

# INDEX

- Ableism, 4–5, 8–9, 14, 73–74, 92  
Ableist perspectives, 79  
Academic research organisations, 81  
Accessibility, 3, 18, 38  
Accommodations, 55  
Accord, 22  
Administrative and procedural issues, 126–127  
Administrative data, 37–39  
    concerns, 39–40  
*Advances in Disability Research Ethics*, 1, 7–10  
Ageism, 5  
2030 Agenda for Sustainable Development, 34, 41  
Allies, 93  
    consent, 97–98  
    findings, 98–104  
    implications of research findings, 105–106  
    inaugural dialogues and retreat, 94–95  
    intersectionality, 95–96  
    lived experience and allies at intersections, 104–105  
    methods, 96–97  
    positionality, 93–94  
    recommendations, 106–108  
Allyship, 95–96  
    allyship-as-action, 95–96  
    system, 9  
Ambition of human rights-based research, 9  
Anti-Discrimination Act (1991), 89  
Artificial intelligence (AI), 43  
Asian and Pacific Islander, 97  
Assistive technologies, 19  
At-risk population, 56  
Australian National Health and Medical Research Council, 24  
Australian National Statement on Ethical Conduct in Human Research (ANSECHR), 23–24  
Australian National Statement on Human Research, 16  
Australian National Statement on Research Ethics, 15  
Australian reform model of deep listening, 31  
Australian Research Council and Universities Australia, 24  
Awareness raising, 3  
Beneficence principle, 4  
Benefit-sharing, 142  
Big data, 43–44  
Biopsychosocial model, 53  
Black, Indigenous, and People of Color (BIPOC), 9, 93, 97  
Black people, 92  
Canadian Human Rights Commission (CHRC), 46n4  
Censuses, 36, 60–61  
Centre for Disability Research and Policy (CDRP), 83

- Child Functioning Module, 59, 65
- Co-design, 116
- Co-produced research, 78
- Co-production, 115
  - in disability research, 115–118
- Co-Researcher Collective, 116
- Cognition, 61–62
- Collective rights, 44
- Committee on Publication Ethics (COPE), 152
- Committee on the Rights of Persons with Disabilities, 42
- Committees, 76
- Communicating evidence for impact (CEFI), 9, 140
  - core research competency and ethical requirement, 145–146
  - grounded in culture of inclusion, intersectionality and allyship, 147–149
  - legal and moral imperative, 143–144
  - participatory process, 146–147
  - propositions, 141–149
  - public good, 141–143
- Communication, 61–62, 139
- Community-based data collection, 40
- Comprehensiveness, 38
- Confidentiality, 18
  - and safety of participants, 126
- Consent, 4, 97–98
- Consumers Health Forum of Australia (2020), 76
- Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), 140
- Convention on the Elimination of Racial Discrimination (CERD), 140
- Convention on the Rights of the Child (CRC), 140
- Coresearchers, 27
- COVID-19 pandemic, 65, 160
  - impact of Covid on data collections, 65
- Criminal justice, 95
  - experiences with criminal justice systems, 99–100
  - involvement, 100–103
- Crisis Helping Out On The Streets model (CAHOOTS model), 107
- Culturally And Linguistically Diverse (CALD), 29
- Culturally and Linguistically Diverse communities (CALD communities), 27
- Cut points, 58–59
- Data, 34
  - collection, 50
  - collection tools to support monitoring, 60–61
  - disaggregation, 37
  - framework for data protection, 43
- Deaf community, 28
- Declaration on Human Rights, 6
- Definitions, 50
  - in research, 50–51
- Demographic and health surveys, 36
- Dignity of risk, 77
- Disability, 8, 19, 21, 25, 34, 45–46, 51, 54, 92
  - approaches to defining population with disabilities, 53–57
  - assessments, 38
  - awareness training, 143
  - case of, 51–52
  - as continuum, 58–65
  - data, 60
  - data sources, 36–40
  - difficulties in functioning, 56–57
  - disability-specific surveys, 37
  - ethical and legal issues in data collection, 40–45
  - gap, 50, 65–66

- harmonisation, 66–67
- limitations in participation, 54–56
- need to identify population with, 52–53
- research, 50, 115–118, 139
- vulnerability, 74–75
- Disability Discrimination Act 1992, 81
- Disability Persons Organisations (DPOs), 144
- Disability research ethics, 1, 30
  - in times of crisis, 164–166
- Disability Research on Independent Living and Learning (DRILL), 114–115
  - administrative and procedural issues, 126–127
  - confidentiality and safety of participants, 126
  - Ethics Committee, 119–121
  - evaluation of DRILL Ethics Committee, 122
  - key interactions between ethics committee and research projects, 122–123
  - negotiation of informed consent, 124–126
  - Programme, 119–121
- Disability Rights Movement (DRM), 6
- Disabled individuals, 20
- Disabled people, 15, 118, 139
- Disabled Persons Organisations (DPOs), 120, 127, 142
- Disaggregation, 37, 54–55, 61
- Dissemination, 140
- Distributive fairness, 142–143
- Division for Inclusive Social Development (DISD), 144
- Easy Read materials, 125
- Easy read participant consent, 132–135
- Education, 37, 56
- Education Management Information System in Fiji, 38
- Educators, 151
- Emancipatory research
  - benefits of, 79–80
  - challenges, 78–79
  - ethical shift, 77–78
- Employment, 56
- Environmental accommodations and supports, 56
- Equality, 3, 82
- Ethical and legal issues in data collection, 40
  - big data, 43–44
  - framework for data protection, 43
  - indicators and data collection, 41
  - participation and community-based data collection, 40
  - principles for collection and use of indigenous data, 44–45
  - privacy and data collection, 41–43
  - right to access information and data, 44
- Ethical decision making, 76
- Ethical leadership, 30
- Ethics, 75
  - generic application of, 6–7
  - negotiations, 127
  - review processes, 114
- Ethics committee, 114
  - co-production in disability research, 115–118
  - ethics process in social research, 118–123
- Ethics process in social research, 118
  - Drill Programme and Drill Ethics Committee, 119–121
- Evaluation, 39
- Exclusionary practices, 25
- Expertise, 79
- Face-to-face meetings, 127
- Facilitators, 26
- Fairness-in-exchange approach, 142
- Fear, 101–102

- First People, 27  
 Focus group/conversation guides, 111–112  
 Four Nations' projects, 120  
 Functional domains, 57  
 Fundamental freedoms, 18  
 Funders, 151–152  
  
 Generic approach, 5  
     in research ethics, 163–166  
 Generic principles, 19–20  
 Generic research ethics, 14  
 Global Activity Limitation Indicator (GALI), 36, 55  
 Global Alliance of National Human Rights Institutions Home (GANHRI), 144  
 Good practice in ethics review, 115  
  
 Harm, 101  
 Harmonisation, 66–67  
 Hearing, 61  
 Helsinki principles, 5  
 Heterosexism, 5  
 Household income and expenditure surveys, 36  
 Household surveys, 36  
 Human rights, 18, 92  
     and equality-based research ethics, 18  
     human rights-based research, 138  
     limits of generic in, 5–6  
     revising and expanding core principles, 18  
     statistics and data collection, 18–20  
 Hybrid matrices, 98  
  
 Inaugural Dialogues and Retreat, 94–95  
 Inclusion, 18, 39, 41, 77  
 Inclusion of people with disabilities in research, 24–26  
 Inclusive language, 27–28  
  
 Inclusive research  
     lived experience narratives, 82–84  
     recruit and advance careers  
         of researchers with disability, 82  
     roadmap to, 80  
     systemwide understanding of vulnerability, disability, and accessibility, 81  
     timely accommodations and adjustments for researchers with disability, 82  
     zero tolerance for ableism, 81  
 Indicators and data collection, 41  
 Indigenous data, principles for collection and use of, 44–45  
 Indigenous Peoples, 44  
 Indigenous/Native American, 97  
 Infodemic, 138  
 Informed consent, 76  
 Inherent vulnerability, 75  
 Institutional Review Board (IRB), 96  
 Integrated ethics, 6  
 International Classification of Functioning (ICF), 19, 73  
 International Labour Organisation, 66  
 Intersection of Injustice, Disability, and Human Rights, 93  
 Intersectional ethics, 6  
 Intersectionality, 29–30, 59, 80, 92, 95–96  
 Irish Disabled Persons Organisations (DPOs), 10  
  
 Justice, 103–104  
  
 Labour force surveys, 36–37  
 Latino/Latina/Latinx/Hispanic, 97  
 Legal obligations, 40  
 LGBTQI communities, 27  
 Lived experience, 72, 79–80  
     narratives, 82  
     negative experiences in academy and key learnings, 83–84

- safe environment, 83
- stop disrespecting and start
  - investing in lived experience researchers, 83
- Living Life to the Fullest, 116
- Measurements, 51
- Medicaid, 93
- Medical examinations, 38
- Mental health, 92
  - experiences with, 99–100
  - system involvement, 100–103
- Meso-environment, 66
- Micro-environment, 66
- Migrants, 27
- Mixed Race, 97
- Model Disability Survey (MDS), 35
- Monitoring, 34, 39
- National Disability Insurance Scheme (NDIS), 29–30
- National Health and Medical Research Council, 75
- National Lottery Community Fund, 119
- Negative experiences in academy and key learnings, 83–84
- Negative feelings, 101–102
- Negotiation of informed consent, 124–126
- Network of Dementia Voices (DEEP)*, 116
- Neurodiverse people, 28
- New Human Rights laws, 6
- Non-ableist research ethics, 5
- Non-discrimination, 3
- Office of the United Nations High Commissioner for Human Rights (OHCHR), 41
- Online accessibility standards, 29
- Organisations of People with Disabilities (OPDs), 8, 45
- Participation, 3, 20, 40
- Participatory research, 116
- Peer research, 116
- Personal data, 46*n*9
  - protection, 41
- Persons with disabilities, 51–52, 58
- Physical accessibility, 29
- Police, 102–103
  - experiences with, 99–100
  - interactions, 102
  - involvement, 100–103
- Policing, 92
  - experiencing multiple forms of, 100
- Policy makers, 59
- Population with disabilities, 56
  - approaches to defining, 53–57
- Population-based data, 42
- Populations, 56
- Positionality, 93–94
- Positivist medical model, 118
- Post-World War II world, 5
- Practitioners, 151
- Privacy, 18, 20
  - and data collection, 41–43
  - requirements, 42
- Process indicators, 41
- Promise of Assistive Technology to Enhance Activity and Work Participation, The*, 19
- PROMoting integrity in the use of RESEARCH results project (PRO-RES project), 15–17, 30
  - formal Agreement, 22
  - revising and expanding PRO-RES toolkit, 22–23, 25
- PT Kereta Api Indonesia, 43
- Public good, 141–143
- Public transportation, 37
- Publishers, 152–153
- ‘Quality’ in disability research, 14
- Questions, 57

- Race/ethnicity, 92
- Racism, 5–6, 94
- Recruitment, 96–97
  - strategies, 25
- Reference groups, 27
- Refugees/asylum seekers, 27
- Reliability, 38
- Research, 72
  - definitions in, 50–51
  - ethics, 119
  - participation, 24–25
- Research Ethics Committees (RECs), 9, 150
- Researchers, 151–152
  - with disability, 89–90
- Respect, 18–20
- Respect principle, 4
- Right to access information and data, 44
- Right to privacy, 41, 46*n*7
- Rights, 103–104
  
- Sample surveys, 61
- Sampling, 96–97
- Scientific, Trustworthy, and Ethical evidence for Policy (STEP), 22
- Scientific knowledge, 25
- Sector-specific surveys, 36
- Seeing, 61
- Self-care, 61
- Self-identification, 56
- Sense-making, 102
- Sexism, 5–6
- Situational vulnerability, 75
- Social action, 107
- Social model, 53
- Social protection, 37
- Social research, 115
- States Parties, 18, 53
  - to CRPD, 149–150
- Statistical confidentiality, 42, 46*n*11
- ‘STEP ACCORD’, 16–17
- Stewardship, 20–21
  
- Structural indicators, 41
- Structural racism, 94
- Surveys, 36–37
- Surviving Race, 93–94, 106
- Sustainable Development Goals (SDG), 35, 52
- Sustained interactivity model, 143
- Systems-level oppression, 100
  
- Transparency, 50
  
- UK General Data Protection Regulation, 124
- UN Declaration, 5
- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 1–2, 7, 14, 34, 72, 89, 93, 115, 159–161
  - accommodations, 28–30
  - ANSECHR, 23–24
  - Australian National Statement on Human Research, 16
  - characteristics, 3–4
  - cross-cutting principles and practices, 3
  - design and conduct of research, 26–28
  - guiding principles, 2–3
  - human rights and equality-based research ethics, 18–20
  - implications for ethical disability research practice, 161–163
  - inclusion of people with disabilities in research, 24–26
  - intersectionality, 29–30
  - online accessibility standards, 29
  - outputs, 29
  - physical accessibility, 29
  - PRO-RES formal Agreement, 22
  - PRO-RES project, 15–17
  - revising and expanding PRO-RES toolkit, 22–23

- significance of omissions, 30
- stewardship, 20–21
- themes, 30–31
- United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), 140
- United Nations International Children’s Emergency Fund (UNICEF), 37
- Universities, 73
- Vedic principles, 15
- Voice of the disability movement, 31
- Voices of disabled people, 7
- Vulnerability, 20, 25, 72
  - ableist conceptualisations of, 142
  - intersectionality, 80
  - narrative surrounding research participants and researchers with disabilities, 75–76
  - as positive, 76–77
  - roadmap to inclusive research, 80–84
  - shifting research paradigms, 77–80
  - traditional constructions, 74–75
- Walking, 61
- Washington City Group on Disability Statistics (WG), 35, 37
- Washington Group Extended Set, 63–64
- Washington Group on Disability Statistics, 50
- Washington Group Short Set, 60–63
- Washington Group/UNICEF Module on Child Functioning, 64–65
- WCAG2, 23, 29
- White Allies, 93
- World Bank Guidebook for Designing Household Survey Questionnaires, 36–37
- Young people, 27
- Zero tolerance
  - for ableism, 81
  - approach, 9