by Indifference campaign, 199

- Deciphering Developmental Disorders (DDD) study, 21
- decision-making capacity, 62, 172, 219
- delivery skills in leadership and management, 224
- delusions, 181
- dementia in Alzheimer's disease (DAD), 136, 140, 143–144
- Dementia Questionnaire for people with Learning Disabilities (DLD), 139
- Dementia Scale for Down's syndrome (DSDS), 139
- Dementia Screening Questionnaire for Individuals with ID (DSQIID), 139
- dementia with intellectual disabilities
- antidementia drugs, 140
  - antipsychotic medication, 140–141
  - carers and, 143
  - co-morbidity treatments, 141–142
  - diagnosis and evaluation, 137–139
  - direct tests, 139
  - environmental factors, 143
  - epidemiological issues, 136–137
  - informant questionnaires, 139
  - introduction to, 132
  - mortality and, 109
  - non-pharmacological interventions/treatment, 142–143, 144
  - pharmacological interventions/treatment, 140–142
  - psychological approaches to, 142–143
  - summary of, 143–144
  - treatments, 139–143
- dementia with Lewy Bodies, 137
- depression
- Alzheimer's and, 29
  - antidepressant medication, 141, 179, 220
  - assessment of, 120, 139
  - autism, 59
  - in children, 121
  - cognitive behavioural therapy for, 131
  - comorbidity, 141
  - Cornelia de Lange syndrome, 31
  - low self-esteem with, 130
  - mood disorders, 59
  - psychological interventions for, 172
  - sex aneuploidy, 34
- Deprivation of Liberty Safeguards (2007), 198–199, 217
- design skills in leadership and management, 224
- developmental delay (DD), 12, 19
- developmental disorders, 149
- developmental history
- assessment, 90
  - diagnosis and evaluation. *See also* assessment
  - adults with intellectual disability, 127–128
  - dementia with intellectual disabilities, 137–139
  - epilepsy, 70*t*
  - importance of, 181–182
  - intellectual disability, 2–4
- Diagnostic and Statistical Manual of Mental Disorders* (DSM 5)
- autism spectrum disorders, 55
  - intellectual disabilities, 126
  - introduction to, 2
  - mental handicap, defined, 197
  - mental retardation, 200
- Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation* (DC-LD), 129–130
- Diagnostic Manual-Intellectual Disability 2* (DM-ID2), 129–130
- diagnostic overshadowing, 127, 166–168
- Dialectical Behaviour Therapy, 154
- diet and epilepsy, 77
- differential diagnosis
- autism spectrum disorders, 168
  - behavioural disorders, 166–168
  - epilepsy, 71*t*, 167
- differential reinforcement, 172*t*
- disability service providers, 97
- Disability Services
- Commission of Western Australia, 7
- Disorders of Intellectual Development (DID), service history
- community care and, 199*t*, 200*t*, 201
  - incarceration of, 194–196
  - introduction to, 12–13, 191
  - legislation and policy documents, 200–201
  - pre-specialist care, 191–193
  - specialist care, 193–194
- DNA (deoxyribonucleic acid), 12
- DNA microarrays, 19
- Down, Langdon, 193
- Down Syndrome
- Alzheimer's disease and, 6, 29
  - behavioural phenotypes, 29
  - celiac disease, 92
  - dementia and, 136
  - epilepsy in, 67
  - genetic risks, 16
  - psychotherapy and, 161
  - self-talk, 123
  - speech difficulties, 42
  - vision impairment impact, 84
- dravet syndrome, 68–69
- dual criterion of intellectual disability, 1
- early vocabulary
- development, 44
- easy read information, 48
- Education, Health and Care Plan (EHCP), 119
- education with intellectual disability, 60, 143
- electroconvulsive therapy (ECT), 215
- electroencephalogram (EEG), 167
- emotional support, 143
- employment with intellectual disability, 60
- endocrine system
- assessment, 93

- England, inpatient care, 206–207
- English Autism Act (2009), 199
- English Mental Capacity Act (2005), 198
- English Poor Law (1834), 193
- environmental factors and intellectual disabilities, 131, 143
- epidemiological community surveys, 4
- epilepsy  
in adults, 130  
aetiology of, 66–67  
antiepileptic medication, 142  
assessment of risk, 72  
autism and, 58  
behaviour assessment, 74  
behavioural phenotype and, 29  
biopsychosocial approach to assessment, 91  
in children, 121  
Cornelia de Lange syndrome, 31  
diagnosis of, 70*t*  
diet and, 77  
differential diagnosis of, 71*t*, 167  
dravet syndrome, 68–69  
epidemiology of, 65, 66*t*  
improving care and outcomes, 78  
introduction to, 65  
lennox-gastaut syndrome, 68  
mental health and, 69–70  
morbidity and mortality, 69, 109  
non-pharmacological interventions, 77–78  
outcome measures, 73–74  
pharmacological interventions, 74–77, 76*t*  
phenotypes, 67  
psychiatric management of, 245  
seizure types, 67–68  
summary of, 75*f*, 78  
surgery for, 77  
treatment, 72–73  
vagus nerve stimulation, 78
- Equality Act (2010), 111
- equality legislation, 217–218
- ethical codes for medical experimentation, 232–233
- eugenics, 147, 194
- European Convention on Human Rights, 213, 214, 216–217
- event recording, 169
- evidence-based health/medicine, 72, 102, 170, 181, 231
- executive function, 56
- exome sequencing, 21–22, 23
- expressive language use, 44–47
- family issues, 117–118
- Farr, William, 102
- fatuus naturalis*, 191
- feeble-minded persons, 191, 195
- fitness to plead, 151
- foetal alcohol syndrome (FAS), 31–32
- foetal valproate syndrome, 31
- forensic psychiatric patients  
background on, 147–148  
community disposal, 152  
court reports, 154  
criminal justice system, 147, 148, 149–151  
fitness to plead, 151  
inpatient services, 152–153  
Mental Health Act, 149, 150, 151  
offending by, 148–149  
prevalence of, 148  
risk assessment, 154–155  
summary of, 155  
treatment, 154
- forensic rehabilitation  
needs, 205
- formulation informed  
intervention plans, 180–183, 182*f*
- fragile X mental retardation protein (FMRP), 32
- fragile X syndrome (FXS), 17, 23, 32–33
- frontotemporal dementia (FTD), 137
- functional analysis of  
behavioural disorders, 168–170
- gastrointestinal system  
assessment, 91–92
- gatekeepers, 237
- General Medical Council (GMC), 184, 225, 247
- genetic pleiotropy, 13
- genetic testing, 22–23
- genetics/genetic risk factors  
autism spectrum disorders, 13  
biomarkers, 240  
copy number variations, 18–21  
Cri-du-chat syndrome, 16  
cytogenetic abnormalities, 13–16  
Down Syndrome, 16  
epilepsy, 72  
exome sequencing, 21–22, 23  
future directions, 23  
genetic testing, 22–23  
introduction, 14, 6, 12–13  
psychiatric disorders, 130  
sex chromosome  
aneuploidies, 16  
single-gene disorders, 16–18  
summary of, 23–24  
whole-genome  
sequencing, 22
- Glasgow Anxiety Scale, 208
- Glasgow epilepsy outcome measure (geos), 74
- Global Burden of Disease study, 4
- Goddard, Henry, 147
- Good Medical Practice, 213, 235
- good prescribing practices, 183, 183–185, 184*f*, 186–187*t*, 187*f*
- Griffiths Report (1988), 198
- Guardianship Order, 152
- hallucinations, 59, 123, 181
- harm to others, 180, 185
- harm to self. *See* self-harm/self-injury
- health inequalities, 6–7
- health literacy of carers, 85
- Health of the Nation Scale-Learning Disability (HoNoS-LD), 208
- health promotion/living assessment, 95
- Health Research Authority (HRA), 233
- healthcare management  
assessment, 95–96
- hearing assessment, 94
- hearing loss, 42
- heterogeneity between genetic abnormalities, 67

- H. pylori* concerns, 92  
Human Genome Initiative, 21  
Human Genome Project (HGP), 21–23  
Human Rights Act, 214, 217  
Human Tissue Act, 236  
hyperactivity, 29, 32  
hypothyroidism, 35, 36–38*t*  
hypoxanthine guanine phosphoribosyltransferase (HPRT), 33
- identification skills in leadership and management, 224  
identity and psychotherapy, 159–160  
Idiot and Imbecile Institution, 193  
idiots, defined, 191–193, 195  
Idiots Act (1886), 193  
imbeciles, defined, 195  
Improving Access to Psychological Therapies (IAPT), 160  
impulsivity in fragile X syndrome, 32  
in-hospital mortality and morbidity, 84  
incarceration history, 194–196  
incidence studies of intellectual disability, 4–5  
inclusive/total communication, 47  
individuation process, 160  
Industrial Revolution, 204  
industrialisation, 192  
infantile spasms, 67  
inflammatory cytokines, 130  
influencing skills in leadership and management, 224  
innocents, defined, 192  
inpatient care  
  care and treatment reviews, 207  
  challenges for, 209  
  England, 206–207  
  for forensic patients, 152–153  
  future planning, 209  
  generic vs. specialist services, 204–206  
  introduction to, 204  
  need for, 205  
  Northern Ireland, 208  
  outcome measures, 208  
  quality issues, 208–209  
  reduction in use of specialist beds, 206–208  
  Scotland, 207  
  treatment issues, 208  
  Wales, 208  
insomnia and hypnotics, 141  
Institution for Idiotic and Imbecile Children, 193  
Institution for Imbecile Children, 193  
institutional discrimination, 103  
instruments of screening  
  autism spectrum disorders, 55, 57  
  dementia in Alzheimer's disease, 138  
  dementia with intellectual disorders, 139  
  epilepsy, 74  
  risk assessments, 154–155  
intellectual criterion of intellectual disability, 1  
Intellectual Development Disorder (IDD), 3  
intellectual disability. *See also* adults with intellectual disability; children with intellectual disability  
  aetiology, 5–6  
  introduction to, 1  
  morbidity, 6–7  
  mortality, 7–8  
  perspectives of, 1–2  
  prevalence and incidence, 4–5  
  profound and multiple intellectual disability, 46  
  summary of, 8  
  terminology, classification and diagnosis, 2–4  
Intellectual Disability (ID) Psychiatry training. *See* training in Intellectual Disability (ID) Psychiatry  
intelligence quotient (IQ), 30  
intelligence quotient (IQ) tests, 1, 106  
inter-personal problems, 173  
International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), 3  
*International Classification of Diseases* (ICD-10), 2, 55, 126, 197, 200  
International Classification of Functioning, Disability and Health (ICF), 2  
International Conference on Harmonisation (ICH), 232  
International Standard Cytogenomic Array (ISCA) Consortium, 19  
interval recording, 169  
interventions. *See also* pharmacological interventions/treatment; treatment  
  adults with intellectual disability, 131  
  anxiety/anxiety disorders, 172  
  complex interventions, 238  
  dementia with intellectual disabilities, 142–143, 144  
  epilepsy, 74–78, 76*t*  
  formulation informed intervention plans, 180–183, 182*f*  
  Outcome Measures for Challenging Behaviour Interventions, 175  
  psychological intervention with intellectual disability, 60  
  understanding challenging behaviour, 180  
interviews for autism spectrum disorders, 56  
Investigational Medicinal Product (IMP), 233  
INVOLVE advisory group, 238  
Kanner, Leo, 53, 54  
Klinefelter syndrome, 33–34  
labelling concerns, 159  
*lacosamide* medication, 77  
*lamotrigine* medication, 75  
language difficulties, 44, 43  
language neurology, 48–49  
leadership and management background, 222–224  
  context for, 224–225  
  introduction to, 222  
  for medical practitioners, 225–226

- resources for, 226–227  
summary of, 228
- Learning Disabilities Mortality Review (LeDeR)  
Programme, 105, 112
- learning disability  
profound and multiple  
learning disabilities, 240
- learning disability (LD)  
assessment scales, 175  
assessment team, 152  
behavioural problems with,  
167, 171  
challenging behaviour, 165  
communication standards,  
51*t*, 52  
defined, 153, 198  
as diagnosis, 198  
health care providers for, 200  
inpatient care, 205–206, 207  
Mental Health Act and, 151  
mild learning disability,  
160, 161  
social services for, 198  
specialists in children's  
homes, 118  
support for, 223, 224  
therapeutic approach to, 173  
training pathways, 247–249
- Learning Disability  
Programme, 207
- least restrictive principle in  
healthcare assessment,  
86–87
- legal provisions and restrictive  
practices  
capacity legislation, 218–220,  
235–236  
equality legislation, 217–218  
European Convention on  
Human Rights, 213,  
216–217  
introduction to, 213–214  
mental health, 214–216  
therapeutic restriction,  
220–221
- lennox-gastaut syndrome, 68
- Lesch-Nyhan syndrome, 33
- levetiracetam medication, 77
- life events, 90, 131
- life expectancy, 84, 107
- life stages and psychotherapy,  
159–160
- Local Delivery Plans, 225
- Local Education and Training  
Boards (LETBs), –248
- London Down Syndrome  
Consortium (LonDownS),  
239–240
- lower motor neuron (LMN)  
pathways, 50
- Lunacy Act (1845), 193
- mainstream services with  
psychotherapy, 160–161
- management and leadership.  
*See* leadership and  
management
- Mansell Report, 166
- Massachusetts Sanitary  
Commission, 102
- Mazars report, 104–105
- medical experimentation,  
232–233
- Medical Research Council  
(MRC), 232, 238
- medication  
antidementia drugs, 140  
antidepressants, 141, 179  
antiepileptics, 142  
antipsychotics, 140–141, 179  
anxiety/anxiety disorders,  
122–123, 220  
assessments for, 94  
biopsychosocial approach to  
assessment, 94  
*clobazam*, 77  
evidence-based health/  
medicine, 72, 102, 170,  
181, 231  
*lacosamide*, 77  
*lamotrigine*, 75  
*levetiracetam*, 77  
*perampanel*, 77  
*start low go slow* policy  
with, 73  
*topiramate*, 75–77
- Medicines and Healthcare  
Products Regulatory  
Agency (MHRA), 232, 235
- Medicines for Human Use  
(Clinical Trials)  
Regulations, 232
- melatonin, 120
- Mendelian disorders, 16–18
- Mental Capacity Act (2005),  
138, 217, 219, 235–236
- Mental Care Hospitals, 196
- Mental Deficiency Act (1913),  
147, 194, 196
- mental handicap, defined,  
197–198
- mental handicap hospitals, 197
- Mental Health Act (1959), 196
- Mental Health Act (1983), 149,  
150, 151, 198, 204, 217
- mental health/illness  
biopsychosocial approach to  
assessment, 94  
epilepsy and, 69–70  
introduction to, 7  
legislation for, 214–216  
physical health and, 83–85
- Mental Health Treatment  
Requirement option  
(MHTR), 152
- mental retardation. *See*  
intellectual disability
- mental subnormality, 196
- mentally defective, 193,  
194, 195
- mentally deficient, 195–196
- Metropolitan Asylums  
Board, 193
- Michael, Jonathan, 104
- mild learning disability, 160, 161
- Modified Overt Aggression  
Scale, 166, 208
- mood disorders, 59
- moral imbeciles, 195
- morbidity  
comorbidity and, 29, 58–60,  
61, 141  
epilepsy, 69, 109  
in-hospital, 84  
intellectual disability, 6–7
- mortality. *See also* cause of  
death  
age at death, 107  
cause of death, 108  
cause-specific mortality,  
108–110  
emergence as key issue,  
103–105  
in-hospital, 84  
introduction to, 7–8, 102  
life expectancy, 107  
potentially unavoidable  
deaths, 109–110  
reducing premature deaths,  
110–111, 112*t*  
standardised mortality  
rates, 107  
standardized mortality ratio,  
106*t*–107–108  
summary of, 111–112  
surveillance component,  
105–107

- Motivation Assessment Scale (MAS), 170
- motor skills assessment, 90
- motor system for speech, 49–50, 50*t*
- multidisciplinary team (MDT), 119–120, 139, 144, 174, 215, 246
- musculoskeletal system assessment, 93
- National Commission for the Protection of Human Subjects of Biomedical and Behaviour Research, 232
- National Health Service (NHS), 204, 233
- National Institute for Health and Care Excellence (NICE), 128, 170–171, 179, 184
- National Institute of Health Research (NIHR), 238, 249
- National Patient Safety Agency (NPSA), 103
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG), 137–138, 143
- negative social determinants of health, 84
- neonatal hypotonia, 30
- neuroleptics in the treatment of aggressive challenging behaviour for people with intellectual disabilities (NACHBID), 236
- neurological disturbance behaviour, 220
- New Poor Law Commissioners, 193
- next generation sequencing (NGS), 13
- NHS Leadership Academy, 226
- NIHR Clinical Research Network (NIHR CRN), 238
- non-pharmacological intervention for dementia, 142–143, 144
- non-synonymous exonic mutations, 21
- normalisation in healthcare assessment, 86–87, 197
- Northern Ireland, inpatient care, 208
- nucleic acid microarrays, 19
- Nuremberg Trials, 231–232
- nutritional concerns, 92
- obsessions, 181
- obsessive compulsive disorder (OCD), 29, 31, 57, 59
- offending behaviour, 61
- Office for National Statistics death certification data, 109
- operant conditioning, 168–169
- Outcome Measures for Challenging Behaviour Interventions, 175
- outward aggression, 180
- over-values ideas, 181
- oxidative stress, 130
- pain assessment, 91
- palliative care status, 84
- parasitic infections, 92
- PASSAD checklist, 168
- Pathological Demand Avoidance (PDA), 54
- Patient and Public Involvement (PPI), 238
- peer review of casework, 88
- penetrance, defined, 12
- People with Disorders of Intellectual Development, 191
- perampanel* medication, 77
- perinatal risk factors in intellectual disability, 6
- person-centred care, 86, 171, 206
- Person Centred Planning, 119
- personality disorder with autism, 58
- pharmacological interventions/treatment, 140, 74–77, 76*t*  
*See also* challenging behaviour and pharmacology; interventions; medication
- phenylalanine hydroxylase (PAH) gene, 17
- phenylketonuria (PKU), 17, 35, 36–38*t*
- photographs, in communication, 45–46, 46*t*
- physical abuse, 117
- physical health  
behavioural phenotypes, 29
- biopsychosocial approach to assessment, 86, 89–96
- in hospital setting, 96–97
- improvements to healthcare assessments, 85–89
- introduction to, 6–7, 83
- mental health and, 83–85
- multidisciplinary approach to, 88
- summary of, 97–98
- pictures, in communication, 45–46, 46*t*
- Police and Criminal Evidence Act (PACE) (1984), 149
- polymerase chain reaction (PCR), 16
- polypharmacy, 129
- portfolio career, 246–247
- Positive Behaviour Support (PBS), 143, 144, 170–171
- potentially unavoidable deaths, 109–110
- Prader-Willi Syndrome (PWS), 17, 18, 30–31
- Pragmatic Language Impairment, 53
- pre-existing disabilities, 128
- pre-existing physical disorders, 128
- pre-specialist care, 191–193
- precentral gyrus, 49
- premature deaths, reduction factors, 110–111, 112*t*
- prenatal risk factors for intellectual disability, 6
- prevalence studies of intellectual disability, 4–5
- prioritised resources in leadership and management, 224
- problem behaviours, 127
- profound and multiple intellectual disability (PMID), 46
- profound and multiple learning disabilities (PMLD), 240
- pseudo-hallucinations, 181
- psychiatric disorders, 19–20
- psychiatric review of assessment, 96
- psychiatrist role, 181
- psychological mindedness, 218
- psychopathic personalities, 196



- psychosis in adults, 129  
 psychosis in children, 123  
 psychotherapy. *See also*  
   challenging behaviour and  
   psychotherapy  
 challenging behaviour, 160  
 choosing modality, 161, 162*t*  
 communication and, 159  
 context for, 158–159  
 dementia with intellectual  
   disabilities, 142–143  
 developing skills in,  
   161–163, 246  
 intervention with intellectual  
   disability, 60  
 introduction to, 158  
 labelling and stigma  
   concerns, 159  
 life stages and identity,  
   159–160  
 mainstream vs. specialist  
   services, 160–161  
 summary of, 163
- quality issues with inpatient  
   care, 208–209  
 questionnaires for autism  
   spectrum disorders, 55
- random controlled trials (RCTs),  
   77, 235–238, 239, 240
- real objects in communication,  
   46, 47*t*
- reasonable adjustments in  
   healthcare assessment, 86
- receptive language  
   communication, 47
- recognized resources in  
   leadership and  
   management, 224
- Reed, Andrew, 193
- Regional Clinical Genetics  
   Services, 22
- Research Autism, 60
- Research Ethics Committees  
   (RECs), 233, 235
- respiratory conditions  
   assessment, 93
- respiratory diseases and  
   mortality, 109
- restricted, repetitive patterns of  
   behaviour, interests or  
   activities (RRBI), 54–55, 59
- restrictive practices. *See* legal  
   provisions and restrictive  
   practices
- Rhett syndrome, 17, 18, 23, 33
- risk assessment, 154–155. *See*  
   also genetics/genetic risk  
   factors
- Rochester Epidemiology  
   Project, 5
- role-playing therapy, 174
- Royal College of Psychiatrists,  
   119, 138, 161, 197, 205,  
   247, 248
- Royal College of Speech and  
   Language Therapists,  
   51*t*, 52
- Royal Commission on the Care  
   and Control of the Feeble  
   Minded, 194
- Schizoid Personality  
   Disorder, 53
- schizophrenia  
   autism and, 59  
   Childhood  
     Schizophrenia, 53  
     genetic risk factors, 13, 19–20  
     16p11.2 deletion  
     syndrome, 21  
     22q11.2 deletion  
     syndrome, 20  
   school issues, 118–119
- Scotland, inpatient care, 207
- Scotland's Census, 126
- Scottish Intercollegiate  
   Guideline Network  
   (SIGN), 208
- seizures, 142, 167
- Selective Serotonin Reuptake  
   Inhibitors (SSRI)  
   antidepressants, 123, 144
- self-fulfilling prophecy, 28
- self-harm/self-injury, 168, 169,  
   180, 185
- self-talk, 32, 123
- Semantic Pragmatic  
   Disorder, 53
- sensory deficits, 29
- severe subnormality, 196
- sex aneuploidy, 33–34
- sex chromosome  
   aneuploidies, 16
- sexual abuse, 117, 159
- sexual offenses, 149
- signing systems, 45
- single-gene disorders, 16–18
- single nucleotide  
   polymorphism (SNP)  
   microarrays, 19
- single nucleotide variants  
   (SNVs), 13
- 16p11.2 deletion syndrome,  
   20–21
- sleep disorders, 120
- Smith-Magenis syndrome, 34
- social anxiety, 31, 32–33, 123
- Social Communication  
   Disorder (SCD), 53
- social contextual processes, 180
- social criterion of intellectual  
   disability, 1
- social factors in psychiatric  
   disorders, 131
- social learning theory, 172
- socio-economic  
   disadvantage, 6
- sodium valproate, 31
- somatic mosaicisms, 23
- Sparrowhawk, Connor,  
   104–105
- spastic paralysis, 50
- specialist care, 160–161,  
   193–194
- specialist registrar (SpR),  
   250
- speech and language  
   therapists, 120
- speech difficulties, 42, 43*t*
- speech neurology, 49
- spoken output, 44
- stakeholders, 237
- standardized mortality ratio  
   (SMR), 107–108
- STAR form, 170
- start low go slow* policy with  
   medication, 73
- stigma concerns, 159
- stimulation-orientated  
   treatments, 142–143
- stop over-medication of  
   people with an  
   intellectual disability  
   (STOMP), 179
- subnormality, 196, 198
- substance misuse  
   disorders, 149
- sudden unexplained death in  
   epilepsy (SUDEP), 69
- Support Needs model of  
   disability, 2
- Suspected Unexpected Serious  
   Adverse Reactions  
   (SUSARs), 235
- symbols, in communication,  
   45, 46

- syndrome-specific behaviours, 168  
 Thalidomide birth related defects, 232  
 Theory of Mind, 56  
 therapeutic restrictions, 220–221  
 time sampling, 169  
 tonic-clonic seizures, 67–68  
 tonic seizures, 68  
*topiramate* medication, 75–77  
 Tourette's syndrome, 121, 168  
 training for people with autism, 60  
 training in Intellectual Disability (ID) Psychiatry curriculum studies, 249, 250*t*  
 higher training opportunities, 252–253, 253*t*  
 introduction to, 245  
 new trainee experiences, 250–251  
 pathway to, 247–249, 248*f*  
 preparation as consultant, 253  
 progressing through training, 251–252  
 reasons to choose, 247  
 training programme director (TPD), 251, 252  
 Transforming Care programme, 153, 199  
 transition cliff, 4  
 transitioning from school, 119  
 treatment. *See also* challenging behaviour and psychotherapy; interventions; psychotherapy  
 cognitive treatment, 154  
 consent-to-treatment procedures, 183  
 dementia with intellectual disabilities, 139–143, 144  
 epilepsy, 72–73  
 forensic psychiatric patients, 154  
 inpatient care, 207, 208  
 stimulation-orientated treatments, 142–143  
 trinucleotide repeat expansion, 32  
 Triple P (Positive Parenting Programme), 117  
 Trisomy X, 34  
 tuberous sclerosis complex (TSC), 34–35, 67  
 Turner syndrome, 33–34  
 22q11.2 deletion syndrome, 20  
 UBE3A gene, 30  
 ubiquitin-protein ligase E3A (*UBE3A*), 18  
 UK Office for National Statistics, 102  
 United Kingdom Supreme Court, 221  
 University of California Santa Cruz (UCSC) genome browser, 21  
 upper motor neuron (UMN) pathways, 50  
 usual behaviour assessment, 90–91  
 vagus nerve stimulation, 78  
*Valuing People*, 205, 222  
*Valuing People Now*, 205, 222  
 verbal aggression, 149  
 vision assessment, 94  
 vision impairment and Down Syndrome, 84  
 vulnerability factors for challenging behaviour, 180  
 Wales, inpatient care, 208  
 Wernicke's area of the brain, 49  
 whole-genome sequencing (WGS), 22, 23  
 William syndrome (WS), 35  
 Wing, Lorna, 53, 54  
 Winterbourne View investigation, 175  
 Witness Intermediary Scheme, 154  
 World Health Organization, 2, 105  
 World Medical Association (WMA), 232  
 World Psychiatric Association (WPA), 3  
 written language communication, 44  
 X chromosome, 12  
 Y chromosome, 12