

INDEX

A

Aberrant Behaviour Checklist, 123
absence seizure, 136
achalasia, 249
acoustic environment management, 180–81
adaptive functioning, impairment of, 4
Adult Continence Guidelines, 313
affective communication assessment (ACA), 54
Alzheimer's disease, 216
American Society of Anaesthesiologists (ASA)
 physical status classification system, 224
amitriptyline, 286
amyotrophic lateral sclerosis, 239
anal plugs, 307
antacid reflux therapy, 190
anterior open bite, 208
anthropometric measurements, 263
aphasia, 52
artificial nutrition support
 enteral tube feeding, 273
 feeding regimens, 276–77
 feeding tubes, 275–76
 parental feeding, 278–85
 routes of administration, 273–75
 of medications, 277–78
 supplementary feeding, 272–73
asphyxiation, 248
aspiration pneumonia, 251
astigmatism. *see* vision impairments and PIMD
atonic seizure, 136
atropine sulphate, 286
auditory processing disorder, 169
augmented mothering, 67
autism, 216–17
autistic spectrum disorders, 6, 50, 279
azithromycin, 189

B

baclofen, 216
bacterial infection, of ears, 170
behavioural observation audiometry (BOA), 177
Behind the ear (BTE) aid, 179
best interests principle, 10
beverages, 273
biological causes, of intellectual disabilities, 5
birth trauma, 5

bisacodyl Senna, 286
bladder diary, 315–16
bladder function, normal, 294
blankness, period of, 136
bleeding tendencies, and dental treatment, 207
blurred vision, 149
blurring lens, 157
body mass index (BMI), 262
body worn (BW) aid, 179
bone anchored (BAHA) aid, 179
bone conduction (BC) aid, 179
botulinum toxin, 189
bowel function, normal, 294–95
 correct posture, 304
bowel habit diary, 301
brainstem evoked response test (BSER), 174
Bristol Stool Form Scale, 299
British Society of Audiology Guidelines on
 Minimum Training Standards for
 Otoscopy and Impression Taking, 175
bronchiectasis, 187
Bronfenbrenner's ecological systems theory, 51
bruxism, 210–11
 treatment of, 211
bulk-forming laxatives, 302

C

café-au-lait spots, 207
carbamazepine, 286
Cardiff Acuity Test, 157
cardiovascular disease, 212–14
cerebral hypoxia, 5, 205
cerebral palsy, 5, 50, 171, 191, 208, 213, 241,
 262, 264–65, 279
cerebrovascular accidents, 215
cervical auscultation, 243
CHARGE syndrome, 171
Child Growth Foundation centile charts, 264
chloral hydrate, 286
chlorhexidine, 209
chlorhexidine gluconate gel, 215
chlorpromazine HCl, 286
cholesteatomas, 171
cholinesterase inhibitors, 216
chronic pulmonary disease, 99
citalopram, 286

356 ■ Index

- clinical assessment of PIMD
 - as an intervention, 107–8
 - case study, 106
 - context of assessment, 99–102
 - cooperation and collaboration in teams, 102
 - definitions and criteria, 106
 - development model, 107
 - elements of, 103–4
 - impact of neurological conditions, 107
 - process of formulation, 104–6
 - recommendations for good practice, 106–8
 - role of informants, 107
 - role of the communication partnership, 104
 - in terms of service organisation, 100–101
 - in terms of service philosophy, 100
 - transdisciplinary approach, 106–7
 - clopidogrel, 219
 - clozaril, 286
 - cochlea implants, 179–80
 - cognitive impairment, 4
 - Collis Curve toothbrush™, 228
 - communication with people with PIMD
 - assessment
 - See *What I Mean* (SWIM), 55
 - affective, 54
 - early, 54–55
 - Manchester pragmatics profile (MPP), 55
 - augmentative and alternative communication, 57
 - case examples
 - Daniel, 53
 - Leda, 48–49
 - Martin, 50
 - categorical view of, 48
 - challenges, 49
 - characteristics, 49–51
 - communicative partner, 54
 - continuous processing model, 48
 - dimensions, 47–49
 - ecological view, 51–55
 - and multimedia profiling, 57
 - observation recording sheet, 54
 - parent–child interaction, 50–51
 - process of, 48–49
 - rich and multiple media, 56–57
 - socially responsive environment, 56–57
 - stages of pre-intentional communication
 - development, 54
 - tuning-in, 57
 - use of objects, 57
 - video recording, 54
 - communication equation, 52
 - communication issues with vision impaired people, 150
 - communication partnership, defined, 51–52
 - communicative intentionality, defined, 46
 - Community Dental Service (CDS), 204
 - compensatory right ventricular hypertrophy, 207
 - competence, of people with PIMD, 27
 - Completely in the canal (CIC) aid, 179
 - complex health situations, Amanda's case
 - experience
 - background, 37–40
 - editors comments, 44–45
 - parent's perspective, 37–40
 - support workers' perspective, 40–44
 - complex partial seizure, 136
 - concentration and attention span, among vision impaired people, 152–53
 - conductive deafness, 169
 - congenital chromosomal aberration, 205
 - congenital cytomegalovirus, 172
 - constipation, 268–69
 - continence
 - assessment, 295–98
 - resources, 317
 - defined, 294
 - food and drinks that irritate bladder, 318–19
 - management, 305–7
 - resources, 324
 - treatment, 298–304
 - Continence Advisory Services, 293
 - continuous positive airway pressure (CPAP)
 - device, 196, 198
 - coordination issues, with vision impaired people, 151
 - corsodyl gel, 209, 215
 - cough reflex, 191
 - craniostenosis, 207
 - Crouzon disorder, 194
 - culturally Deaf, 172–73
- D
- deafblindness, 153
 - dehydration, 268
 - dementia, 216, 239
 - depigmented skin, 207
 - Developmental Assessment for Individuals with Severe Disabilities (DASH-2), 104
 - DH Valuing People, 173
 - Diagnostic and Statistical Manual, definition of PIMD, 6
 - diazepam, 286
 - dicycloverine HCl, 286
 - directiveness, 51
 - Disability Discrimination Act (1995), 220
 - domiciliary care
 - alteration of medication, 219
 - antibiotic prophylaxis, 218
 - communication, 220
 - fear, 218
 - lack of operator skill, 219–20

lack of time, 219
surgery, 220
timing of appointments, 218
Down's syndrome, 5–6, 50–51, 170–71, 191,
205–6, 250–51, 280
Down's syndrome Medical Interest Group
Surveillance guidelines – hearing
impairment, 173
drop attack, 136
DSM-IV-TR criterion, 8
dual diagnosis, of mental illness, 8
dysfunctions of taste and smell, 7
dyspepsia, 249
dysphagia, 11
assessment of, 241–43
causes/conditions, 239–41
compensatory techniques, 244
considerations
asphyxia, 248
dementia, 250–52
gastroesophageal, 249–50
oral health, 249
respiration, 248
defined, 236
eating and drinking guidelines, 254
ethics and best interest, 244–45
glossary of terms, 254–55
implications for nurses, 252
management of, 243–44
multidisciplinary intervention, 245
normal swallow, stages of, 237–41
risk assessment form, 253
risk monitoring form, 253
roles of multidisciplinary team members,
246–47
signs and symptoms, 252
working in partnership with carers, 245–48

E

early communication assessment (ECA), 54–55
electric toothbrushes, 211
electroencephalogram (EEG), 135
emotional intelligence, 63
emotional literacy, 63
emotional well-being, 11–12
defined, 63
helping people with, 63
holistic approach, 66–67
importance, 63–64
intensive interactions, 67–68, 70–74
issues concerning physical contact, 73–74
Kellett's research, 71
mutual pleasure from interaction, 69
neglect of, 64–66
and quality of life issues, 63–64
role in mental health, 64

role of intentional communication, 69–70
significance of staff awareness of emotional
states, 65
and social development, 63
specialist intervention, 67–74
encephalitis, 239
enteral tube feeding (ETF), 269
environmental equipment, 181–82
epiglottis
closure of, 187
insertion of a nasopharyngeal airway, 195
surgery of, 190
epilepsy, 191, 251, 281
breathing, 136
care pathway process map, 140–41
carers' needs, 142–43
challenges, 138
classification of seizures, 135–36
defined, 135–37
epilamabanein, 135
evidence-based practice, 138–39
impact on people with PIMD, 137–38
incidence rate, 137
information, 139
integrated care pathway concepts, 140
likelihood of occurrence, 137
risk of mortality, 138
role in meeting the needs, 139–42
seizure types, 136–37
services for people with, 137
triggers with seizures, 137
West of Berkshire survey, 139–40
Epilepsy Outcome Scale, 142
Eustachian tube, 170
excessive salivation, 209
eye gazing, 47
eye poking, 149

F

Fair Access to Care, 160
Fallot's tetralogy, 207
fibre diet, 300
fibre endoscopic evaluation, of swallowing, 243
florid inflammation, of the gums, 206
fluid intake, 298–302
fluoxetine, 286
flu vaccine, 192
focal attacks, 136
foetal Rubella syndrome, 171
food textures, 272
foreign-body aspiration, 191–92
fragile X syndrome, 5, 171, 283
functional hearing assessment, 177–78

G

gastritis, 249
gastroesophageal reflux disease (GERD), 190, 250

358 ■ Index

gastro-oesophageal reflux disorder (GORD), 278
 investigations, 190
 management, 190–91
gastrostomy tube, 188–89
General Dental Council (GDC), 203
generalised seizures, 135
glue ear, 170
glycopyrrolate, 189
government objectives, for intellectual disability
 services, 79
grand mal seizures, 135
group action planning, 80

H

habitual mouth breathers, 205
haloperidol, 286
hand-held health records, 86
health action plan (HAP), 84–86
 DH principles of health action planning, 84
health problems, with PIMD, 9
health profiling
 screening, 87–89
 checklist, 88
 READ CODE system, 89
 Royal College of General Practitioners, 88
 use of PHPs, 86
hearing impairment
 assessment, 174–75
 barriers in services, 174–75
 behavioural observation audiometry (BOA),
 177
 cholesteatomas, 171
 common causes, 169–70
 conductive deafness
 middle ear, 170–71
 outer ear, 170
 damaged ossicles, 171
 evidence-based practice, 173
 evoked response audiometry, 176
 functional hearing assessment, 177–78
 impact of, 172–73
 intervention
 acoustic environment, 180–81
 cochlea implants, 179–80
 employment of environmental equipment,
 181–82
 hearing aids, 178–79
 vibrotactile aid, 180
 otoacoustic emissions, 176
 otoscopy, 175–76
 perforated eardrums, 171
 sensorineural deafness, 171–72
 tympanometry, 176–77
hearing loss, 12
heartburn, 249

heel-prick blood test, 5
heightened gag reflex, 211
Helicobacter pylori, 249–50
hemiplegia, 208
hiatus hernia, 249
high-vaulted palate, 208
hydration, 266–67
 maintenance of, 267
hyoscine, 286
hypertension, 212
hypoglycaemia, 207
hypotonia, 191

I

ICD-10 classification, of intellectual disability, 4
idiosyncratic behaviour patterns, 46
imipramine, 286
incontinence, 292
individual service design, 80
indwelling catheters, 306
informed consent for dental treatment, 225–28
intellectual disability, 4, 73
 biological causes, 5
 diagnosis of, 4
 ICD-10 classification of, 4
 social and environmental causes, 5
intermittent self-catheterisation (ISC), 306
International Normalisation Ratio (INR), 219
In the canal (ITC) aid, 179
In the ear (ITE) aid, 179
intrauterine infections, 205
invasive (tracheostomy) ventilation, 198
iron-containing compounds, 210
isocarboxazid, 286
ispaghula husk, 286, 302

K

Kay Picture Test, 157
kernicterus (bilirubin encephalopathy), 172
Klinefelter syndrome, 283

L

lactulose, 286, 302
lamotrigine, 286
learning and development, among vision
 impaired people, 151
learning disability, 3
learning disability continence care pathway
 assessment tool, 308–12
least restrictive option, 10
Lesch-Nyhan syndrome, 211
lidocaine, 214
lifestyle planning, essential, 80
liquidised fruit drinks, 270
lithium carbonate, 286
lithium citrate, 286

long-term ventilation, 197
lorazepam, 286
lung damage, due to aspiration, 187

M

malnutrition, 260–62
Manchester pragmatics profile (MPP), 55
McGill action planning system (MAPS), 80
McKesson mouth propTM, 230
memory development, among vision impaired people, 152
meningitis, 5
Mental Capacity Act, 9–11
mental health problems
and aspects of psychosocial development, 122
assessment and diagnosis of, 114–15
assessment issues, 121–22
assessment tools, 123–24
attributes, 114–15
cognitive behaviour therapy, 126
developmental perspective in assessment and diagnosis, 122–23
emotional needs, 123
formulations of an individual's difficulties, 124–25
ICD criteria, 115
identification of, 65
interventions
biological, 125–26
psychological, 126–27
and mental health, 114
pharmacotherapy, 125–26
potential vulnerability factors for developing psychiatric disorder in people with intellectual disabilities, 116
prevalence
according to the criteria, 117
among adults, 116
among children, 116
with an intellectual disability, 115–16
with severe and profound intellectual disabilities, 116–17
risk factors, 117
for people with profound intellectual disabilities, 117–18
risk of 'diagnostic overshadowing,' 118
services and support, 127–28
signs
anorexia nervosa, 120
anxiety, 119
bulimia nervosa, 120
challenging behaviour, 120–21
delusions, 119
depression, 119

eating disorders, 120
genetic syndromes, 121
mental illness, 118
obsessive-compulsive disorder, 119
'overly-demanding' behaviours, 119
personality disorders, 120
pica and food regurgitation or rumination, 120
psychosis, 118–19
psychotic depression, 119
rapid cycling bipolar disorder, 119
training and knowledge of practitioners, 128
training of staff, 128
mental retardation, 4
menu planning, 266
methyl cellulose, 286
midazolam, 222
mild intellectual disability, 4–5
Mini PAS-ADD, 116
mixed deafness, 169
Mood, Interest and Pleasure Questionnaire (MIPQ), 22
motor processes, among vision impaired people, 152
movicol, 286, 302
MRI scan, 135
multiple sclerosis (MS), 215–16
multi-sensory environments (MSEs), 56–57
myoclonic seizure, 136

N

nasogastric feeding, 273
nasojejunal placement, 274
National Deaf Children's Society, 173
National Health Service (NHS), 91
National Newborn Hearing Screening Programme (NHSP), 174
National Special Interest Group on Hearing Impairment in People with Learning Disabilities, 182–83
nebulisation, 193
neuromuscular weakness, 191–92
NHS Quality Improvement Scotland, 173
Nissen fundoplication, 190
nitrazepam, 286
non-invasive (mask) interface, 197–98
non-oral feeding, 188
non-treated phenylketonuria (PKU), 284
normal swallow, stages of, 237–41
nutritional consequences, of syndromes associated with an intellectual disability, 279–84
nutritional risk assessment
constipation, 268–69
dehydration, 268
effective screening, 260

360 ■ Index

nutritional risk assessment (*Contd.*)
 hydration, 266–67
 malnutrition, 260–62
 menu planning, 266
 of nutritionally risk population, 260
 nutritional requirements, 265
 nutritional status, 264
 nutritional support, 269–71
 obesity, 262–64
nutritional support
 healthy eating guidelines, 387
 medications, 286
nystagmus, 149

O

obesity, 262–64
occipital lobe damage, 7
oesophageal stage, of swallowing, 239, 242
oesophageal stricture, 249
oesophagitis, 249
‘older’ people with PIMD, concept of, 9
opportunistic health screening, 87
oral health
 assessment, 229
 checklist for dental treatment with IV sedation,
 214
 of children, 204
 defined, 202
 dental treatment for people with intellectual
 disabilities, 221–32
 domiciliary care
 alteration of medication, 219
 antibiotic prophylaxis, 218
 communication, 220
 fear, 218
 lack of operator skill, 219–20
 lack of time, 219
 surgery, 220
 timing of appointments, 218
 ethnicity and cultural attitudes to, 205
 GDC guidelines, 203
 importance of regular care
 anterior open bite, 208
 autism, 216–17
 cardiovascular disease, 212–14
 cerebral palsy, 208
 cerebrovascular accidents, 215
 dementia, 216
 Down’s syndrome, 205–6
 dysphagia, 249
 excessive salivation, 209
 Fallot’s tetralogy, 207
 heightened gag reflex, 211
 high-vaulted palate, 208
 multiple sclerosis (MS), 215–16
 Prader-Willi syndrome, 207

 self-injurious behaviour, 211–12
 tooth erosion, 209–10
 tooth grinding (bruxism), 210–11
 tuberous sclerosis, 207
 Williams’ syndrome, 207
 provision of continuing care by dentist and
 carer, 221
oral preparatory stage, of swallowing, 237
osmotic laxatives, 302
ossicles, 171
osteosclerosis, 207
otoacoustic emissions (OAE), 174, 176
otoscopy, 175–76
overriding aorta, 207
oxygen therapy, 196

P

pads and pants, 305–6
Parkinson’s disease, 239
paroxetine, 286
partial seizures, 135–36
participation behaviour, 26
patchy vision, 149
pelvic floor exercises, 298
percutaneous endoscopic gastrostomy (PEG),
 215, 274
percutaneous endoscopic jejunostomy (PEJ),
 274
perforated eardrum, 171
perinatal factors, of intellectual disability, 5
persistence behaviour, 47
personal child health record (PCHR), 86
personal futures planning, 80
Personal Health Profile, 154
person-centredness with PIMD, 26–27, 296
 approaches, 79–82
 benefit on the life experiences, 83–84
 capacity in mainstream services, 82
 case example, 40–44
 challenges, 83
 development of, 80–81
 role of active support, 81–82
 services, 3, 8
 in the strategic context, 82
pharyngeal stage of swallowing, 237–39, 242
phenelzine, 286
phenylalanine diet, 5
phenylketonuria, 5
phenytoin, 286
physiotherapy, 209
planning alternative tomorrows with hope
 (PATH), 81
pneumonias, 191
postural care
 case example, 341–46
 night-time positioning, 329

- empowerment of families and personal assistants through training, 337–40
 - equipment acquisition and funding, 340–41
 - establishing trusting relationships and working in partnership, 336
 - need identification, 333–36
 - support, 341
 - principles, 328–31
 - Prader-Willi syndrome (PWS), 207, 278, 282
 - presumption of capacity, 9
 - prevalence of PIMD, 8
 - Primary Care Trusts (PCTs), 87, 143
 - profound intellectual and multiple disabilities (PMID)
 - biological factors, 5
 - causes of intellectual disability, 4–5
 - clinical descriptions, 6–8
 - defining intellectual disability, 3–4
 - definition, 6
 - implementation of *Valuing People*, 91–92
 - issues with
 - concept of capacity, 9–11
 - discrimination, 348–51
 - health, 9
 - integration of health and social care services, 11–12
 - meeting complex needs, 352–53
 - prevalence, 5–6, 8
 - social and environmental factors, 5
 - prompted voiding, 305
 - proximity seeking behaviour, 47
 - psychotic illness, 8
 - pulmonary stenosis, 207
 - pulse oximetry, 243
 - pureed food, 271
- Q**
- Quality of Life Index, 22
 - quality of life (QOL) concept
 - approach levels
 - individual, 26–27
 - organisational, 27
 - societal, 27–28
 - assessment of, 20–22
 - context of physical, social and cultural environments, 24–25
 - direct behavioural measures, 20
 - discrepancy analysis, 20
 - ethnographic approaches, 20–21
 - individuals with intellectual disabilities, 23–24
 - multidimensional scaling approach, 20
 - need for, 25–28
 - self-assessment of, 20
 - social indicators, 20
 - conceptualisation of the QOL construct, 16–20
 - principles, 16–20
 - satisfaction as dependent measure, 18
 - satisfaction as measure, 18
 - self-determination, 19
- R**
- rapid cycling bipolar disorder, 119, 124
 - rectal plugs, 307
 - recurrent chest infections, 191–92
 - reduced visual field, 149
 - refraction test, 154
 - rehabilitation officers for the visually impaired (ROVIs), 160
 - respiratory health, 12
 - respiratory issues and care
 - aspiration issues
 - foreign-body, 191–92
 - into lungs, 187–89
 - of oral secretions, 189–90
 - signs of, 188
 - chronic changes to lung gas exchange, 197
 - compliance issues in the management of lung disorders, 193
 - ethical issues, 199
 - gastro-oesophageal reflux, 190–91
 - home ventilation equipment and additional support, 198–99
 - invasive (tracheostomy) ventilation, 198
 - long-term ventilatory support, 194–97
 - non-invasive (mask) interface, 197–98
 - thoracic cage abnormalities, 192–93
 - Rett syndrome, 241, 283
 - risperidone, 286
 - Royal National Institute for Deaf People, 173
- S**
- Schema of Appraisal of Emotional Development* (SAED), 123
 - schizophrenia, 8
 - Scottish Executive Promoting health, 173
 - See What I Mean* (SWIM), 55, 104
 - seizure disorders, 7
 - self-determination, 47
 - self-injurious behaviour, 19, 49, 211–12
 - self perception among vision impaired people, 152
 - Senna, 302
 - Sense, 173
 - sensorimotor intelligence, 50
 - sensorineural deafness, 169, 171–72
 - simple partial seizure, 136
 - sip-feeds, 272–73
 - skimmed milk powder, 270
 - skin fibromas, 207
 - Snellen letter chart, 157
 - Snoezelen, 56

362 ■ Index

- social exclusion of vision impaired people, 149–50
 - social responsiveness of the communication partner, 56
 - spacial perception among vision impaired people, 151–52
 - spina bifida, 50
 - status epilepticus, 136
 - sterile feed preparations, 276
 - stimulant laxatives, 302
 - stroke, 239
 - SurgicelTM (oxidised cellulose), 219
 - systematic desensitisation, 156
 - systematic variation, in behaviour, 47
- T**
- target group, defined, 8
 - temazepam, 286
 - temporal lobe seizure, 136
 - thickeners, 271–72
 - thoracic cage abnormalities, 192–93
 - thoracic skeleton, deformations and malformations of the, 192
 - thyroxine therapy, 5
 - timed toilet routine, 303
 - guidelines, 320–23
 - timed voiding, 305
 - tonic clonic seizure, 136
 - tonic seizure, 136
 - tooth erosion, 209–10
 - tooth grinding (bruxism), 210–11
 - topiramate, 286
 - total blindness, 149
 - Tourette syndrome, 283
 - tracheostomy, 189
 - tranexamic acid, 219
 - tranlycypromine, 286
 - trauma, 239
 - tube flushing techniques, 278
 - tuberous sclerosis, 207
 - tunnel vision, 149
 - tympanometer, 176
 - tympanometry, 176–77
- U**
- ulcer, 249
 - upper airway obstruction, 194
 - urinalysis, 296
 - specimen collection, 314
 - urine sheaths, 306
- V**
- vaccine programmes, 169
 - Valuing People*, 78–79, 90, 138
 - ventilatory failure, 194
 - ventricular septal defect, 207
 - vibrotactile aids, 180
 - videofluoroscopy swallow study, 243
 - Vineland Adaptive Behaviour Scales, 103, 123
 - vision impairments and PIMD, 148–49
 - eye care
 - appearance of eyes analysis, 163–64
 - application of eye drops, 157–58
 - assessment of acuity, 157
 - assessment of eye pressure, 158
 - behaviour analysis, 164
 - checklists, 163–65
 - components to an eye test, 154
 - experience at the optometrist, 155–57
 - feedback, 158–59
 - functional assessment, 160–61
 - glasses, 159
 - helping people with poor sight, 161–62
 - low-vision services, 160
 - movement analysis, 165
 - responses to objects, 165
 - responses to other people, 164
 - role of the health facilitator/health supporter, 154–55
 - surgery, 159
 - testing, 157
 - visual field testing, 158
 - social effects of
 - assessing people, places and situations, 151–52
 - autonomy and independence, 153
 - balance, movement and mobility, 152
 - communication, 150
 - concentration and attention span, 152–53
 - coordination, 151
 - knowledge of self and self-image, 152
 - learning and development, 151
 - memory, 152
 - motivation, 150–51
 - social exclusion, 149–50
 - space, size and abstract concepts, 152
 - trust, 152
 - use of hearing, 153
 - variations in sight, 162
 - visual field tests, 154
 - visual impairment, 7
 - vitamin C, 210
- W**
- wax blockages, in ear, 170
 - wax migration, in the individual, 170
 - Weetabix, 302
 - whole life planning, 81
 - Williams' syndrome, 207
 - World Health Organization, 7
- X**
- xerostomia, 216