

# Index

Note: page numbers in *italics* refer to figures and tables

- adolescents  
 advance directives, 112, 114, 116–117  
 age of consent, 19  
 assent, 10–11  
 autonomy, 7–8, 19, 20, 23–24  
 emerging, 2, 10  
 paradox, 24–25  
 parental role, 24, 28  
 treatment refusal, 24, 28  
 capacity, 7–8, 24–25  
 competency, 19, 20  
 confidentiality, 18–21  
 conflicts with physicians/parents, 10–12  
 decision-making, 7–12, 24  
 emancipated minor exception, 9–10  
 legal authority, 9–10  
 parental involvement, 19  
 public health exceptions to consent, 9  
 developing independence, 18  
 emancipated minors, 9–10, 114  
 emerging independence, 21  
 end-of-life treatment decisions, 11  
 gender identity, 161  
 genetic testing, 183–184  
 Hodgkin's disease, 7, 12  
 information withholding, 32–36  
 maturity, 27  
 organ donation for end-stage kidney disease, 143, 144–145  
 parents  
 advance directives, 114, 117  
 authority, 8–9  
 autonomy, 24, 28  
 conflicts with, 10–12  
 decision-making involvement, 19  
 tensions with, 18–19  
 public health exceptions to consent, 9  
 right to self-determination, 19  
 sexual activity, 213  
 stem cell therapy, 194  
 transitional status, 19, 33  
 treatment refusal, 23–26  
 autonomy, 24, 28  
 trust in doctor, 20  
 adult-onset conditions, predictive tests, 74, 181, 183–185  
 advance directives, 112–117  
 adolescents, 112, 114, 116–117  
 cystic fibrosis, 112, 116–117  
 guidance in planning, 113  
 health care proxy, 113  
 pediatric patients, 114  
 surrogates' decision-making guidance, 113–114  
 types, 112–113  
*see also* not resuscitate (DNR) orders  
 adverse events, 38  
 age of consent, adolescents, 19  
 alpha fetoprotein (AFP), maternal serum screening, 69  
 alternative therapies, 7  
 American Sign Language (ASL), 154  
 amniocentesis, 69–70  
 amniocyte culture, 69–70  
 analgesia, 105  
 anencephaly, 69, 175  
 anorexia nervosa, treatment refusal, 23, 24–26  
 antidepressants, 149  
 antipsychotics, 149  
 antivirals, allocation in pandemics, 201  
 anxiolytics, 149  
 apnea testing, brain death, 120  
 array-based comparative genomic hybridization (aCGH), 70, 73  
 Ashkenazi Jews, genetic testing, 183  
 assent, 1, 2  
 adolescents, 10–11  
 capacity for, 4  
 communication in, 2  
 decision-making capacity, 2  
 level of understanding, 3  
 model, 4  
 assisted reproductive technology, 63–67  
 autonomy, 63, 64, 65  
 ethics, 64–66  
 guidelines, 65–66  
 justice principle, 65  
 payment for, 66  
 regulations, 65–66  
 attention deficit disorder (ADD), 149  
 attention deficit hyperactivity disorder (ADHD), 149  
 autonomy, 2  
 assisted reproductive technology, 63, 64, 65  
 cognitive disabilities, 168  
 constrained parental, 85–86  
 disorders of sex development, 163  
 emerging, 2, 10  
 maternal–fetal conflict, 52, 53  
 paradox, 24–25  
 parental, 85–86, 182, 206–207  
 patient, 63  
 pregnant woman, 58  
 reproductive, 168  
 respect for, 46, 63, 64, 65  
 youth boxing, 212  
*see also* adolescents, autonomy  
 behavior  
 incompetent/unethical physicians, 231–232  
 sex-dimorphic, 162  
 behavioral problems, 148, 149  
 beneficence principle, 14, 140, 156, 168  
 benefit, 14  
 benevolent deception, 41  
 best interests, 14, 30  
 alleviation of suffering, 126  
 cochlear implants for deafness, 158  
 delivery room decision-making, 79–80  
 forgo life-sustaining therapies, 102  
 injured child, 29  
 lethal conditions, 177  
 newborn resuscitation, 79–80  
 parental refusal of vaccination, 207  
 persistent vegetative state, 126–127  
 physicians, 216, 217–219  
 symptom control in dying children, 137–138  
 treatment withdrawing/withholding in newborns, 85–86  
 youth boxing, 213

- 'better' bodies, 150–151  
 ethical issues, 150–151
- 'better' genes, 151–152  
 ethical issues, 151–152
- 'better' minds, 149–150  
 parental quest, 148–149
- bioethics training for ethics  
 consultants, 236
- blindness, retrolental fibroplasia,  
 186–187
- blood transfusions, religious beliefs,  
 11, 28–29
- boundary issues, 226–230  
 gifts from patients/families, 228–229  
 physician intimate relationships  
 with patients/family members,  
 227–228  
 political/policy, 229–230  
 sexual relationships, 227–228  
 treating own child, 226–227
- bowel necrosis *see* necrotizing  
 enterocolitis
- boxing *see* youth boxing
- brain death  
 apnea testing, 120  
 clinical criteria, 119  
 determination, 119, 120  
 diagnosis, 120  
 equivalence to death, 121  
 extradural hemorrhage, 118  
 legal standard, 120
- brain hypoxic injury, hypothermia for,  
 190–191
- BRCA mutation, 181, 183–184, 185
- capacity, 2  
 adolescents, 7–8, 24–25  
 age at, 8  
 assent, 2, 4  
 decision-making, 3, 7–8  
 developing, 2  
 information giving, 33–34  
 Rule of Sevens, 8  
*see also* competency
- cardiomyopathy, dilated, 32
- cardiopulmonary resuscitation (CPR),  
 108–109, 114–115
- care, ethics of in maternal–fetal  
 conflict, 53–54
- caregivers  
 goals, 3–4  
*see also* parent(s)
- casuist approach to ethics, 116
- cerebral palsy, 90
- cesarean section  
 emergency for fetal distress, 51, 55  
 maternal terminal illness, 54  
 maternal–fetal conflict, 51  
 multiple births, 64  
 treatment refusal, 54
- chaperones, 228
- chemotherapy, 1, 5, 7
- child endangerment, maternal–fetal  
 conflict, 54
- chorionic villus sampling (CVS),  
 69–70
- circumcision  
 female, 46–47  
*see also* male circumcision
- clinical research, 194–197  
 disclosure, 222  
 fetal care centers, 60–61  
 generalizable knowledge, 195  
 informed consent, 196–197  
 informing participants, 196–197  
 parental consent, 191, 196  
 peer review, 195  
 recording, 195  
 risk–benefit balance, 196  
 stem cell therapy, 194–195  
 targeting, 195  
 therapeutic misconception,  
 196–197  
 useful data, 195  
*see also* innovative technology
- cochlear implants, 154–159  
 best interests, 158  
 case resolution, 158–159  
 Deaf community response, 155–157  
 devices, 154–155, 155  
 effectiveness, 157, 158  
 ethical principles, 156–157  
 harm principle, 158  
 legal cases, 157–158  
 parental decision-making, 158  
 usage, 154–155
- coercion, treatment refusal, 28
- cognitive disabilities, sterilization,  
 166–172  
 abuse, 167, 171  
 autonomy, 168  
 beneficence principle, 168  
 definition, 167  
 ethical issues, 171–172  
 goals, 168–169  
 interests of others, 170  
 interests of person, 170  
 justice principle, 168  
 male minors, 169–170  
 nonmaleficence principle, 168  
 parental decision-making, 171  
 pregnancy, 167, 168, 169  
 relative risks, 170–171  
 requests for, 167–168  
 risk–benefit assessment, 170–171  
 sexual abuse, 169  
 vasectomy, 169–170
- coma, irreversible, 118
- comfort care, 235
- communication  
 assent process, 2  
 deafness, 156, 157  
 information provision, 34  
 medical error disclosure, 41  
 serious illness, 33  
 treatment refusal, 30  
 truthfulness, 33
- competence, physician, 223, 224–225,  
 226, 232
- competency, 20  
 adolescents, 19, 20  
*see also* capacity
- complete androgen insensitivity  
 syndrome (CAIS), 160–161, 164
- confidentiality, adolescents, 18–21
- conflicts of interest, 215–219  
 industry representatives, 215–217  
 medical training, 222  
 physicians, 216, 217–218
- congenital adrenal hyperplasia (CAH),  
 160, 162, 164
- congenital anomalies, prenatal  
 diagnosis, 135
- consent laws, public health policy, 9
- conservation criteria, resource  
 allocation, 201
- constrained parental autonomy, 85–86
- contextual features, treatment  
 withdrawing/withholding in  
 newborns, 86
- contraception, 9, 167
- Convention on the Rights of the Child  
 (UN), 19
- cultural issues, 30  
 death diagnosis, 120  
 disorders of sex development, 163  
 information withholding, 33  
 male circumcision, 43  
 newborn resuscitation, 83, 86
- cystic fibrosis  
 advance directive, 112, 116–117  
 carrier testing, 181, 182–183, 184,  
 185  
 immunoreactive trypsinogen  
 screening, 182–183  
 lung transplantation, 112  
 pre-implantation genetic diagnosis,  
 70  
 screening technologies, 182–183
- dead bodies, technique practice, 223
- Deaf community, 155–156, 157–158  
 response to cochlear implants,  
 155–157
- deafness, 154–159  
 best interests, 158  
 case resolution, 158–159  
 communication, 156, 157  
 cultural issues, 154, 155–156  
 education of children, 156

## Index

- deafness (*cont.*)  
 ethical principles, 156–157  
 harm principle, 158  
 hearing parents, 155  
 paternalism, 156
- death  
 biological concept, 119  
 cardiopulmonary standard, 119  
 determination of, 118  
   brain death equivalence, 121  
   extradural hemorrhage, 118  
   standards, 119, 120  
   variations, 120  
 diagnosis, 119, 120  
 neocortical, 119  
 physician-assisted dying, 123–129  
 risk with symptom control in dying child, 138  
*see also* brain death
- deception, benevolent, 41
- decision-making, 1  
 allocation of power, 11  
 assent, 2  
 barriers to for children, 3  
 capacity, 3, 7–8  
 emancipated minor exception, 9–10  
 end-of-life care, 103  
 family-centered, 163  
 forgo life-sustaining therapies, 102–103  
 guidance for surrogates, 113–114  
 joint, 3–4  
 legal authority of minors, 9–10  
 mature minor exceptions, 10  
 model, 4  
 newborns with intractable suffering, 132–133  
 non-therapeutic interventions, 47–48  
 participation by child, 2, 3, 46  
 physician-assisted dying, 125  
 pregnant woman, 59–60  
 public health exceptions to consent, 9  
 religious freedoms, 11  
 respect for parents and child, 46  
 roles, 4  
 shared, 2, 3–4  
 status of parties, 4  
 surrogate, 1–2, 113–114  
*see also* adolescents, decision-making; delivery room, decision-making; parent(s), decision-making
- decisional capacity in physician-assisted dying, 125–127
- decisions, validity, 3
- delivery room  
 decision-making, 77–81  
 best interests, 79–80
- counseling of parents, 78  
 ethical issues, 77  
 ethical principles, 77–80  
 fairness, 77–78  
 honesty, 77–78  
 newborn's rights, 79  
 parents' rights, 78–79  
 plans, 80–81  
 prematurity, 81  
 prognosis, 78  
 staff discussions/preparation, 80  
 withdrawing/withholding treatment, 80  
 delivery at 23 weeks' gestation, 77
- dependency, regression to, 3
- devices, marketing *see* industry representatives
- diethylstilbestrol (DES), 191
- dilated cardiomyopathy, 32
- diphtheria, risk, 207
- directed genetic change *see* genetic engineering
- disability  
 fiscal scarcity, 177  
 futility, 108  
 hGH supplementation, 150  
 paradox, 91–92  
 relationship with gestational age, 94–95  
 short stature, 150  
 treatment decisions, 176
- disasters, resource allocation, 199–203  
 children's vulnerability, 202
- disclosure  
 clinical research, 222  
 medical training, 222  
*see also* medical error, disclosure
- disorders of sex development (DSD), 160–164  
 autonomy, 163  
 cultural issues, 163  
 ethical issues, 162–163  
 ethical principles, 161–162  
 family-centered decision-making, 163  
 informed consent, 162–163  
 legal issues, 162–163  
 management, 163–164  
 nomenclature, 162, 163  
 nonmaleficence, 163  
 science, 162  
 surgical interventions, 162–164
- DNA, fetal, 68, 69–70  
 maternal circulation, 71–72
- DNA sequencing, 74  
 fetal, 68, 69–70
- do not resuscitate (DNR) orders, 114–116  
 goals of therapy, 115
- Down syndrome, 69, 176
- drugs, marketing *see* industry representatives
- duty-based approach to ethics, 116
- dying child  
 aggressive treatment request, 235, 237–238, 239  
 caring for, 138  
 incurable disease, 131–132  
 options of last resort, 139  
 symptom control  
   intractable symptoms, 139  
   opioid use, 138–139, 140  
   principle of double effect, 138, 139  
   risk of death, 138  
   support for prioritizing, 138–139  
 symptom management, 137–140  
*see also* end-of-life care; physician-assisted dying
- eating disorders, treatment refusal, 23, 24–26
- education  
 deaf children, 156  
 ethics committee role, 238
- egalitarianism, 201–202
- emancipated minors, 9–10, 114
- embryo, moral status, 70–71
- embryo transfer, 64
- emergency medical services, do not resuscitate orders, 115
- end-of-life care, 11, 34  
 decision-making, 103  
 decisions for newborns, 132  
 discontinuing medically provided fluids and nutrition, 103–104  
 dispute resolution over life-sustaining interventions, 101–105  
 fetal, 61  
 information withholding, 34  
*see also* dying child; forgo life-sustaining therapies (FLT); terminal illness
- end-stage kidney disease, organ donation, 143, 144–145
- enhancement, definition, 148–149
- enhancement technologies, 148–152  
 'better' bodies, 150–151  
 'better' genes, 151–152  
 'better' minds, 149–150  
 hGH supplementation, 150–151  
 stimulant drugs, 149–150
- epidermolysis bullosa, 131–132, 135
- equal treatment of people, 201–202
- ethics committees, 238–239  
 composition, 238  
 roles, 238–239

- ethics consultants, bioethics training, 236
- ethics consultation, 235–238  
 information withholding, 35  
 models, 236  
 necrotizing enterocolitis aggressive treatment request, 237–238  
 parent/family involvement, 236–237  
 process, 236–237  
 request for, 235–236  
 standards, 237
- ethnic groups, genetic testing, 183
- euthanasia, 124, 133  
*see also* Groningen protocol
- extradural hemorrhage, determination of death, 118
- extremely low gestational age neonates (ELGANs), 94  
 costs, 97  
 informed consent, 95  
 international variations in rates, 97  
 moral issues, 96  
 outcomes, 95  
 policies for treatment, 96  
 poor countries, 97–98  
 practice variations between countries, 95–96  
 treatment variations, 95–96  
 zones, 95  
*see also* prematurity, extreme
- fairness, decision-making in delivery room, 77–78
- families  
 coping mechanisms, 34  
 disaster situations, 202  
 ethics consultation involvement, 236–237  
 interests in treatment withdrawing/withholding, 110  
 organ donation, 144
- family beliefs, 27–30, 34
- family-centered care, immunization, 209
- family-centered decision-making, 163
- family planning services, adolescents, 9
- father, role in fetal intervention, 60
- feeding, oral, 103
- female circumcision, 46–47
- females, virilized chromosomal, 160, 164
- feminist ethics, maternal-fetal conflict, 53–54
- fetal care, ethical relationships, 58
- fetal care centers, 57–62  
 informed consent, 61  
 justice principle, 60  
 medical team interests, 60–61
- research and innovation, 60–61
- fetal distress, emergency cesarean section, 51, 55
- fetal DNA  
 maternal circulation, 71–72  
 sequence, 68  
 sequencing, 69–70
- fetal intervention, 57–62  
 ethical issues, 58  
 father's role, 60  
 fetal death risk, 61  
 fetus as patient, 58–59  
 myelomeningocele, 57–58, 59, 61  
 pregnant woman, 59–60  
 sacrococcygeal teratoma, 58, 61
- fetus, 52, 58–59  
 death risk with fetal intervention, 61  
 palliative care, 61  
 prenatal genetic testing, 68–75  
 rights to beneficence, 52  
 sex determination, 72
- fidelity, 32–33
- fiduciary relationship, 217
- Five Wishes, 113
- folic acid supplementation, 69
- forgo life-sustaining therapies (FLT), 101, 102  
 best interests, 102  
 care considerations after decision, 104  
 criteria for, 102  
 decision-making, 102–103  
 harm principle, 103  
 parents' wishes, 103  
 quality of life, 102
- formalist approach to ethics, 116
- futility, 106–111  
 abandoning, 109–110  
 cardiopulmonary resuscitation, 108–109  
 concept, 102  
 defining, 106–108  
 disability, 108  
 ethical issues, 106  
 legal authority, 108  
 lethal trisomy syndromes, 175–176  
 physician unilateral decision, 110  
 physiologic, 107–108, 175–176  
 qualitative, 108–109, 176  
 quantitative, 107–108, 175–176  
 status epilepticus, 106  
 treatment, 107–108
- genes  
 'better', 151–152  
 disease-associated, 73  
 sexual development, 162
- genetic counseling, 185
- genetic engineering, 151, 152
- genetic testing, 181–185  
 adolescents, 183–184  
 BRCA mutation, 181, 183–184, 185  
 cystic fibrosis carriers, 181, 182–183, 184, 185  
 ethnic groups, 183  
 genetic information, 73–74  
 newborn screening, 181–184  
 policy statements, 183  
 predictive tests for adult-onset conditions, 74, 181, 183–185  
*see also* pre-implantation genetic diagnosis; prenatal genetic diagnosis
- gestational age, 94–95
- gifts from patients/families, 228–229
- girls, virilized chromosomal, 160, 164
- gonadal dysgenesis, 162
- Groningen protocol, 131–135  
 after 5 years, 135  
 creation, 133–134  
 international response, 134–135  
 misunderstandings, 134–135  
 requirements for termination of life, 134
- group B streptococcus (GBS)  
 screening, 190
- growth hormone, human (hGH), 150–151
- Guthrie test, 181
- harm principle, 14, 15  
 cochlear implants for deafness, 158  
 forgo life-sustaining therapies, 103  
 information withholding, 35  
 treatment withdrawing/withholding in newborns, 86  
 vaccination refusal by parents, 207–209
- head injury, parental refusal to consent to CT scan, 14, 15, 16–17
- health care proxy, 113
- health-related quality of life (HRQL), 90
- hemoglobinopathies, genetic testing, 183
- hermaphrodites, 161, 162
- HIV infection, 35, 44–45
- Hodgkin disease  
 adolescent patient, 7, 12  
 family beliefs, 27, 30  
 treatment refusal, 27, 30
- honesty, decision-making in delivery room, 77–78

## Index

- human growth hormone (hGH),  
 150–151  
 adverse effects, 150  
 costs, 150  
 human subjects research *see* clinical  
 research  
 hydration, 139  
 withholding, 124, 125, 132  
 hypothermia for hypoxic brain injury,  
 190–191
- immunization  
 school-entry laws, 208  
*see also* vaccination
- immunoreactive trypsinogen (IRT)  
 screening for CF, 182–183
- impaired providers, 231–234  
 ethical issues, 232–233  
 intervention, 233
- in vitro fertilization (IVF), 63–67  
 ‘better’ genes, 151  
 guidelines, 65–66  
 justice principle, 65  
 multiple births, 63–64  
 number of embryos transferred, 64  
 payment for, 66  
 pre-implantation genetic diagnosis,  
 68  
 regulations, 65–66
- incompetent children, physician-  
 assisted dying, 127–128
- incompetent providers, 231–234  
 ethical issues, 232–233  
 identification, 231–232  
 intervention, 233
- industry representatives, 215–217  
 influence on prescribing, 216–217  
 marketing practices, 215–217  
 reciprocity from physicians, 216,  
 217
- infertility, complete androgen  
 insensitivity syndrome, 161,  
 164
- influenza pandemic, 199–200,  
 202–203
- information  
 developmentally appropriate, 33–34  
 disclosure, 34, 35–36  
 provision for communication, 34
- information withholding  
 from children/adolescents, 32–36  
 cultural issues, 33  
 difficulties, 34  
 end-of-life care, 34  
 ethics consultation, 35  
 harm, 35  
 parental request, 34  
 plan negotiation, 34  
 serious illness, 32  
 informed consent, 2
- actual, 223–224  
 clinical research, 196–197  
 disorders of sex development,  
 162–163  
 extremely low gestational age  
 neonates, 95  
 fetal care centers, 61  
 implied, 223–224  
 medical error disclosure, 38  
 medical training, 222–223  
 objections, 223–224  
 opt-out, 224  
 parental, 191, 233–234  
 reasonable person/subjective  
 standard, 222
- informed refusal, pregnant woman, 59
- innovative technology, 186–191  
 antenatal steroids, 189–190  
 group B streptococcus (GBS)  
 screening, 190  
 hypothermia for hypoxic brain  
 injury, 190–191  
 supplemental oxygen for respiratory  
 distress syndrome, 186–187  
 total parenteral nutrition, 188–189  
*see also* mechanical ventilation
- instrumental value criteria, resource  
 allocation, 200–201
- intensive care, infants dependent on,  
 132
- interests of child, promotion in non-  
 therapeutic interventions,  
 45–46
- intergenerational equity principle, 201
- investment refinement criteria, 201
- involuntary euthanasia, 124
- Jehovah’s Witnesses, treatment  
 decisions, 11
- justice principle  
 cognitive disabilities, 168  
 fetal care centers, 60  
 in vitro fertilization, 65  
 maternal-fetal conflict, 52–53  
 newborn screening, 181–182
- kidney  
 injury from medication error, 37  
 live donation, 143  
 organ donation for end-stage  
 kidney disease, 143, 144–145
- labial adhesions, urinary catheter, 231,  
 233–234
- legal authority  
 cochlear implants, 157–158  
 Deaf community, 157–158  
 decision-making, 9–10  
 futility, 108  
 quality of life, 89
- treatment refusal, 29  
 treatment withdrawing/  
 withholding, 84, 110
- legal issues, disorders of sex  
 development, 162–163
- legal liabilities, pediatricians in  
 prenatal genetic diagnosis,  
 68–69, 72–73
- lethal conditions  
 best interests, 177  
 costs, 177–178  
 engaging with parents, 178–179  
 ethical issues, 174  
 parental disagreement with  
 provider, 176–177  
 parental requests for interventions,  
 174  
 resource scarcity, 177–178  
 surgical interventions, 174, 176–  
 177, 179
- lethality, 175
- life cycle criteria in resource  
 allocation, 201
- life-sustaining interventions  
 definition, 101–102  
 discontinuing medically provided  
 fluids and nutrition, 103–104  
 dispute resolution, 101–105  
 medical technology, 101  
*see also* forgo life-sustaining  
 therapies (FLT)
- life years, maximizing, 200
- lumbar puncture, medical training,  
 221–222, 224–225
- lung transplantation, cystic fibrosis,  
 112
- male circumcision, 43–48  
 case resolution, 48  
 complications, 45  
 cultural issues, 43  
 ethics, 43, 45  
 historical and origins, 44  
 as medical intervention, 44  
 medical risks/benefits, 44–45  
 pain, 45  
 religious beliefs, 44  
 request for, 43
- mass casualty incident, children, 202
- maternal serum screening, 69
- maternal–fetal conflict, 51–55  
 autonomy, 52, 53  
 interference, 53  
 threshold, 53  
 cesarean section, 51, 54  
 child endangerment, 54  
 ethical issues, 51  
 ethical principles, 51–53  
 ethics of care, 53–54  
 feminist ethics, 53–54

- justice principle, 52–53  
 legal precedents/perspectives, 54  
 moral obligations, 51–53  
 nonmaleficence, 52  
 principle-based approach, 53  
 professional humility, 54–55  
 woman's moral obligations, 52
- mechanical ventilation  
 development, 187–188  
 resource allocation, 199, 202–203  
 symptom control in dying child, 137–138  
 withholding/withdrawing, 132
- medical care, providing to own/relatives'/friends' children, 226–227
- medical error, 38  
 benevolent deception, 41  
 disclosure, 37–42  
 challenges, 40  
 conflicts of interest, 40  
 effective, 41  
 informed consent, 38  
 physician attitudes/experiences, 39  
 procedure, 40  
 threshold, 40  
 transparency, 38, 40  
 trust, 38  
 truthfulness, 38–39
- frequency, 38  
 informing parents, 234  
 parent expectations, 39  
 root cause analysis, 42  
 serious, 40  
 therapeutic privilege, 41
- medical technology, life-sustaining, 101
- medical training  
 alternative strategies, 223  
 competence development, 223, 224–225  
 conflicts of interest, 222  
 disclosure, 222  
 informed consent, 222–223, 224  
 lumbar puncture, 221–222, 224–225  
 objections to consent, 223–224  
 opt-out, 224  
 patient participation, 221–225  
 pelvic examination, 223  
 potential risks for patients, 221–222  
 reasonable person standard, 222  
 risks, 222–223  
 subjective standard, 222  
 technique practice on dead bodies, 223
- medically provided fluids and nutrition (MPFN), discontinuing, 103–105
- medication overdose, 37
- informing parents, 39–40  
 investigation, 42  
 issues, 37–41  
 multiple failures in care, 38  
 resolution of case, 41–42  
 root cause analysis of error, 42
- medications, marketing *see* industry representatives
- medulloblastoma, recurrent causing seizures, 101, 104–105
- meningitis, bacterial, 226
- meningococcal septic shock, 123, 128–129
- menses failure, 160–161
- mental health treatment, adolescents, 9
- mental retardation *see* cognitive disabilities
- multidisciplinary teams, information disclosure, 34, 35–36
- multiple births, 63–67  
 cesarean section, 64  
 in vitro fertilization, 63–64  
 risks to children, 63–64  
 risks to mother, 64
- multiplier effect, 200–201
- mutual pretense, 34
- myelomeningocele, 57–58, 59, 61  
*see also* spina bifida
- narrow social utility, 200–201
- necrotizing enterocolitis, 145, 146  
 aggressive treatment request, 235, 237–238, 239
- Nemehah tradition, 7
- neocortical death, 119
- Netherlands  
 euthanasia for intractable suffering, 133  
 prenatal diagnosis of congenital anomalies, 135  
 treatment withdrawing/withholding, 132
- neural tube defects, maternal serum screening, 69
- neurodevelopmental impairment, prematurity, 78, 81
- newborn(s)  
 end-of-life decisions, 132  
 intractable suffering, 132–133  
 poor countries, 97–98  
 quality of life assessment, 89–92  
 resuscitation, 77, 81  
 best interests, 79–80  
 cultural issues, 83, 86  
 ethical principles, 96–97  
 outcomes, 78  
 prognosis, 78  
 treatment withdrawing/withholding, 80
- rights, 79
- screening, 73, 181–184  
 justice principle, 181–182
- treatment withdrawing/withholding, 80, 83–87  
 best interests, 85–86  
 conclusion to case, 86–87  
 contextual features, 86  
 end-of-life decisions, 132  
 ethics, 83–85  
 intractable suffering, 132  
 legal issues, 84  
 parental authority, 85–86  
 policy, 84  
 resuscitation, 80  
 value, 96–97  
*see also* extremely low gestational age neonates (ELGANs); prematurity
- newborn screening (NBS) program, 181  
 mandatory, 182, 184  
 policy statements, 183
- non-therapeutic interventions, 43–48  
 decision making, 47–48  
 ethical consideration balancing, 46–47  
 ethical principles, 45–47  
 information for parents, 47–48  
 physician obligations, 45–46  
 promotion of interests of child, 45–46  
 request assessment, 47  
 respect for parents and child in decision-making, 46
- non-voluntary active euthanasia, 124, 126
- nonmaleficence principle  
 cognitive disabilities, 168  
 disorders of sex development, 163  
 maternal–fetal conflict, 52  
 symptom control in dying child, 140
- normative theories of ethics, 116
- nuchal translucency testing, 69
- nutrition  
 oral feeding, 103  
 during palliative sedation, 139  
 total parenteral nutrition development, 188–189  
 withholding, 124, 125, 132  
*see also* medically provided fluids and nutrition (MPFN)
- oligohydramnios, 57
- opioids, symptom control in dying child, 138–139, 140
- organ donation, 143–145  
 end-stage kidney disease, 143, 144–145  
 ethical issues, 143–144  
 families, 144

## Index

- organ donation (*cont.*)  
 live, 143–145  
 minors, 144
- organ transplantation, 145–146  
 post-transplant lymphoproliferative disease, 145–146  
 rejection, 145–146  
 small bowel, 145–146
- osteosarcoma, metastatic, 1, 5
- oxygen, supplemental, 186–187
- palliative care *see* dying child; end-of-life care; terminal illness
- palliative sedation, 124, 133, 139
- pandemics  
 antiviral allocation, 201  
 influenza, 199–200  
 resource allocation, 199–203  
 vaccine allocation, 201
- paraphimosis, 44
- parent(s)  
 advance directives for pediatric patients, 114  
 autonomy, 182, 206–207  
   constrained, 85–86  
 barriers to child participation in decision-making, 3  
 care role, 34  
 caregiver respect for role, 34  
 consent  
   for clinical research, 191, 196  
   to treatment, 233–234  
 counseling for delivery room decision-making, 78  
 deaf of deaf children, 154, 155–156  
 decision-making, 8–9, 34  
   authority, 14–15  
   autonomy, 206–207  
   cochlear implants, 158  
   delivery room, 78–79  
   ethics consultation, 237  
   harm principle, 15  
   legal challenges, 15  
   non-therapeutic interventions, 46  
   physician interference, 15  
   shared, 3–4  
   sterilization in cognitive disability, 171  
 engaging with for lethal conditions, 178–179  
 ethics consultation involvement, 236–237  
 expectations in medical errors, 39  
 fitness for, 63  
 in forgo life-sustaining therapies, 103  
 hearing of deaf children, 155  
 information for non-therapeutic interventions, 47–48  
 informing about medical errors, 39–40, 234  
 lethal conditions  
   disagreement with provider, 176–177  
   requests for interventions, 174  
 quest for ‘better’, 148–149  
 request to withhold information, 32, 34  
 rights, 15, 28, 78–79  
 state intervention, 15  
 therapeutic alliance, 205, 209  
 treatment refusal, 14–17  
 vaccination refusal, 205–209  
   best interests, 207  
   ethical issues, 205–208  
   factors influencing, 206  
   harm principle, 207–209  
*see also* adolescents, parents
- parental authority  
 adolescents, 8–9  
 caregiver respect for, 34  
 delivery room decision-making, 78–79  
 state intervention, 15  
 treatment refusal, 27  
 treatment withdrawing/withholding in newborns, 85–86
- parental permission, 1–2
- paternalism, deafness, 156
- peer review, clinical research, 195
- pelvic examination, medical training, 223
- penile cancer, prevention with male circumcision, 44–45
- persistent vegetative state, 126–127  
 interests of child, 126–127  
 suffering of child, 126
- pertussis, risk, 207–208
- pharmaceutical industry *see* industry representatives
- phenylketonuria screening, 181, 182
- philosophical reasons, school-entry immunization law opt-out, 208
- phimosis, 44
- physician(s)  
 attitudes  
   lethal trisomy syndromes, 175  
   medical error disclosure, 39  
   sexual activity in adolescents, 213  
 best interests, 216, 217–219  
 competence, 226, 232  
   development in medical training, 223, 224–225  
 conflicts of interest, 215–219  
   industry representatives, 215–217  
 conflicts with adolescents, 10–12  
 delivery room decision-making, 80  
 duty, 2, 232–233  
 futile situations, 110  
 gifts from patients/families, 228–229  
 impaired/incompetent, 231–234  
   ethical issues, 232–233  
   intervention, 233  
 interference with parental decision-making, 15  
 intimate relationships with patients/  
   family members, 227–228  
 non-therapeutic interventions, 45–46, 47  
 political/policy issues, 229–230  
 professional standards, 226  
 qualitative futility, 108  
 quality of life assessment, 89  
 reciprocity, 216, 217  
 sexual relationships, 227–228  
 therapeutic alliance with parents, 205, 209  
 trust of adolescents, 20  
 trustworthiness, 217  
 unethical, 231–234  
   intervention, 233  
 youth boxing opposition, 211
- physician-assisted dying, 123–129  
 children lacking decisional capacity, 125–127  
 ethical arguments in support, 125  
 forms, 124  
 incompetent children, 127–128  
 minors with decisional capacity, 125  
 persistent vegetative state, 126–127  
 terminal illness, 125–126
- physician–patient relationship, 217  
 therapeutic alliance, 205, 209
- policy  
 boundary issues, 229–230  
 making by ethics committees, 238  
 public health, 9  
 statements for genetic testing, 183  
 treatment withdrawing/withholding from newborns, 84
- political/policy issues, 229–230
- poor countries, newborns, 97–98
- positive-pressure ventilation (PPV), 187–188
- post-transplant lymphoproliferative disease, 145–146
- power of attorney, durable, 113
- prayer, 27, 29
- pre-implantation genetic diagnosis, 70–71  
 ‘better’ genes, 151, 152  
 genetic information, 73–74  
 in vitro fertilization, 68  
 savior siblings, 71  
 scope of use, 71
- pregnancy-associated plasma protein-A (PAPP-A), 69
- pregnancy/pregnant woman

- autonomy, 58  
 cognitive disabilities, 167, 168, 169  
 decision-making, 59–60  
 fetal intervention, 59–60  
 informed refusal, 59
- prematurity  
 prenatal steroids in labor, 189–190  
 total parenteral nutrition, 188
- prematurity, extreme  
 care practice variations, 94–98  
   between countries, 95–96  
   moral issues, 96  
 case narrative, 94  
 costs, 97  
 cultural issues, 83  
 decision-making in delivery room,  
   77, 81  
 ethical issues, 77  
 international variations in  
   rates, 97  
 neurodevelopmental impairment,  
   78, 81  
 outcomes, 85  
 policies for treatment, 96  
 prognosis, 94–95  
 quality of life assessment, 89, 92  
 survival, 94  
*see also* extremely low gestational  
 age neonates (ELGANs)
- prenatal genetic diagnosis, 68–75  
 amniocentesis, 69–70  
 ‘better’ genes, 151, 152  
 chorionic villus sampling, 69–70  
 congenital anomalies, 135  
 genetic information, 73–74  
 legal liabilities for pediatricians,  
   68–69, 72–73  
 maternal serum screening, 69  
 pediatrician implications, 72  
 predictive tests for adult-onset  
   conditions, 74  
 trisomy syndromes, 69
- prescribing, pharmaceutical industry  
 influence, 216–217
- principle-based analysis, sterilization  
 requests, 167–168
- principle-based approach to maternal-  
 fetal conflict, 53
- principle of double effect (PDE), 138,  
 139
- prioritarianism, 200
- professional humility, maternal–fetal  
 conflict, 54–55
- professional standards, physicians, 226  
 self-regulation, 231
- pseudo-hermaphroditism, 162
- psychosis, adolescent confidentiality,  
 18, 21
- public health  
   policy, 9  
   resource allocation, 200
- quality-adjusted life-years (QALY), 97
- quality of life, 89–90  
 definitions, 90  
 disability paradox, 91–92  
 forgo life-sustaining therapies, 102  
 measurement instruments, 90  
 perceptions of health professionals,  
   91  
 self-reporting in children, 90–91  
 short stature, 150
- quality of life assessment  
 cerebral palsy, 90  
 clinical implications, 92  
 legal issues, 89  
 newborns, 89–92  
 physicians, 89  
 prematurity, 89, 92  
 proxy responses, 90  
 utility measures, 91  
 very low birthweight, 90–91
- reciprocation, 216, 217
- religious beliefs  
 blood transfusions, 11, 28–29  
 male circumcision, 44  
 school-entry immunization law  
   opt-out, 208  
 treatment withdrawing/withholding  
   in newborns, 86
- religious freedoms, 9, 11, 30  
 treatment refusal, 27–28, 29–30
- reproductive autonomy, 168
- research *see* clinical research
- resource allocation  
 conservation criteria, 201  
 disasters, 199–203  
   children, 202  
 egalitarianism, 201–202  
 ethical criteria, 200–202  
 instrumental value criteria, 200–201  
 investment refinement criteria, 201  
 issues unique to children, 202  
 life cycle criteria, 201  
 mechanical ventilation, 199,  
   202–203  
 pandemics, 199–203  
 public health, 200  
 saving the most, 200  
 sickest first, 200  
 social value criteria, 200
- resource scarcity, lethal conditions,  
 177–178
- respiratory distress syndrome  
 antenatal steroids, 189  
 supplemental oxygen, 186–187
- resuscitation *see* newborn(s),  
 resuscitation
- retinopathy, oxygen-induced/  
 retrolental fibroplasia, 186–187
- Rh incompatibility, fetal DNA in  
 maternal blood, 72
- rights of children, 28, 30  
 delivery room decision-making, 79
- risk–benefit balance for clinical  
 research, 196
- Ritalin *see* stimulant drugs
- role constraints, 3
- rule of rescue, 200
- Rule of Sevens, 8
- sacroccygeal teratoma, fetal  
 intervention, 58, 61
- savior siblings, 71
- sedatives, 105  
*see also* palliative sedation
- self-administered physician-assisted  
 dying, 124
- self-determination, right to, 19
- self-regulation of profession, 231
- septic shock, meningococcal, 123
- serious illness  
 adolescent transitional status, 33  
 communication, 33  
 withholding information, 32
- sex  
 cultural construct, 162  
 fetal determination, 72  
 separation from gender, 161  
 types, 161
- sex development disorders  
*see* disorders of sex  
 development (DSD)
- sex-dimorphism, 162
- sexual abuse, cognitive disabilities,  
 169
- sexual activity in adolescents, 213
- sexual development, genes, 162
- sexual relationships, physicians,  
 227–228
- sexually transmitted infections (STIs),  
 9
- short stature, 150
- single gene disorders  
 fetal DNA in maternal blood, 72  
 pre-implantation genetic  
 diagnosis, 70
- sleep disruption, Werdnig–Hoffmann  
 disease, 137
- small bowel transplantation, 145–146  
 case resolution, 146  
 ethical issues, 145–146  
 neurocognitive deficits, 146  
 survival, 146
- social value criteria in resource  
 allocation, 200
- societal importance, death diagnosis,  
 120

## Index

- spina bifida, 69  
   maternal serum screening, 69  
   *see also* myelomeningocele  
 spinal muscular atrophy, 137  
 state intervention, parents, 15  
 status epilepticus, 106, 110–111  
 stem cell therapy, 194–195  
   potential harm, 195, 196  
 sterilization, cognitive disabilities,  
   166–172  
   abuse, 167, 171  
   compulsory, 167  
   definition, 166–167  
   ethical issues, 171–172  
   interests of others, 170  
   interests of person, 170  
   parental decision-making, 171  
   principle-based analysis of requests,  
     167–168  
   relative risks, 170–171  
   requests for, 167–169  
   risk–benefit assessment, 170–171  
 steroids, antenatal, 189–190  
 stimulant drugs, 149–150  
 streptococcus group B (GBS)  
   screening, 190  
 substance abuse treatment,  
   adolescents, 9  
 substituted judgement, 85  
 suffering, unbearable  
   best interests of child, 126  
   dying from incurable disease,  
     131–132  
   epidermolysis bullosa, 131–132, 135  
   euthanasia, 133  
   infants not dependent on intensive  
     care, 132–133  
   intractable symptoms in dying  
     child, 139  
   meningococcal septicaemia, 123,  
     128–129  
   newborns, 132–133  
   non-terminally ill children, 127–  
     128  
   palliative sedation, 124  
   persistent vegetative state, 126  
   physician-assisted dying, 123  
   terminal illness, 125–126  
 surgical interventions  
   disorders of sex development,  
     162–164  
   lethal conditions, 174, 176–177, 179  
 surrogate decision-making, 1–2,  
   113–114  
 survival, arbitrary cutoff point, 107  
 tandem mass spectrometry, 181  
 Tay–Sachs disease, genetic testing, 183  
 terminal illness, 125–126, 138  
   *see also* dying child; end-of-life care  
 tetanus risk, 207  
 therapeutic alliance, 205, 209  
 therapeutic misconception, 196–197  
 therapeutic privilege, 41  
 thinking, independent by child, 4  
 total parenteral nutrition (TPN),  
   development, 188–189  
 tracheal–esophageal fistula, 174, 176  
 training *see* medical training  
 transitional status, adolescents, 19, 33  
 treatment  
   effective, 107–108  
   futility, 107–108  
 treatment refusal  
   adolescents, 23–26  
   autonomy, 24, 28  
   negotiation, 25  
   physical force use, 25  
   cesarean section, 54  
   coercion, 28  
   communication, 30  
   family beliefs, 27, 30  
   Hodgkin disease, 27, 30  
   legal authority, 29  
   by minors, 29–30  
   parental authority, 27  
   by parents, 14–17  
   prayer, 27, 29  
   pregnant woman, 59  
   religious freedoms, 27–28, 29–30  
 treatment withdrawing/withholding,  
   106  
   competent patient, 109  
   cost grounds, 109  
   disputes in status epilepticus, 106  
   infants dependent on intensive care,  
     132  
   interests of family, 110  
   legal authority, 110  
   mechanical ventilation, 132  
   not serving interests of patient, 109  
   status epilepticus, 106  
   suffering of patient, 109  
   *see also* newborn(s), treatment  
     withdrawing/withholding  
 triage, 200, 202  
   modified, 200  
 trisomy, 174, 175  
   costs, 177  
   natural history, 178  
   physician attitudes, 175  
   treatment decisions, 176  
 trisomy syndromes  
   lethal, 175–176  
   prenatal genetic testing, 69  
   treatment decisions, 176  
 trust, medical error disclosure, 38  
 trustworthiness, 217  
 truthfulness, 33, 38–39  
 truth-telling, partial, 35  
  
 UN Convention on the Rights of the  
   Child, 19  
 understanding, level of, 3  
 unethical providers, 231–234  
   ethical issues, 232–233  
   identification, 231–232  
   intervention, 233  
 urinary catheter, labial adhesions, 231,  
   233–234  
 urinary tract infection, 44–45  
  
 vaccination  
   family-centered care, 209  
   parental autonomy, 206–207  
   parental concerns, 205, 206, 209  
   parental refusal, 205–209  
     best interests, 207  
     ethical issues, 205–208  
     factors influencing, 206  
     harm principle, 207–209  
   school-entry immunization laws,  
     208  
   under-immunization of children,  
     206  
 vaccine allocation in pandemics, 201  
 vasectomy, cognitive disabilities,  
   169–170  
 ventricular septal defect, trisomy 18,  
   174, 176  
 very low birthweight, quality of life  
   assessment, 90–91  
 vesico-amniotic shunting, 57,  
   59, 61  
 voluntary active euthanasia, 124  
  
 welfare of patients, duty of physicians, 2  
 Werdnig–Hoffmann disease, 137  
  
 youth boxing, 211  
   autonomy, 212  
   benefits, 213  
   best interests, 213  
   ethical issues, 212–214  
   goals, 213  
   harm, 212–213  
   injury risk, 211–212  
   physician opposition, 211  
   ringside medical supervision, 211,  
     212, 213–214  
   risk, 212–213