

Index

- Åberg, R., 127
- abortion, genetic testing and continuing controversy on, 3–5. *See also* selective abortion
- accessibility, and health systems
assessment, 254
- accommodation, and evaluation of quality of life for people with disabilities, 73–6, 95
- Acharaya, A., 135
- achondroplasia, 231
- activities of daily living, and objective measures of quality of life, 7–8
- Adams, R. M., 170n12
- adaptation: and concept of health-related quality of life, 11; and evaluation of quality of life for people with disabilities, 73–6, 95; and retrospective assessment of prevention of genetic disability, 157, 158–9
- age weighting, and health-related quality of life assessments, 40
- Alexander, L., 186
- Almeida, C., 239, 246
- Americans with Disabilities Act (ADA), 61, 68, 72, 96, 102, 107
- Amundson, R., 13, 17–18, 21, 106
- Anand, S., 135
- Andorra, and health attainment, 244
- anencephaly, 231
- Arnesen, T., 134
- Asch, A., 4, 19, 20, 76, 173, 174, 179, 184, 194, 196, 201, 202, 204, 205, 211n1, 222–3
- Ascher, T., 209
- attachment, and retrospective evaluation of prevention of genetic disability, 157, 159–61
- autonomy, and social context of decisions
on prenatal testing and selective abortion, 217–35. *See also* self-determination
- Bach, J. R., 117
- Banerji, D., 238
- Barnes, C., 221
- Beresford, B., 226
- Bickenbach, J., 20, 21, 258, 259
- biological sciences, and concepts of genetic diversity and normal function, 106–107
- biomedical ethics, and disability rights movement, 101–22. *See also* moral theory; values
- biostatistical normality (BSN). *See* normality
- Boorse, C., 105–107, 109, 110
- Bowling, A., 7, 8, 9, 247
- Braveman, P., 239
- Brennan, T., 170n11
- British National Health Service, and prenatal screening, 179, 227–9, 232, 233
- Britton, J., 229
- Brock, D. W., 17, 19, 60, 69, 80, 92, 94, 97, 98, 105–106, 108–10, 111, 113, 115, 121, 123n3, 136, 219, 220
- Brown, I., 21n1
- Bruntland, G. H., 237, 246
- Buchanan, A. E., 80, 92, 121, 122
- Bury, M., 13–14
- Caplan, R., 260
- Chang, R., 162
- choices: Disabled-or-Normal versus Disabled-or-None, in prevention of genetic disability, 144–52, 154–5, 167,

Index

- choices (*cont.*)
 168; on preconception testing, 194–7;
 and preferences in quality of life
 measurement, 8–9; and social context of
 decisions on prenatal testing and
 termination of pregnancy, 217–35. *See*
also parents
- chronic pathology, and view of health as
 public asset, 48–9, 60, 63
- civil rights, and disability rights
 movement: and bias in biomedical
 ethics, 101–22; and reconceptualization
 of disability, 13, 14–15
- Clarke, A., 228
- Coburn, D., 240
- Collins, F., 61–2
- commodification, and view of health as
 resource or asset, 43–64
- consumerism, and reasons for prenatal
 testing, 177, 178, 180, 181
- contraception, and preconception
 screening, 151
- coping, and evaluation of quality of
 life of people with disabilities, 73–6,
 95
- cost-effectiveness: assessments of quality
 of life and development of health policy,
 3, 28, 34; standpoints of patients and
 subjective assessments of quality of life,
 62. *See also* economics; U.S.
 Cost-effectiveness Panel
- Crocker, J., 209
- Cuba, and health attainment, 244
- Cyprus, and health attainment, 244
- cystic fibrosis, 71, 173, 174, 207–208, 231
- DALE (disability-adjusted life
 expectancy), 241, 245, 248, 250–1, 254–5,
 259
- DALYs (disability-adjusted life years),
 125–40, 249
- Daniels, N., 20, 37, 47–8, 49, 58, 59, 64–5n4,
 105–106, 107–108, 109, 110, 121, 123n3,
 252, 260–1
- Davidio, J. F., 209
- Davis, D., 221
- Day, H., 9
- death: emotional burden on parent of
 premature, in impaired child, 205–208;
 and retrospective evaluations by
 parents of disabled children, 152–3. *See*
also end-of-life treatment; life
 expectancy
- Declaration of Alma-Ata
 (WHO/UNESCO, 1978), 237–8
- democracy, and transparency problem in
 health policy, 40–1
- desirability, and concepts of worth and
 well-being in health state scores, 125,
 126–7, 128–31, 139
- difference: prevention of genetically
 transmitted disabilities and
 normalization, conformity, and
 intolerance of, 91; and standpoints of
 patients in subjective assessments of
 quality of life, 62. *See also* normality
- Different Number Choice, 145–8
- disability: disability rights movement and
 bias in biomedical ethics, 101–22;
 health-related quality of life and current
 rethinking of, 10–15; justice theory and
 view of health as public asset, 49–51;
 objective measures of and prevention of
 genetic, 67–99; social responses to and
 moral arguments on selective abortion,
 225–7. *See also* functional status;
 impairment; wrongful disability
- disability-adjusted life expectancy. *See*
 DALE
- disability-adjusted life years. *See* DALYs
- Disabled-or-Normal and
 Disabled-or-None choices, 144–52,
 154–5, 167, 168
- discrimination: and economic efficiency in
 performance assessments of health
 systems, 249–50; and objections to
 programs screening for genetic
 disabilities, 167–8; and standard view of
 disability and quality of life in health
 policy, 114
- Down syndrome, 173, 174, 205, 220,
 229–30, 231
- Duchenne muscular dystrophy, 231
- Duster, T., 172
- Dworkin, R., 184, 185, 225, 258
- economics: and social costs of genetic
 diseases and disabilities, 91–4; World
 Health Organization and performance
 assessment of health systems, 244,
 246–50, 253, 256. *See also*
 cost-effectiveness
- education: concerns about measurement
 and assessment in, 37; and prevention of
 genetically transmitted disabilities, 92
- end-of-life treatment: quality of life and
 controversy over, 2; relevance of
 disability in resource allocation for,
 94–9
- environment: and impact of health on
 well-being, 30–2; and rethinking of
 concept of disability, 10, 12, 72–3, 101
- Equal Employment Opportunity
 Commission (EEOC), 61

Index

- equality: and assessments of population health and national health systems, 237–62; and trade-offs between equity and efficiency in QALYs, 132–3
- Erickson, P., 9
- Erikson, R., 127
- eugenics, 147, 172, 228, 231
- Evans, D. B., 251
- expressivism, and prenatal testing, 223–4
- family, pluralism in concepts of, as factor in decisions on prenatal testing, 172–211. *See also* parents
- Farrant, W., 231, 232
- Feinberg, J., 185–6, 221
- Feinstein, A. R., 9
- Floyd, S., 201
- fragile X syndrome, 71, 205
- France, and *World Health Report*, 2000, 237
- Frenk, J., 247
- Fuhrer, M. J., 117
- functional status: classification of levels of, 224; and objective measures of quality of life, 7–8, 9; and species-typical health, 48. *See also* normality
- Gakidou, E., 256
- Gates, E., 4
- gender, and prenatal testing, 167, 193
- generic assessments, of health-related quality of life, 33–6
- genetic counseling, and nondirectiveness, 230–1
- genetic diversity, and concept of normal function, 106–107
- genetic testing: and chronic pathologies, 63; disability rights movement and reconceptualization of disability, 14–15; literature on ethical and social issues in, 15–16; pluralism in concepts of parenthood and family as factor in decisions on, 172–211; and prevention of genetically transmitted disabilities, 67–99, 142–69; protection of autonomy in decisions about, 217–35; and risks of labeling, 60–2; and role of quality of life in reproductive decision making, 3–5. *See also* preconception genetic testing
- genetic therapy, and prevention of genetic disability, 154
- Gill, T. M., 9
- Gillam, I., 182
- Global Burden of Disease (GBD) Project, 134, 247–8
- Glover, J., 169n1
- Goffman, E., 178, 182, 189
- Gold, M. R., 130, 135
- Green, J., 230, 231, 233
- Griffin, J., 69
- Guttmann, A., 37
- Guyatt, G., 35
- haemophilia, 231
- Hanson, K., 135
- Hanushek, E. A., 37
- harm: and assumptions about impairment, 189; moral principles and prevention of, 82–7, 89–90, 220, 222; parental selectivity and postbirth rejection of disabled child, 201–202
- Harris, J., 131, 221
- health: and assessments of population health and national health systems, 237–62; as commodity in health policy and genetic testing, 43–64; definition of, and concept of quality of life, 5–6, 21–2n2, 32–3, 38–9; determination of impact on well-being, 29–32. *See also* functional status; health care; population health; quality of life; reproductive health; well-being
- health care: and clinical versus policy uses of quality-of-life measures, 27–41; and genetic therapy, 154; and increasing importance of quality of life, 2–5; physicians and counseling on prenatal testing, 231–2; role of health, disability, and quality of life in assessments of population health and national systems of, 237–62. *See also* end-of-life treatment; health; policy; reproductive health; resource allocation
- health-related quality of life (HRQL): and calculations of QALYs, 95, 96; and current rethinking of disability, 10–15; development of concept, 5–7; generic versus specific assessments of, 33–6; and impact of health on well-being, 29–32; indeterminacy of health and concept of, 32–3; objective and subjective components of, 7–10; problems in definition of, 28–9; and requirement of transparency in health policy, 39–41; social justice and reductions in quality of life, 117. *See also* quality of life
- Health Status Index (HSI), 109–10
- Hsiao, C., 238
- Huether, C. A., 4
- Human Genome Project, 67, 122
- Huntington's disease, 71, 231

Index

- identity: concept of personhood and selective abortion in prevention of genetic disability, 77–9; personal versus genetic views of, 82. *See also* nonidentity problem
- ideology, models of disability and bias in biomedical ethics, 101–22
- impairment: impact of concept of quality of life on health policy, 12; interactive and social models of disability, 13–14; and pluralism in concepts of parenthood and family in decisions on prenatal testing, 172–211. *See also* disability
- Impersonal Comparative Principle, 145–8
- Imrie, R., 13, 259
- informed consent, and right to refuse medical treatment, 72
- interactive model, of disability, 13
- International Classification of Impairments, Disabilities, and Handicaps (ICIDH)*, 22n4
- International Monetary Fund, 242
- in vitro* fertilization (IVF), and preconception testing, 195
- Jamison, D. T., 247
- Jankey, S. G., 9
- Japan, and health attainment, 244
- Jeshion, R., 170
- justice: moral theory and association of health and, 46–8; and view of health as commodity, 44–5, 49–50; and World Health Organization framework for performance assessments of health systems, 246–58. *See also* social justice
- Juvenile Batten's Disease, 207
- Kamm, F., 64–5n4
- Kawachi, I., 240
- Kennedy, J. P., 240
- Kent, D., 212n3
- Kerr, A., 231
- Kittay, L., 202
- Knaul, F., 247
- Knox, A. J., 229
- Koch, T., 256
- Kuppermann, M., 4
- labeling, and genetic testing, 60–2. *See also* stigma
- Lancet, The* (journal), 246
- Leber congenital amaurosis, 71
- Lesch Nyhan syndrome, 70, 76, 81, 89, 180
- life expectancy: and Impersonal Comparative Principle, 148; serious disabilities and reduction of, 97. *See also* quality-adjusted life expectancy (QALE)
- Light, D., 260
- Lippman, A., 4, 227–8, 230
- Longmore, P. K., 112
- Lopez, A. D., 30, 241
- Lukes, S., 232
- Luque, J. A., 37
- Macintyre, S., 232
- Maclean, A., 218
- Major, B., 209
- Marteau, T., 231, 232
- Mathers, C., 135, 248, 251
- Mawer, S., 212n3
- McDowell, I., 9, 27, 247
- McKie, J., 252
- McMahan, J., 18, 19, 21, 84, 90, 178–9
- measures and measurement, of quality of life: clinical versus policy uses of, 27–41; and concept of health as personal asset, 52–3; development of instruments for, 22n5, 125–40; objective and subjective components of, 7–10; people with disabilities as critics of, 12–13; and pharmaceutical industry, 3; role of health, disability, and quality of life in assessments of population health and national health systems, 237–62. *See also* DALYs; health-related quality of life (HRQL); QALYs; quality of life
- medical model, of disability, 101–103, 104, 107, 109–10, 116, 120, 121
- Menzel, P. T., 54–5, 113, 123n4, 131, 253
- Milligan, M., 60
- mobility: measure of in Health Status Index, 109–10; and problem of transportation for people with disabilities, 119–20
- moral theory: and association of health and justice, 46–8; and autonomy in decisions about prenatal testing, 217–35; and selective abortion as means of preventing disability, 77–87, 142–4, 197–200. *See also* values
- morbidity, social and economic factors in, 228. *See also* impairment
- mortality, and health systems assessment, 247. *See also* death
- Moum, T., 136
- multi-attribute utility instruments (MAU), 130
- multiculturalism, and multifunctionalism in health care policy, 63

Index

- Mundy, L., 195
- Murray, C. J. L., 30, 40, 73, 135, 240, 241, 247, 248, 252
- Murray, T., 48, 56–8, 59, 133
- Nagler, M., 211n1
- National Association on Disability, 73
- National Digital Archives of Datasets (NDAN), 179
- Navarro, V., 238–9, 242
- Neuber, S. L., 209
- Newell, C., 9, 27, 247
- New York Times*, 152
- nonidentity problem, and prevention of genetically transmitted disease, 79–87. *See also* identity
- Non-Person-Affecting Harm Principle (NPA), 84–7, 89–90, 93, 98
- Nord, E., 9, 18, 40, 129, 130, 131, 133, 134, 250, 251, 253
- normality: dependence of opportunity on, 107–108; and standard view of quality of life, 105–106. *See also* biostatistical normality; functional status; species-typical health
- Norway, and resource allocation in health policy, 55
- Nosek, M., 117
- objectivity: and concepts of quality of life, 69; and measurement of health-related quality of life, 7–10; and standard view of quality of life, 108–10, 111–13
- opportunity: dependence of on normality, 107–108; and standard view of quality of life and disability, 105–106, 115–16
- Organization for Economic Co-operation and Development, 238
- Ottawa Charter (1986), 238
- Parens, E., 204, 211n1
- parents: and pluralism of preferences on prenatal testing and selective abortion, 142–69; preconception testing and strength of preferences of, 194–7; and social context of decisions on prenatal testing and selective abortion, 217–35; synecdoche and selectivity in concepts of parent-child relationship and decisions on prenatal testing, 172–211
- Parfit, D., 79, 83, 85, 145, 147, 162
- Parker, M., 234
- paternalism, and health-related quality of life assessments, 36, 40
- Patrick, D. L., 9
- Pearlman, R. A., 129
- Pembrey, M., 228
- perfectionism, and reasons for prenatal testing, 177, 178, 180, 181
- Person-Affecting Harm Prevention (PA), 83–7, 89–90
- personal asset, view of health as, 51–6
- person trade-off technique (PTO), and disability weights in DALYs, 133
- Peters, P. G., 84
- pharmaceutical industry, and quantitative measures of quality of life, 3
- phenylketonuria, 231, 232–3
- physician-assisted suicide, 2
- pluralism, and decisions on prevention of genetic disability, 161–6, 172–211
- Pogge, T., 37
- policy: and clinical uses of quality-of-life assessments, 27–41; and commodification of health, 43–64; increasing importance of quality of life, 2–5; interventions for people with disabilities and concept of health problems in, 12; and literature on well-being and quality of life, 15–16; “opt out” versus “opt in” on prenatal testing, 232; role of health, disability, and quality of life in assessments of population health and national health systems, 237–62; and standard view of disability and quality of life, 113–16. *See also* accessibility; cost-effectiveness; health care; reproductive health; resource allocation
- politics, and social context of decisions on genetic screening, 227–9. *See also* policy
- Pomerantz, D., 201
- population health: concepts of health, disability, and quality of life in assessments of national health systems and, 237–62; environment and assessments of disability and, 31
- Porter, A., 232
- Potler, C., 117
- preconception genetic testing: and selective abortion as means of preventing disability, 79, 150–1, 152, 153–4, 165–6; and strength of preferences against children with genetic impairments, 194–7
- preferences. *See* choices; parents
- prenatal testing. *See* genetic testing
- projectivism, and reasons for prenatal testing, 176–7
- prospective evaluation: and concept of health as personal asset, 53–4; and selective abortion as means of preventing genetic disability, 152–69

Index

- public asset, view of health as, 48–51
 Purdy, L., 180
- QALE (quality-adjusted life expectancy), 132
- QALYs (quality adjusted life years): and development of measurement instruments, 125–40; in discussions of health care rationing and prioritization, 113, 114–15; and relevance of disability to resource allocation in end-of-life treatment decisions, 95, 96
- quality-adjusted life expectancy. *See* QALE
- quality-adjusted life years. *See* QALYs
- quality of life: concepts of, and assessments of population health and national health systems, 237–62; concepts of, and development of instruments for measurement, 125–40; disability rights movement and bias in biomedical ethics, 101–22; health-related versus non-health-related concepts of, 22n3; increasing importance of in health care and public policy, 2–5; and literature on ethical and social issues in genetic testing, 15–16; prevention of genetically transmitted disabilities and objective measures of, 67–99; standpoints of patients and subjective assessments of, 62. *See also* health-related quality of life; measures and measurement; well-being
- radical model, of disability, 13
- Rapp, R., 218
- Rawls, J., 21, 208
- Raymer, G., 179
- Rehnquist, W. B., 61
- Renwick, B., 21n1
- reproductive health: autonomy and social context of decisions on prenatal testing, 217–35; concern about quality of life in decision making on, 3–5; genetic testing and prevention of genetically transmitted disabilities, 67–99, 142–69; pluralism in concepts of parenthood and family as factor in decisions on, 172–211
- resource, view of health as, 43–5
- resource allocation: and performance assessment of health systems, 249–50; and relevance of disability in end-of-life treatment decisions, 94–9
- retrospective evaluation: and concept of health as personal asset, 52–4; and selective abortion as means of preventing genetic disability, 152–69
- Revicki, D. A., 22n3
- Richardson, J., 250, 253
- Roan, S., 4
- Rock, M., 256
- Roe v. Wade* (1973), 3, 78
- Royal College of Physicians of London, 228
- Ruddick, S., 209
- Ruddick, W., 176–7, 203, 212–13n9
- Sackett, D. L., 73
- Safilos-Rothschild, C., 13
- Sagarin, E., 13
- Salmon, J. A., 39, 248
- Salomon, J. A., 135
- Same Number Choices, 145–8
- Sandel, M., 212n6
- satisfaction: coping and evaluation of quality of life in people with disabilities, 76; quality of life measurements and judgments of, 8
- Satz, D., 182
- SeeAbility (Seeing beyond Disability), 207
- selective abortion: concept of personhood and prevention of genetic disability, 77–9; nonidentity problem and prevention of genetic disability, 79–87; and pluralism in concepts of parenthood and family, 172–211; preferences and choices of parents in prevention of genetic disability, 142–69; and protection of autonomy in decisions about prenatal testing, 217–35
- self-determination: and concept of quality of life, 70; and right to refuse medical treatment, 72. *See also* autonomy
- Sen, A., 247
- Shakespeare, T., 19–20, 21, 222, 226
- sickle-cell anemia, 207–208, 231
- Silvers, A., 16–17, 21, 63, 72, 76, 91, 107
- Singer, P., 211, 221
- Smith, D. M., 209
- social justice: and reductions in quality of life, 116–17; and role of environment in concept of disability, 10, 12. *See also* justice
- social model, of disability, 13, 14, 101–103, 107–108, 109, 116, 119, 120, 121–2
- society: and autonomy of decisions on prenatal testing and pregnancy termination, 217–35; and prevention of genetically transmitted disabilities, 87–94

Index

- species-typical health, and justice in health policy, 49–51, 60. *See also* normality
- specific assessments, of health-related quality of life, 33–6
- Spilker, B., 3, 22n3
- spina bifida, 231
- standpoint, and variations in judgments of health and quality of life, 56–63. *See also* prospective assessments; retrospective assessments
- Stason, W. B., 130
- Statham, H., 233
- Steinberg, D. L., 226
- stereotyping, and prenatal genetic testing, 173–6, 189, 191–2
- Stewart, A., 129
- stigma, and prenatal genetic testing, 173–6, 179–80, 181, 182, 189, 190. *See also* labeling
- subjectivity: and concepts of quality of life, 69; and measurement of health-related quality of life, 7–10; and standard view of quality of life, 109, 111–13; and standpoints of patients in assessment of quality of life, 62
- summary health measure, and assessment of health-related quality of life, 30
- synecdoche, and prenatal testing for genetic disability, 172–211
- Tay-Sachs disease, 70, 76, 81, 89, 207–208, 220
- Tilton, M. C., 117
- Torrance, G. W., 73
- transparency problem, and quality-of-life assessments in health policy, 39–41
- trisomy 18, 207–208
- Ubel, P., 129, 131, 258
- Uhlmann, R. F., 129
- Umanski, L., 112
- Union of the Physically Impaired Against Segregation (UPIAS), 13
- United States, and *World Health Report*, 2000, 237
- U. S. Cost-effectiveness Panel, 135
- Universal Declaration of Human Rights, 129
- utilitarianism, and measures of health-related quality of life, 38, 39
- values: attachments as, 160–1; and definitions of quality of life, 137–9, 140; and pluralism in prospective and retrospective evaluations, 162–6; and transition from prospective to retrospective evaluation of selective abortion, 155–7; and transparency problem in health policy, 39–41. *See also* moral theory
- Vehmas, S., 221
- Wachbroit, R., 16, 20, 21
- Wald, N. J., 228
- Walker, S. R., 3
- Walters, J., 256
- Washington, A. E., 4
- Wasserman, D., 11, 19, 20, 205
- Watson, J., 220
- Weinberg, N., 129
- Weinstein, M. C., 130
- well-being: and concept of health as personal asset, 52–3; and concept of worth in health state scores, 125, 126–7, 128–30, 139; determination of impact of health on, 29–32; role of in quality of life measurement, 9–10. *See also* quality of life
- Wikler, D., 121
- Wilfond, B. S., 230
- Williams, A., 131–2, 246, 260
- Winter, R. M., 169n1
- Wolfson, M., 130
- World Bank, 238, 242
- World Health Organization (WHO): and assumptions about health, disability, and quality of life in *World Health Report*, 2000, 237–62; and classification of levels of functioning, 22n4; and definition of “handicap,” 118, 123n7; and definition of “health,” 5–6, 21–2n2, 38–9; and development of instruments to measure quality of life, 22n5; and quantitative methods of valuing health states, 136; and view of health as resource, 43
- World Health Report*, 2000 (WHO), 237–62
- worth, and concept of well-being in health state scores, 125, 126, 128–30, 139
- Wright, B., 13
- wrongful life: and intrusions on reproductive freedom, 92; and nonidentity problem, 80–2, 84–5. *See also* Lesch Nyhan syndrome