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Enability

**Enabling Inclusive Quality of Life
in Young People with Multiple Disabilities
and Complex and Intense Support Needs:
Concepts and Good Practices**

**With contributions
from 70 professionals
and parents**

In 2013 we created a European project "Enablin+" to develop an innovative interprofessional in-service training programme, to improve inclusion and quality of life for children with the most complex disabilities, who are in need of intensive and continuous support.

The name *ENABLIN +* has three aspects. "Enabling" is the opposite of disability; it means to enable the person to function; the IN stands for "inclusion"; and the "+" stands for "multiple disabilities" or "extraordinary multiple needs", in learning, communicating, mobility, often also in eating and other aspects of self-care or behavioural challenges..

This book contains the most important results of the project. A first part is about research on needs assessment and quality of life. A second part gives an overview of continuous support systems in the partners' countries. Then a new interprofessional training programme is outlined. A fourth part describes various projects of "good practice" and results of pilot projects in inclusive education, enhancing activity and participation in various life areas, communication and integrated support.

This book is aimed at those who are responsible for training the various professionals working in the field of children and youngsters with complex and intensive support needs – educators, auxiliaries, teachers, therapists, doctors, etc., as well as volunteers and parents.

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Enabling & Including Young People
with Complex & Intense Support Needs



Lifelong Learning Programme

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Contents

Purpose and outline of this book	11
Principles and goals of the Enablin+ project <i>Jo Lebeer</i>	15
PART I	
Who are they? Assessing support needs and quality of life	23
CHAPTER 1	
A history of the care of the “forgotten”: multiple disabilities ... The challenge of learning <i>Elisabeth Zucman</i>	25
CHAPTER 2	
Quality of life and supports paradigm <i>Claudia Claes</i>	43
CHAPTER 3	
How to evaluate quality of life <i>Katja Petry, Bea Maes, Carla Vlaskamp</i>	51
CHAPTER 4	
The ICF (International Classification of Functioning, Disability and Health) as a reference in the assessment of functioning and needs of children with multiple disabilities <i>Adelinda Candeias, Maria José Saragoça, António Portelada, Edgar Galindo</i>	63
CHAPTER 5	
“Those who do not speak.” Some considerations concerning people with intense and complex support needs <i>Marc Benedetti</i>	77

CHAPTER 6		
Needs assessment research in nine European regions: a summary		83
<i>Nuno Costa, Jo Lebeer, Adelinda Candeias</i>		
CHAPTER 7		
Children with complex and intensive support needs: the Italian reality/evaluation towards inclusion: does it make a difference?		93
<i>Marina Rodocanachi & Anna Dal Brun</i>		
CHAPTER 8		
How to support caring interaction		99
<i>Andreas Fröhlich and Sara Nijs</i>		
<i>Sara Nijs</i>		
CHAPTER 9		
Parents' voices		105
<i>Graça Gonçalves, Rui Gonçalves, Sara Martins, Hugo Pilate, Jacques Lodomez</i>		
PART 2		
Current support systems in eight European regions for children with complex and intensive support needs		119
CHAPTER 10		
Current support systems for children with complex support needs in Belgium		121
<i>Jo Lebeer & Heleen Neerinckx</i>		
CHAPTER 11		
Current support systems in The Netherlands		129
<i>Rianne Kleine Koerkamp, Inge Kroes, Mia Nijland</i>		
CHAPTER 12		
Support systems for children with multiple disabilities and complex care needs in France		135
<i>Anne-Marie Boutin, Philippe Camberlein, Christine Plivard</i>		
CHAPTER 13		
Current support systems In Romania		147
<i>Reka Orban, Eniko Batiz, István Szamosközi</i>		
CHAPTER 14		
Current support systems in Bulgaria		159
<i>Magdalena Tsoneva</i>		

CHAPTER 15	
Current support systems in Italy	167
<i>Marina Rodocanachi & Anna Dal Brun</i>	
CHAPTER 16	
Current support systems in Portugal	173
<i>Adelinda Candeias, Clarisse Coelho, Maria José Saragoça, Vítor Franco, Carla Merca</i>	
PART 3	
Training for an inclusive quality of life	185
CHAPTER 17	
What kind of training do people supporting children with complex and intensive support needs, need?	187
<i>Beno Schraepen, Christine Plivard, Jo Lebeer, Eniko Batiz & Reka Orban</i>	
CHAPTER 18	
Experience in France of training professionals to work with children with complex and intensive support needs	197
<i>Christine Plivard</i>	
CHAPTER 19	
Lighting the fire: From competency-based towards value-based learning	203
<i>Beno Schraepen</i>	
CHAPTER 20	
Experience with new in-service training to improve quality of life, activity and participation in children with intense and complex support needs	213
<i>Enikő Batiz, Reka Orban, Jo Lebeer, Mia Nijland, Beno Schraepen, Marina Luisa Rodocanachi Rodi, Heleen Neerinckx, Christine Plivard, Zvezdelina Atanasova, Adelinda Candeias</i>	
CHAPTER 21	
Quality of life of youth with complex and intensive support needs: personal conceptions of professionals in the context of training	231
<i>Maria João Carapeto, Adelinda Candeias, Cátia Coelho, Nuno Costa, Luísa Grácio and Vítor Franco</i>	

PART 4**Examples of good practice to improve activity, participation and inclusive quality of life 245****CHAPTER 22****Criteria for good practice in supporting inclusion and activities 247**

António Portelada, Adelinda Candeias, Jo Lebeer, Beno Schraepen, Nuno Costa, Ana Lúcia João

CHAPTER 23**Good practice in inclusive education 257****23-1 – Villa Clementina: an inclusive day-care nursery 257**

Mieke De Strooper, Katleen Ballon & Katia Verhaeren

23-2 – Inclusive education teamwork in school 260

Jo Lebeer, Inge Wagemakers, Luk Dewulf, Silke Ledegen, Eveline Timmermans, An Beckwee

23-3 – Good practice of inclusive education with children with multiple disabilities in Portugal 267

Maria José Saragoça, Maria Paula Antunes, Ana Paula Paiva, Adelinda Candeias

23-4 – Together to School classes: A School Where Everyone Belongs 269

Susan Teutenberg, Joke Visser

23-5 – From the relationship to the educational project: the process of including a girl with Rett Syndrome in the classroom 272

Gabriele Baldo

23-6 – Initiative of inclusive education: Adapei de la Corrèze (France) 280

Florence Bergamasco et Lauratie Krouit

23-7 – Kozmutza Flóra – Special school for hearing impaired children 284

Réka Orbán, Enikő Batiz, Csilla Kiss, Ildikó Péter

References to Chapter 23 290**CHAPTER 24****Good practices in child/family-oriented intervention 291****24-1 – Quality of Life Centre 291**

Mia Nijland

24-2 – Professionalizing staff in Multiplus 293

Anneleen Penne

24-3 – Lus: Circles of support for a community-based inclusive approach 293

Geertrui Vandelanotte

24-4 – Réseau Lucioles: a parents-professionals knowledge network 294

Jo Lebeer

24-5 – Team Network “Rare Disability” Ile-de-France 296

Eric Zolla & Karine Goust

24-6 – The EMG Knowledge Network for Parents and Professionals 300

Mia Nijland

24-7 – From Advocacy Association to Inclusive Services: Early Intervention & Private-Public Service Cooperation Initiatives in Portugal <i>Adelinda Araujo Candeias & Clarisse Coelho</i>	302
24-8 – Karin Dom Early Childhood Intervention Centre <i>Magdalena Tsoneva</i>	307
24-9 – Integrated rehabilitative approach: a model of care for children with a rare disease <i>Marina Luisa Rodocanachi Roidi, Francesca Cozzi, Francesca Grange, Valentina Francesca Gestra</i>	309
24-10 – Home support centre Service d' Education Speciale et de Soins à Domicile (SESSAD) <i>Christine Plivard</i>	318
Example: Time for a toilet: Prevention and management of pain in toileting and handling of child care and young adults with multiple disabilities	319
24-11 – “Preparing for life” transition adolescents’ project <i>Marina Luisa Rodocanachi Roidi</i>	320
24-12 – Rather this way! Acting positively, even with problem behaviour <i>Boelina Sikma</i>	322
24-13 – Triple-C: Restoring Life To ‘Normal’ <i>Hans Van Wouwe & Dirk Van De Weerd</i>	328
24-14 – From School To Playground: Belonging and Participation for Children with Complex Care Needs <i>Reka Orbán, Enikő Batiz, Kinga Csata</i>	330
References to Chapter 24	337
 CHAPTER 25	
Good practice in promoting activities and participation	341
25-1 – Centro Benedetta D’Intino and Alternative Communication: meeting together <i>Aurelia Rivarola</i>	341
25-2 Let’s get involved: Integrated summer camp <i>Nagley Bertoldi Losa, Mauro Santoro, Marina Luisa Rodocanachi Roidi</i>	357
25-3 Inclusive theatre company <i>Marika Socha</i>	364
25-4 The Songbox <i>Mariëlle Jacobs</i>	368
25-5 – Music and Children with complex and intensive support need: a music therapy approach <i>Angelo Raffaele Colletti, Kumiko Toshimori, Marina luisa Rodocanachi Roidi</i>	370
25-6 – Experience it! Activity-promoting workshops <i>Thyra Koeleman</i>	374
25-7 – Music, a different type of communication – MGL a different choir <i>Enikő Batiz, Réka Orbán, Csilla Kiss, Ildikó Péter</i>	378

25-8 Communication Focused Family-Centred Interventions for Children with Complex and Intense Support Needs <i>Réka Orbán, Enikő Batiz, Ildikó Antal</i>	381
References to chapter 25	389
PART 5	
Conclusions	389
CHAPTER 26	
Quality of life and integration of care & education in children with complex and intensive support needs: Recommendations to policy makers <i>Mia Nijland, Jo Lebeer, Adelinda Candeias, Marina Rodocanachi, Magdalena Tsoneva, Enikő Batiz, Eric Zolla</i>	391
CONTRIBUTING AUTHORS	397
THE ENABLIN+ WORK PROGRAMME	407

Purpose and outline of this book

In 2013 a group of professionals and parents, from eight European countries, from various professional backgrounds and types of institutions, created a European project to develop an innovative interprofessional in-service training programme, which would train people to improve inclusion and quality of life for children with the most complex disabilities, who are in need of intensive and continuous support. The Enablin+ project ran officially, i.e. supported by the Life-Long Learning Programme “Leonardo” of the European Commission, from January 2014 to June 2017.

To develop this training, we first did some research into the needs of children, their caregivers and the professionals working with them. We looked into existing support systems and the way they facilitate or hinder activities and participation. We searched for examples of good practice regarding integration of care and inclusive education. Then, we set up a variety of training activities in the partner countries and an international train-the-trainer conference and workshops.

This handbook is intended to accompany the interprofessional training programme developed by the Enablin+ project group. It contains the most important results of the project based on research reports, articles, project descriptions and results of pilot projects. It is aimed at those who are responsible for training the various professionals working in the field of children and youngsters with complex and intensive support needs – educators, auxiliaries, teachers, therapists, doctors, etc., as well as volunteers and parents.

This handbook is complementary to the booklet *Enabling Activity and Participation. Supporting Young People with Complex and Intense Support Needs*, which is meant to be a process book to accompany trainees during their training. That booklet (with attached DVD) contains a more detailed description of the training scenario, a description of thirteen videos of examples of good practice regarding inclusion and integration of care and education, and brief background information. The booklet has been translated in English, Dutch, French, Italian, Romanian, Hungarian, Bulgarian and Portuguese.

Although none of the partners belongs to an English-speaking country, this handbook is, paradoxically, published only in English, for two reasons. First, its content is more academic

and we assume that the people teaching at academic institutions can read English. The second reason was entirely pragmatic; budgetary constraints forced us to publish only one language version. We preferred the smaller booklet and DVD to be accessible to all professionals and students in different languages, compared to the present handbook being only in English.

Part I deals with the subject of needs assessment: how to assess the real needs of children and families with very significant and multiple disabilities. It starts with a chapter by the late Elisabeth Zucman – one of the pioneers of care for children with multiple and complex disabilities in France and one can say world-wide – on the history of care and support for these children. This is followed by an introductory text on quality of life (QoL), a text about how to assess quality of life, a chapter on how to assess using the ICF framework, another text on how the Italian model supports inclusion, a chapter summarising the European needs assessment, a text about how to support and caring interaction, and a chapter where parents' voices are shared. The main purpose of Part I is to present the complex subject of needs assessment; throughout chapters 2-9, different dimensions of “needs” are presented, whether those needs come from the children, from the parents, or from a specific type of disability. Some of those needs emerge from the different models of assessment, and others are identified while learning about QoL, a concept of paramount importance when talking about supporting children. Also addressed here, is the topic of interconnectedness between support and care, where we argue that in order to have a successful approach, relationships need to be established, dramatically improving the children's development.

Part II addresses the subject of current support systems in Belgium, Netherlands, France, Romania, Bulgaria, Italy, and Portugal. It is clear that European countries invested in diverse policies concerning support systems. Such differences are observable between countries more focused on individualized and technical support (e.g., Belgium, Holland, France), and others where support systems are more focused on educational and social inclusion (e.g. Portugal), or, as in Romania and Bulgaria, support systems that are still evolving.

Part III revolves around training for quality of life. The first chapter explains what kind of training and competencies professionals feel they need, in the next chapter, the French CESAP training organisation presents how they provide their training, in chapter three we address the kind of competencies people who support children with complex and intensive support needs require. In the fourth text, preliminary results of an innovative ‘common core’ training programme for inclusion and quality of life are reported. Lastly, we examine the conceptions of quality of life of professionals participating in a pilot training programme at the University of Evora.

In Part IV, examples of good practice in integrating care and inclusive education, activity and participation are presented. The first chapter presents a summary of research and discussion about the criteria for good practice, as regards the promotion of quality of life and initiatives towards activity and participation. Then we present a selection of good practice, in this respect, from the different partner countries. As each country has its own systems of support, this means that we needed a flexible concept of good practice. Our conceptualisation of good practice takes into account that some countries are more focused on technical

and individualized supports (e.g., therapies, methodologies, assistive technologies), as other countries focus more in social and educational approaches.

Finally, Part V concludes with recommendations for policy makers concerning improving quality of life, integrating care and education, and promoting activity and participation of children with complex and intensive support needs.

The editors

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