

# Contents

Foreword 1 .....	13
Foreword 2 .....	15

## Part 1 Children's needs and human rights

1. Change agents – improving the situation of children with disabilities . . . . .	19
<i>Siv Elin Nord Sæbjørnsen, Mariana Josephat Makuu, and Atle Ødegård</i>	
Aims of this book. . . . .	20
The NOREC project – Children with disabilities & UN rights conventions . . . . .	20
Children with disabilities in Tanzania . . . . .	22
Children with disabilities in Norway . . . . .	24
Needs of children with disabilities . . . . .	25
The need for interprofessional collaboration. . . . .	26
The chapters . . . . .	27
References. . . . .	31
2. Children's basic needs: How do we create resilience in children, so they can thrive and sustain positive development? . . . . .	33
<i>Klara Øverland and Heidi Elisabeth Nag</i>	
Children's situation in the world and contextual challenges – how to create a healthy upbringing . . . . .	33
Method . . . . .	34
The importance of good mental health and life management. . . . .	35
Focus on children's human rights and sustainable life conditions . . . . .	37
Attachment and development . . . . .	37
Brain development and stress in children requires a “serve and return” relationship. . . . .	39
Risk factors can have a negative impact on children's health . . . . .	40
Child abuse and toxic stress . . . . .	40
Protective factors and resilience in children's lives . . . . .	42
How to strengthen core skills and build a resistant and supportive community . . . . .	42
The importance of cooperation and system work to protect children and create a thriving community . . . . .	43
How can children who experience toxic stress and trauma be helped? . . . . .	44
Depression and anxiety in children . . . . .	47
Children who are in need of special services and help, due to physical and developmental problems. . . . .	47

How can supportive relations be helpful for children and adults? . . . . .	48
Play and art are important for children and adults . . . . .	49
Education is important for creating resilience in children . . . . .	49
Summary . . . . .	50
References . . . . .	51
<b>3. Social work with children and human rights . . . . .</b>	<b>55</b>
<i>Jonathan Parker and Sara Ashencaen Crabtree</i>	
Introduction . . . . .	55
Social work and children: A chequered development . . . . .	56
The Second World War and the development of human rights . . . . .	58
Human rights and childcare social work . . . . .	59
Child soldiers . . . . .	60
Child brides . . . . .	63
Child exploitation . . . . .	67
The rise of the populist right – against young criminals, support for young people . . . . .	68
The turn to protection/safeguarding and isomorphic convergence . . . . .	70
Conclusions . . . . .	72
References . . . . .	73
<b>4. The rights to primary education for children with intellectual disabilities in Tanzania . . . . .</b>	<b>76</b>
<i>Mariana Josephat Makuu, Naftali Ng'ondi, and Siv Elin Nord Sæbjørnsen</i>	
Introduction . . . . .	76
Aims of the study . . . . .	78
Methodology . . . . .	79
Results and discussion . . . . .	80
Implementation of the international and regional guidelines in Tanzania . . . . .	80
Tanzania's national policy guidelines . . . . .	83
Inclusive education in Tanzania . . . . .	83
Special schools in Tanzania . . . . .	84
Teachers, teaching, and learning materials . . . . .	86
Supporting children with intellectual disabilities . . . . .	86
Limitations of the study . . . . .	88
Conclusion . . . . .	88
Implications for practice and research . . . . .	88
For the Ministry of Education, Science, and Technology . . . . .	88
For local government authorities . . . . .	89
For researchers . . . . .	89
References . . . . .	89

<b>5. Special healthcare needs of children with disabilities in Tanzania: Challenges and recommendations.</b> . . . . .	94
<i>Deodatus Kakoko, Emmanuel Kigadye, and Sarah Hean</i>	
Introduction . . . . .	94
Challenges to access . . . . .	95
Lack of resources. . . . .	95
Poor communication between health services and caregivers . . . . .	95
Lack of specialized centres. . . . .	96
Cultural discrimination . . . . .	96
Lack of knowledge on how to deal with the child in the family. . . . .	96
Lack of knowledge in primary care professionals . . . . .	97
Lack of data and research . . . . .	97
Lack of political will . . . . .	98
Recommendations. . . . .	98
Better identification of children with special health care needs. . . . .	98
Alleviating the financial burden of disability . . . . .	100
Improved communication and coordination of health information. . . . .	100
Increasing specialized services and upskilling of primary care professionals and caregivers . . . . .	101
Prioritizing research and national data sets . . . . .	102
Conclusion . . . . .	102
References. . . . .	102

## **Part 2 Theoretical perspectives and research approaches**

<b>6. Disability as a socially-relational process – and so what?</b> . . . . .	109
<i>Hans Petter Iversen, Guro Fiskergård Werner, and Siv Elin Nord Sæbjørnsen</i>	
Introduction . . . . .	109
Methodology and methods . . . . .	110
Perspectives on disability . . . . .	111
The medical model/disease model . . . . .	111
The social model. . . . .	111
The relational model – the GAP model. . . . .	112
Theoretical approach. . . . .	113
A socially-relational model – disability as socially-relational processes. . . . .	113
Communication and recognition. . . . .	113
Power and powerlessness. . . . .	114
Professions and collaboration. . . . .	116
Function, functioning, and functionalism – or was it enabling and emancipation? . . . . .	117
A short theoretical detour: Contradictions as paradoxical practices. . . . .	119
Discussion. . . . .	120
Topic 1: Simultaneous enabling and restriction – and so what? . . . . .	120

Topic 2: Power: Inclusion and exclusion – and so what? . . . . .	121
Topic 3: The importance of recognition – and so what? . . . . .	123
Topic 4: Professions and collaboration: Interprofessionalism – and so what? . . . . .	125
Conclusions . . . . .	126
Disability and/or enabling are relational phenomena . . . . .	126
Disability and/or enabling are communication phenomena . . . . .	126
Disability and/or enabling are recognition phenomena . . . . .	126
Disability and/or enabling is the phenomenon of power and powerlessness . . . . .	127
Disability and/or enabling are collaborative phenomena . . . . .	127
References . . . . .	127
<b>7. The relations between Tanzanian cultural practices and understanding of the terms respect and human rights . . . . .</b>	<b>131</b>
<i>Inger Helen Solheim and Mariana Josephat Makuu</i>	
Introduction . . . . .	131
The study . . . . .	132
Theoretical framework and cultural findings . . . . .	133
Collectivistic cultures, values, and norms . . . . .	133
The Cultural Dimensions Theory and Tanzania . . . . .	134
Student responses and how to understand and interpret them . . . . .	136
Conclusion . . . . .	141
References . . . . .	142
<b>8. Challenges associated with the importation of minority world constructions into majority world settings . . . . .</b>	<b>144</b>
<i>Sandra Marie Weltzien</i>	
Introduction – The WEIRD problem . . . . .	144
The invisibility of research on disability in the majority world . . . . .	146
The vital role of culture . . . . .	147
The issue of self-construal orientation . . . . .	149
A way out of WEIRDness? . . . . .	151
1. Hearing the locals . . . . .	151
2. Gaining cultural knowledge . . . . .	152
3. Awareness of ethical challenges . . . . .	153
Conclusion . . . . .	154
References . . . . .	155
<b>9. Interprofessional collaboration and research networking in Global North–Global South Partnerships . . . . .</b>	<b>159</b>
<i>Sarah Hean</i>	
Introduction: The problem and need for social innovation in organizations working with children with disability . . . . .	159

Being socially innovative for children with disability . . . . .	159
The NOREC project as a permutation of cocreators . . . . .	160
Drawing on the experiences of other heterogenous consortia . . . . .	161
Distributed responsibility . . . . .	162
Benefits of cross-sector international consortia . . . . .	164
Optimal functioning of a consortium of Tanzanian and Norwegian partners. . . . .	165
Unequal status in Tanzanian–Norwegian collaborations . . . . .	166
A decolonization analysis: The North-South Divide . . . . .	168
Coloniality of knowledge . . . . .	169
Coloniality of power . . . . .	169
Coloniality of being . . . . .	171
Ways forward and recommendations . . . . .	171
Consideration of the disparities in number and size of participating institutions . . . . .	171
Improving awareness of national and institutional priorities and constraints . . . . .	171
Improving awareness of key competences/interests within the consortium . . . . .	172
Encouraging Afro European reciprocity and making explicit the mutual benefit to both national states, organizations, and individuals. . . . .	173
Creating a safe space for consortium activity . . . . .	173
Ongoing evaluation/reflections on the consortium and its social innovation processes . . . . .	173
References. . . . .	177
<b>10. Involving service users with intellectual disabilities in research . . . . .</b>	<b>179</b>
<i>May Østby and Hege Bakken</i>	
Introduction . . . . .	179
Inclusive research – nothing about us without us . . . . .	181
Principles for inclusive research . . . . .	182
Why include persons with ID in research? . . . . .	183
Democracy and equality . . . . .	183
Relevance and usefulness. . . . .	184
Finances and politics . . . . .	184
Added values . . . . .	184
Scepticism – important reflections. . . . .	184
Inclusive research and CRPD. . . . .	185
The right to full and effective participation. . . . .	186
Equality in opportunity . . . . .	186
Success and challenges in inclusive research – what to be aware of . . . . .	186
Time . . . . .	187
Knowledge . . . . .	187
Power dynamics . . . . .	187

Contributions .....	188
Tokenism .....	188
Accessibility .....	188
The relationship .....	189
Summary .....	189
References .....	190

**Part 3 Implications for education and practice**

**11. The professional helper – a presentation of a reflection model developed in Norway .....** 195

*Ole David Brask, May Østby, and Atle Ødegård*

Introduction .....	195
Case .....	196
Reflection .....	197
Reflection – the most important thing? .....	197
Different types of reflection .....	198
Reflection on one’s own role .....	200
The core role model .....	200
The role of partner .....	203
The directive role .....	203
The role of bridge-builder .....	203
The role of driver .....	204
Case analysis .....	204
The knowledge base .....	205
The helping relationship .....	206
The family and the network .....	206
Discussion: Grounding of the core role model .....	207
Grounding in human rights .....	207
Grounding in culture .....	209
Grounding in living conditions .....	211
Final remarks .....	213
References .....	214

**12. A mind for citizenship – on the value of the inclusion of persons with severe disabilities .....** 217

*Roar Stokken and Torhild Lillemark Høydalsvik*

Introduction .....	217
Analytical framework .....	218
Method .....	220
The “eye-language” in the mediating triangle .....	221
The development of new means .....	223

How voicing herself changes her as subject . . . . .	224
The rules demanding normality . . . . .	227
“It just turned out this way” . . . . .	228
“You are not allowed to feel sorry for Edny” . . . . .	229
Risk is a part of life . . . . .	230
The reciprocal division of labour . . . . .	231
Edny, her communities, and her activities . . . . .	233
Coda . . . . .	236
References . . . . .	237
<b>13. “I cannot do it alone”: Teachers as change agents for inclusive education . . . . .</b>	<b>239</b>
<i>Vibeke Vågnes, Kari Ludvigsen, and Cosmas Mnyanyi</i>	
Introduction . . . . .	239
Background . . . . .	240
Relevant research and theory . . . . .	241
Methods . . . . .	244
Findings according to the schools and teachers . . . . .	245
School A and teacher George . . . . .	246
School B and teacher Ruth . . . . .	248
School C and teacher Angel . . . . .	251
Discussion . . . . .	253
How the teachers experience the possibilities for change . . . . .	254
The challenges facing the teachers as change agents . . . . .	255
Time . . . . .	255
Teacher competencies and the professional culture . . . . .	256
Local community, parent, and government support . . . . .	257
Material context . . . . .	257
Conclusion . . . . .	258
References . . . . .	259
<b>14. Improving learning for children with intellectual disabilities with a focus on visual functioning . . . . .</b>	<b>262</b>
<i>Gunvor Birkeland Wilhelmsen, Marion Felder, and Jacqueline Massawe</i>	
Introduction . . . . .	262
Theoretical background . . . . .	263
Vision problems connected to intellectual disabilities . . . . .	264
Stimulating vision . . . . .	265
The assessment and intervention process – Baraka . . . . .	267
Ethics . . . . .	268
Assessment – methods and materials . . . . .	268

Accommodation and convergence.....	269
Assessment results .....	270
Intervention – methods and materials.....	272
Results intervention .....	273
Discussion.....	275
It is crucial to understand vision challenges.....	277
Conclusion .....	278
References.....	278
<b>Authors.....</b>	<b>283</b>