

Jo Lebeer, Adelinda Candeias, Eniko Batiz,
Reka Orban, Marina Rodocanachi (Eds.)

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

Contents

Purpose and outline of this book
Principles and goals of the Enablin+ project
Jo Lebeer

15

PART I

Who are they? Assessing support needs and quality of life

CHAPTER 1

A history of the care of the “forgotten”: multiple disabilities ... The challenge of learning
Elisabeth Zucman

23

CHAPTER 2

Quality of life and supports paradigm
Claudia Claes

43

CHAPTER 3

How to evaluate quality of life
Katja Petry, Bea Maes & Carla Vlaskamp

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
Adelinda Candeias, Maria José Saragoça, António Portelada & Edgar Galindo

61

CHAPTER 5

“Those who do not speak.” Some considerations concerning people with intense and complex support needs
Marc Benedetti

77

Jo Lebeer, Adelinda Candeias, Eniko Batiz, Reka Orban, Marina Rodocanachi (Eds.)
Enability

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

Antwerp – Apeldoorn

Garant

2023

415 p. – 24 cm

ISBN 978-90-441-3940-2

D/2023/5779/32

NUR 847

Cover design: Danny Juchtmans | D Sign Graphics

Cover image: R.M. Nunes | Shutterstock

© The authors & Garant-Uitgevers n.v.

All parts of the book are protected by copyright. Every use beyond the narrow limitations
of the copyright is inadmissible without the prior permission from the copyright owners.

This is also valid for photocopying, translations and micro film copies
as well as storage and utilisation in electronic systems.

Garant

Somersstraat 13-15, B-2018 Antwerpen

Koninginnelaan 96, NL-7315 EB Apeldoorn

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

CHAPTER 15	Current support systems in Italy <i>Marina Rodocanachi & Anna Dal Brun</i>
------------	---

CHAPTER 16	Current support systems in Portugal <i>Adelinda Candeias, Clarisse Coelho, Maria José Saragoça, Vitor Franco & Carla Merca</i>
------------	---

PART 3
Training for an inclusive quality of life

CHAPTER 17	What kind of training do people supporting children with complex and intensive support needs, need? <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 <i>Christine Plivard</i>
------------	---

CHAPTER 19	Lighting the fire: From competency-based towards value-based learning <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 <i>Enikő Batiz, Reka Orban, Jo Lebeer, Mia Nijland, Beno Schraepen, Marina Rodocanachi, Heleen Neerinx, 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 <i>Maria João Carapeto, Adelinda Candeias, Cátia Coelho, Nuno Costa, Luisa Grácio & Vitor Franco</i>
------------	---

PART 4

Examples of good practice to improve activity, participation and inclusive quality of life

CHAPTER 22

Criteria for good practice in supporting inclusion and activities

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

CHAPTER 23

Good practice in inclusive education

23-1 – Villa Clementina: an inclusive day-care nursery
Mieke De Strooper, Kathleen Ballon & Katia Verhaeren

23-2 – Inclusive education teamwork in school
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
Maria José Saragoça, Maria Paula Antunes, Ana Paula Paiva & Adelinda Candéias

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

23-6 – Initiative of inclusive education: Adapei de la Corrèze (France)
Florence Bergamasco & Lauratie Krouit

23-7 – Kozmutza Flóra – Special school for hearing impaired children
Reka Orbán, Enikő Batiz, Csilla Kiss & Ildikó Péter

References to Chapter 23

CHAPTER 24

Good practices in child/family-oriented intervention

24-1 – Quality of Life Centre
Mia Nijland

24-2 – Professionalizing staff in Multiplus
Anneleen Penne

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

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

24-5 – Team Network “Rare Disability” Ile-de-France
Eric Zolla & Karine Goust

24.6 – The FMG Knowledge Network for Parents and Professionals

24-7 – From Advocacy Association to Inclusive Services: Early Intervention & Private-Public Service Cooperation Initiatives in Portugal
Adelinda Candéias & Clarisse Coelho

24-8 – Karin Dom Early Childhood Intervention Centre
Magdalena Tsoneva

24-9 – Integrated rehabilitative approach: a model of care for children with a rare disease
Marina Luisa Rodocanachi Roidi, Francesca Cozzi, Francesca Grange & Valentina Francesca Gestra

24-10 – Home support centre Service d'Education Speciale et de Soins à Domicile (SESSAD)
Christine Plivard

Example: Time for a toilet: Prevention and management of pain in toileting and handling of child care and young adults with multiple disabilities

24-11 – “Preparing for life” transition adolescents’ project
Marina Rodocanachi

24-12 – Rather this way! Acting positively, even with problem behaviour
Boelina Sikma

24-13 – Triple-C: Restoring Life To ‘Normal’
Hans Van Wouwe & Dirk Van De Weerd

24-14 – From School To Playground: Belonging and Participation for Children with Complex Care Needs
Reka Orbán, Enikő Batiz & Kinga Csata

References to Chapter 24

CHAPTER 25

Good practice in promoting activities and participation

25-1 – Centro Benedetta D’Intino and Alternative Communication: meeting together
Aurelia Rivarola

25-2 Let’s get involved: Integrated summer camp
Nagley Bertoldi Losa, Mauro Santoro & Marina Rodocanachi

25-3 Inclusive theatre company
Marika Socha

25-4 The Songbox
Mariëlle Jacobs

25-5 – Music and Children with complex and intensive support need: a music therapy approach
Angelo Raffaele Colletti, Kumiko Toshimori & Marina Rodocanachi

25-6 – Experience it! Activity-promoting workshops
Thyra Koeleman

25-7 – Music, a different type of communication – MGL a different choir
Enikő Batiz, Reka Orbán, Csilla Kiss & Ildikó Péter

25-8 Communication Focused Family-Centred Interventions for Children with Complex and Intense Support Needs <i>Réka Orbán, Enikő Batiz & Ildikó Antal</i> References to chapter 25	381 389
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>	391 397
CONTRIBUTING AUTHORS	407
THE ENABLIN+ WORK PROGRAMME	

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.

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 1 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

Adelinda Candeias, Jo Lebeer, Eniko Batiz, Reka Orban, Marina Rodocanachi
November 2023

Acknowledgements

We thank the Enablin+ partners who contributed to the development & implementation of training and data collection:

BE: Bea Maes, Anneleen Penne, Sara Nijs (University of Leuven); Boelima Sikma (DeLovie, Poperinge), Claudia Claes & Marie-Rose Pauwels (University College Ghent), Birgit Vermeulen (Zevenbergen, Ranst)

NL: Inge Kroes & Rianne Kleine Koerkamp, Centre for Education & Care, Wijhe

IT: Anna Dal Brun, Jessica Matera, Nagley Bertoldi, Don Gnocchi Foundation, Milan

FR: Eric Zolla, Anne-Marie Boutin, CESAP

FR-Réunion: Elisabeth Houot, Laurence Richard, Marlène Grégoire, Nacer Djoudi, Marika Socha, Association St-François d'Assise, Ste Suzanne; Marc Benedetti, consultant

BG: Magdalena Tsoneva, Apostol Apostolovitch, Karin Dom Centre, Varna

PT: Nuno Costa, Catia Coelho, Maria José Saragoça, António Portelada, Heldemerina Pires, Luísa Grácio, Vitor Franco, Hugo Rebelo, Maria Carapeto, Edgar Galindo, Clarisse Coelho, Ana Paula Antunes, Bruno Martins, Carla Merca, Sara Martins, Graça Gonçalves, Rui Gonçalves, University of Evora, APPACDM, APCE

RO: Szamosközi István, Kotta Ibolya, Kiss Szidónia, János Réka, Demeter Kármén, Szabó Kinga, Kálcza-Jánosi Kinga, Pordea Anett, Maior Edit, Farcas Susana, Babes-Bolyai University, Department of Applied Psychology, Cluj-Napoca

The authors would like to give a special thanks to Juliet Goldbart & Claire Pierson, Manchester Metropolitan University, for evaluating the project; to Juliet Goldbart again for correcting the English language and to Nagley Bertoldi for translating from Italian to English.

Funding:

This project has been funded with support from the European Commission, Life Long Learning Programme. (1/1/2014-30/6/2017). Contract n° 541981-LLP-1-2013-1-BE-LEONARDO-LMP. This document reflects the views of the authors only, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

The authors report no conflict of interest.

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.

Jo Lebeer is a medical doctor and emeritus professor in Disability Studies at the University of Antwerp (Belgium); **Adelinda Candeias** is professor of Psychology at the School of Health and Human Development at the University of Évora (Portugal). **Eniko Batiz** is Head of the Department and **Reka Orban** is a lecturer in Special Education at the Department of Applied Psychology of the Babes Bolyai University in Cluj-Napoca (Romania); **Marina Rodocanachi** is a medical doctor specialized in Neurology and Rehabilitation Medicine at the Don Gnocchi Foundation in Milan (Italy)