TABLE OF CONTENTS

Section 1: The development of community living: Trajectories and turning points 15

1.1 Introduction to the book and to the development of community living (*Jan Šiška and Julie Beadle-Brown*) 17
Overview of the book and its aims 17
A note on terminology 19
Documenting trajectories and turning points towards community living 20
Quality 22
Making system change 24
Introduction to Section 1: The current situation for people with disabilities 24
What do we know in terms of the current situation of people with disabilities and the implementation of the UN Convention? 26
Outline of this section 28
References 30

1.2 Deinstitutionalisation and community living: The past, the present and the future (*Julie Beadle-Brown, Milan Šveřepa, Jan Šiška with contributions from the late Jim Mansell*) 33
Interview with Jim Mansell 34
Interview with Milan Šveřepa 38

1.3 25 years after deinstitutionalisation – current status of community living in Norway (*Jan Tøssebro*) 47
Introduction 47
Background 48
Arguments – the critique of institutional care 48
The second phase of deinstitutionalisation – full dissolution 50
Experiences during the reform years 52
Much improved housing conditions/living arrangements 53
Family: From opposition to support 53
More self-determination in everyday matters 54
The revolution that "disappeared" 54
Beyond the reform years 54
Understanding the long-term outcomes 56
Concluding remarks 60
References 60

1.4 The current situation regarding personal assistance and independent living in Sweden (*Johanna Gustafsson*) 63
Introduction 63

Personal assistance and assistance allowance 64
Self-determination – an important principle 65
Financing and the cost of personal assistance 66
Personal assistance workers 67
Use of personal assistance and assistance allowance 68
Hours of assistance 69
The meaning of personal assistance 70
References 72

1.5 Ireland's journey to a person-centred approach to disability support services (*Christine Linehan*) 77
Introduction 77
Historical context 78
Developments in Irish disability legislation 79
Developments in Irish disability policy 81
Developing standards 86
Implementation and monitoring 88
Conclusion 90
References 90

1.6 From hospitalisation to (de-?) institutionalisation: The challenges of implementing Art. 19 in Austria (*Gertraud Kremsner*) 95
A (very) brief history of institutionalisation 95
The current status quo: Challenges in implementing Article 19 of the UN-CRPD 98
Conclusion (and limitations) 99
References 100

1.7 Independent living and community inclusion in Brazil (*Flavia H. Santos, Luciana M. Fonseca, Eder R. Silva*) 103
Contextualizing disabilities in Brazil 103
Ratification of the Convention on the Rights of Persons with Disabilities in Brazil 105
The importance of self-advocacy 108
Policies on deinstitutionalization 111
Inclusion in the education system 113
Inclusion in the workforce 115
Final considerations 116
Conclusion 117
Acknowledgements 118
References 118

1.8 Towards community-based disability support services in Czechia: Nearly there? (*Jan Šiška and Pavel Čáslava*) 123
Introduction 123
Quality of social services and direct payments 127
Deinstitutionalisation 129
Summary 131
References 132

Section 2: Defining, measuring and ensuring high quality services 135

2.1 Definitions of quality and the importance of measuring and focusing on service quality (*Jan Šiška and Julie Beadle-Brown*) 137
Introduction to defining, delivering and measuring high quality of life 138
Structural and process factors 141
References 145

2.2 Ensuring quality – the living conditions approach in Scandinavia (*Jan Tøssebro*) 149
Introduction 149
Why was a living conditions approach chosen? 150
What about the alternatives? 151
On the living conditions approach 153
Adaptation to the life circumstances of intellectually disabled people 155
Current status 156
References 157

2.3 Active Citizenship as a measure of outcomes and the quality of social services (*Šárka Káňová, Jan Šiška and Julie Beadle Brown*) 159
Introduction 159
Citizenship and disability 162
Researching active citizenship through community living and participation 164
Living situation 166
Choice over living situation 166
Support for living in the community 167
Participating in the community – social relationships and social inclusion 168
Conclusion 169
References 170

2.4 Ensuring quality in practice – person-centred approaches (Jill Bradshaw) 173
Introduction 173
Person-centred approaches 174
What does person-centred mean? 174

What are the different elements of a person-centred system? 175
Person-centred planning 175
What do we know about the impact of person-centred planning on outcomes? . 176
Person-centred action 176
Person-centred active support 178
Why is active support important? 178
What does person-centred active support look like? 179
Is active support useful outside of settings supporting people with intellectual disability? 180
Is person-centred active support effective? 181
Positive behaviour support 182
Why is positive behaviour support important? 182
What does positive behaviour support look like? 183
Is PBS useful outside an intellectual disability setting? 184
Is PBS effective? 184
The SPELL Framework 184
Why is the SPELL Framework important? 185
What does the SPELL Framework look like? 185
Is SPELL Framework useful for people other than those who are autistic?... 187
Is the SPELL Framework effective? 188
Support for communication 188
Why is support for communication important? 188
What does good support for communication look like? 189
Is support for communication relevant to those who do not have intellectual or developmental disabilities? 190
Is good support for communication effective? 190
Conclusions and implications 190
References 191

2.5 Promoting independence and safety with medication technology for people with disabilities (*Alaina Gallagher, Seunghee Lee, James Houseworth, and Betul Cakir-Dilek*) 197
Introduction 197
Issues in Medication Management 198
Use of Technology to Support Medication Adherence 199
Case Study 200
Dose Health 202
Conclusion 203
References 203

2.6 Personal assistance as a support for the quality of life of people with disabilities (*Magdalena Hanková, Soňa Kalenda and Julie Beadle-Brown*).... 205
Introduction 205

Personal assistance in the Czech Republic 206
Participants and data collection methods 208
Findings of the study 208
Conclusion 214
References 216

Section 3: Making change at the systems level – what is needed for successful implementation of the UN-CRPD 221

3.1 Section 3 Overview: Introduction to system wide change *(Julie Beadle-Brown and Jan Šiška)* 223
References 233

3.2 Balancing the rights of respect for autonomy and protection from harm: Lessons from the Mental Capacity Act 2005 (England and Wales) *(Camilla Parker)* 239
Mental Capacity Act 2005: Overview 241
Recognition of the right to decide: Challenging assumptions 243
Supporting the person's decision-making 244
Respecting the person's views 246
Conclusion 248
References 248
Cases 249

3.3 Definitions of and barriers to high-quality services and support, particularly in the context of independent living in Sweden *(Johanna Gustafsson)* 251
Introduction 251
Quality in personal assistance 252
Performing personal assistance 254
Assignments for personal assistants 257
Good living conditions – an outcome of personal assistance 258
Accessibility, a holistic viewpoint and continuity of personal assistance 259
Influence, participation and self-determination in personal assistance 260
Are the intentions of personal assistance fulfilled today? 264
References 265

3.4 Exploring the intellectual disability data landscape for policy and service directions: An Irish perspective *(Mary-Ann O'Donovan, Sarah Craig, Philip McCallion, Mary McCarron and Elaine Byrne)* 269
Introduction 269
Definitions and demarcation 270
Case study: Ireland 271

NÁRODNÍ LÉKAŘSKÁ KNIHOVNA V PRAZE

Disaggregating data 274
Q1. Is the broad category of intellectual, interpersonal and learning disability a good predictor of service use and need? 274
Demographic profile 275
Health profile 276
Help with everyday activities and activities of daily living 276
Use and need for services 277
Considering co-morbidity in data 279
Q2: does having multiple disabilities result in differing service use and need? 280
Q3: does survey and administrative serve to contradict or complement the evidence base for service providers? 280
NIDD 2006 compared with NIDD registrations as per NDS 2006 280
Health service access 283
Discussion 285
Conclusion 287
References 288

3.5 Measuring outcomes of people with disabilities in the US: Current challenges and opportunities
(Renáta Tichá, and Brian Abery) 291
Introduction 291
Long-Term Services and Supports (LTSS) and Home and Community Based Services (HCBS) 292
National Quality Forum (NQF) measurement framework 294
Purposes of outcome measurement 295
Compliance with HCBS policies and quality improvement 297
Quality of service delivery 298
Measuring outcomes of people with disabilities 299
Importance of person-centered measurement 300
Improving measurement quality: The Research and Training Center on HCBS Outcome Measurement 302
Challenges of HCBS outcome measurement 305
State and Federal Level: Compliance and Quality Improvement 305
Provider agency/managed care organization level: Quality of service delivery ... 306
Individual level: Personal outcomes 307
Future directions: opportunities to improve HCBS outcome measurement 307
State and federal level: Compliance and quality improvement 307
Provider agency/managed care organization level: Quality of service delivery ... 308
Individual level: Personal outcomes 309
Conclusion 309
References 310

3.6 The role of local planning in the implementation of the UNCPRD
(Johannes Schädler and Lars Wissenbach) 313
Introduction 313
Implementation of the UN-CRPD and local public planning 315
Local planning and local path dependencies 318
Local planning as a cross-level and cross sectoral approach 319
Local planning as intervention and collective learning processes 321
Local planning as a "looping" approach 323
Conclusion 326
References 327

Index 329
Authors' biographies 331