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 (BER), 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
Index

clinical assessment of PIMD
as an intervention, 107–8
case study, 106
context of assessment, 99–102
coopration 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
eye, 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
editor’s 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
genital chromosomal aberration, 205
genital cytomegalovirus, 172
cystic fibrosis, 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
cranioosteoelastic, 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
dicycloverineHCI, 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
epilamambanein, 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

Index  357
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),
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,
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
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, 223–28
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
Index

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 prop®TM, 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
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
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

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
- persistency 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

self-injurious behaviour, 211–12
- tooth erosion, 209–10
- tooth grinding (bruxism), 210–11
- tuberous sclerosis, 207
- Williams’ syndrome, 207
- 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
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
Prader-Willi syndrome (PWS), 207, 278, 282
Primary Care Trusts (PCTs), 87, 143
profound intellectual and multiple disabilities (PMID)
biological factors, 5
discussion, 4–5
definition, 3–4
implementing 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
promoting 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
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
conceputalisiation 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
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
Surgicel™ (oxidised cellulose), 219
systematic desensitisation, 156
systematic variation, in behaviour, 47

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
tranylcypromine, 286
trauma, 239
tube flushing techniques, 278
tuberculosis, 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

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