enablin+

Enabling & Including Young People
with Complex & Intense Support Needs

Train-the-trainer course

Enabling Quality of Life in Young People with Multiple Disabilities and Complex and Intense Support Needs: from Theory to Practice

How to Train Multidisciplinary Teams and Families for a Better Quality of Life

Programme & Abstract book

22nd & 23rd September 2016
Venue: IRCCS Santa Maria Nascente
Via Capecelatro 66 – Sala Cardini
Milano

Education and Culture DG
Lifelong Learning Programme

Fondazione Don Carlo Gnocchi Onlus

Deliverable 13a

Organizing Committee

Marina Rodocanachi , Anna Dal Brun, , Jessica Matera (Don C. Gnocchi Foundation, Milan)
Hugo Rebelo (University of Evora)
Heleen Neerinckx (University of Antwerp & Multiplus, University of Leuven)
Jo Lebeer (Univ. Antwerpen, BE); Eric Zolla, (CESAP, Paris).

Scientific Committee

Marina Rodocanachi, Anna Dal Brun & Lucia Angelini (Don C. Gnocchi Foundation, Milan)
Christine Plivard & Anne Marie Boutin (CESAP, Paris)
Adelinda Candeias & Maria José Saragoça (University of Evora)
Enrico Castelli (Neurorehabilitation Department Children's Hospital Bambin Gesú, Roma)
Jo Lebeer & Beno Schraepen & Heleen Neerinckx (University of Antwerp)
Bea Maes (Catholic University of Leuven)
Istvan Szamoskozi & Reka Orban (Babes-Bolyai University of Cluj-Napoca, Romania)
Mia Nijland (Expert Centre BNK, Wijhe, NL)
Magdalena Tsoneva (Karin Dom Centre, Varna, Bulgaria)

Conference secretariat:

Jessica Matera Don C. Gnocchi Foundation, Milan
Email: jmatera@dongnocchi.it Tel. +39 02 40308305

Acknowledgements

The organizers wish to thank

- Monsignor Bazzari, president of the Don Gnocchi Foundation
- Don Gnocchi Foundation for hosting this training and conference and the staff: Jessica Matera & Nagley Bertoldi
- Dr. Anna-Maria Caruso, Children's Rights Officer City of Milano
- Prof. Ssa Susanna Mantovani & Roberta Garbo , Bicocca University, Faculty of Educational Science and delegate for Disability
- The Special Interest Group "Profound Intellectual and Multiple Disabilities" of the International Association of Intellectual and DEvelopmental Disabilities (IASSIDD), headed by Prof. Bea Maes of the Catholic University of Leuven (Belgium), Prof. Juliet Goldbart, Prof. Geneviève Petitpierre, Dr. Petra Poppes (Groningen, the Netherlands), Dr. Sara Nijs (University of Leuven)
- All the speakers and workshopleaders at the workshop and conference
- Children and Youth'Parents

Partners

Co-ordinator			
University of Antwerp INCENA-Inclusion & Enablement i.c.w. Multiplus Expert Centre	Expert Centre for Education & Care Wijhe	Comité d'Etudes, d'Education et de Soins Auprès des Personnes Polyhandicapées	Babes-Bolyai University, Department of Applied Psychology - Cluj-Napoca
Belgium	The Netherlands	France	Romania
Association St-François d'Assise – Pôle Handicap	Karin Dom Foundation – Varna Centre for Children with Special Needs	Rehabilitation Centre Vismara & IRCCS S.M. Nascente, Milan	Centre for the study of Psychology & Education - Evora
Isle de la Réunion-FR	Bulgaria	Italy	Portugal

Disclaimer. This project has been funded with support from the European Commission, Life Long Learning Programme. Contract 541981-LLP-1-2013-1-BE-LEONARDO-LMP from 1/1/2014-30/4/2017) .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.

Table of contents

PROGRAMME 4

ABSTRACTS PLENARY SESSION THURSDAY SEPTEMBER 22ND 6

Training for dealing with children with complex and intense support needs in Europe 6

Children with complex and intensive support needs: the Italian reality 9

Training needs in Romania of staff working with children with multiple disabilities 11

Presentation of the experiences with the pilot applications in The Netherlands, France, Belgium and Portugal 12

Enablin Quality of Life through meaningful learning : Common Core Training for parents and professionals supporting children with complex and intensive support needs 28

ABSTRACTS OF WORKSHOPS 31

Workshop 1 How to train behaviour management 31

Workshop 2 How to train physical/health wellbeing aspects 34

Workshop 3 How to train integration of education & support/ aspects of participation/ aspects of learning & activities; design action plans based on observation 37

Workshop 4 How to train communication, intentionality and capacity to make choices 41

Workshop 5 How to train aspects of assistive technology 45

Workshop 6 How to train ethical aspects /Quality of Life and dealing with families 47

Programme

Thursday **Sept.22** **Morning** 9.00 – 13.00	Plenary: (In English/Italian with consecutive translation)
	Chair: Anna Dal Brun (Don Gnocchi Foundation) (Università Bicocca Milano) 09:00: **Welcome and introduction to the course** (Roberto Costantini, Presidio Nord1 of Don Gnocchi Foundation Director & Marina Rodocanachi, Child Neuropsychiatry and Rehabilitation Unit – Don Gnocchi Foundation) 09:15 **Training for dealing with children with complex and intense support needs in Europe** (Jo Lebeer, Coordinator of Enablin+ University of Antwerp, Belgium) 09:30 **Children with complex and intensive support needs: the Italian reality** Marina Rodocanachi & Anna Dal Brun, Don Gnocchi Foundation IRCCS Santa Maria Nascente, Milan 10:00 **Common training needs European partners, Romania, Bulgaria** (Reka Orban, Eniko Batiz, Magdalena Tsoneva) 10:45 Coffee break 11:15 **Presentation of the experiences with the pilot applications in The Netherlands, France, Belgium and Portugal** (Mia Nijland – Jo Lebeer – Hugo Rebelo & Adelinda Candeias – Christine Plivard) 12:00 **Presentation of common core training + training model** (Mia Nijland , NL) 12:30 Welcome word by Paolo Prof. Paolo Mocarelli, scientific director of Don Gnocchi Foundation
13.00 -14.00	Lunch + Visit of Don Gnocchi Foundation: Care Lab – DAT

Thursday **22 Sept.** **Afternoon** 14.00 -17.00	Workshop 1	Workshop 2	Workshop 3
	(in English with consecutive translation to Italian)	(Italian with consecutive translation English/French)	(in Italian/English with consecutive translation)
	How to train behaviour management **Discussant:** Petra Poppes ('s Heeren Loo, NL)	**How to train physical/health wellbeing aspects** **Discussant:** Paolo Banfi – Carlo Bianchi (Fondazione Don Gnocchi, IT & Anne-Marie Boutin CESAP, FR)	**How to train integration of education & support/ aspects of participation/ aspects of learning & activities; design action plans based on observation** **Discussant:** Mia Nijland (Expert Centre for Integration & Care, Wijhe, NL)
	Moderator: Giorgio Seragni (Don Gnocchi Foundation)	**Moderator:** Odoardo Picciolini (Policlinic of Milan Foundation)	**Moderator:** Jael Kopciowski (Association Una chiave per la mente & CRESCI, Asssociation for Integrato integrated aducational and cognitive development Trieste)
	Case presentation: Case 1: Petra Poppes ('s Heeren Loo, NL) Case 2: M. Cometa, F. Sacchi, MT. Giordano (Don Gnocchi Foundation, Legnano)	**Case presentation:** Case 1: F. Cimorelli, R. Mapelli (Don Gnocchi Foundation, Pessano) Case 2: M. Rodocanachi, AM Sanchez, K. Toshimori, V. Gestra,T. Lopez, A. Dal Brun (Don Gnocchi Foundation, Vismara) and parents	**Case presentation:** Case 1: G. Baldo, B. Bettini (ODFlab-University of Trento & Cooperative the Bridge) Case 2: Jo Lebeer, Beno Schraepen & Heleen Neerinckx (University of Antwerp and Catholic University of Leuven) Case 3: Zvezdelina Atanasova, Andreas Andreou,Nikoleta Yoncheva, Karin Dom Foundation, Varna, BG

Friday morning Sept. 23 9.00 – 13.00	Workshop 4	Workshop 5	Workshop 6
	(in English with consecutive translation to Italian)	(in English/italian with consecutive translation to IT)	(in Italian/English with consecutive translation)
	How to train communication, intentionality and capacity to make choices **Discussant:** Juliet Goldbart (Professor of Developmental Disabilities, Manchester Metropolitan University, UK)	**How to train aspects of assistive technology** **Discussant:** Ivana Olivieri & team (CARELAB & SIVALAB, Don Gnocchi Foundation IRCCS SMNascente, IT)	**How to train ethical aspects /Quality of Life and dealing with families** **Discussant:** Mario Mozzanica (Emer. Prof. Univ. Catt. Milano & Don Gnocchi Foundation Ethical Committee, IT)
	Moderator: Anna Dal Brun (Don Gnocchi Foundation, SMNascente, IT)	**Moderator:** Elena Brazzoli (Don Gnocchi Foundation, IT)	**Moderator:** Carlo Riva (L'abilità, Milan, IT)
	Case presentations: Case 1: Juliet Goldbart (Professor of Developmental Disabilities, Manchester Metropolitan University, UK) Case 2: N. Schiappacassi, E. Bortolozzi, F. Restelli , A. Dal Brun (Don Gnocchi Foundation IRCCS SMNascente)	**Case presentations:** Case 1: A. Rivarola Case 2: Marlène Gregoire (Cem Sainte Suzanne, ASFA, Ile de la Réunion)	**Case presentations:** Caso 1: V. Franco, H Pires, (University of Évora PT) Caso 2: K. Goust (Relais Handicaps Rares, Île de France, FR) Caso 3: D. Raddi, A. Dal Brun, C. Guerini Rocco, P. Cartamantiglia, A. Colletti, M. Rodocanachi (Don Gnocchi Foundation, Vismara) and parents
12.00 -13.00 13.00- 14.00	Visit Don Gnocchi Foundation: Care Lab & Siva Lab Lunch		
Friday Afternoon 23 Sept. 14.00 -17.00	**Closing session – plenary** Chairman: Adelinda Candeias (Evora University), Jo Lebeer (Antwerp University) & Roberta Garbo (Milano Bicocca University) Report of the workshops (the 6 discussants) Finalize the common core training + subsequent training format Final questionnaire for ECM (for Italian participants – health professions)		

Abstracts Plenary session Thursday September 22nd

Training for dealing with children with complex and intense support needs in Europe

Jo Lebeer[1], Coordinator of Enablin+ University of Antwerp, Belgium

The project ENABLIN+ is addressed at the needs of children and youth with complex and intense support needs (CISN), and the people who support them: a variety of professionals, from doctors to educators- “floor workers” to parents.

With this European project, we wanted to develop an interdisciplinary in-service training, where professionals and parents of various professional backgrounds *learn together*, so as to make them better “equipped” to deal with the complex needs of children with CISN; the ultimate aim is to enhance the quality of life of the children who are in great need for support and education.

We are very grateful to the organizers of this Train-the-trainers workshops and Conference in Milan, to have brought together experts from the Enablin+ European partners, from the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) as well as from our host partner Don Gnocchi Foundation and other Italian centres, as well as parents.

The goal of this meeting is to share the rich experience of everyone present, to share new ideas and examples of practices, in order to arrive at a shared training concept, which responds to the needs for training, signalled in richer as well poorer EU member states, to meet the increasing demands for supporting children with CISN, as became clear in our needs analysis research (Lebeer et al., 2015).

Basic framework to train for a quality of life support to children with CISN

The basic frameworks of this training are (1) first of all the 2006 Convention of the United Nations on the rights of persons with disabilities, forcing countries to take measures of de-institutionalisation and to organize the possibility of including children with a disability in normal schools & life; (2) the quality of life criteria as forwarded by the IASSIDD (Buntinx & Schalock) and (3) Nussbaum’s capability approach (Nussbaum, 2006; Le Fau, 2014).

The UN Convention on the Rights of People with Disability mentions eight principles:

1. Respect for inherent dignity, autonomy
2. Non-discrimination
3. Full and effective participation in society
4. Respect for difference and acceptance of people with disability as part of human diversity
5. Equality of opportunities
6. Accessibility
7. Equality men and women
8. Respect for evolving capacities of children with disabilities and for the right of children to preserve their identities
   Martha Nussbaum describes the “Basic constituent capabilities necessary to lead a human life:
9. Life (being able to live to the end of a human life)
10. Bodily health
11. Bodily integrity
12. Senses, imagination and thought
13. Emotions: attachment to things and people
14. Practical reasons (conception of good)
15. Affiliation
16. To live with concern for in and in relation to the world of nature

---

[1] MD PhD, associate professor at University of Antwerp, Faculty of Medicine & Health Sciences, Disability Studies, INCENA project on Inclusion & Enablement. He specialized in cognitive neurorehabilitation and ecological health care. He coordinated several European projects in this thematic field and is currently coordinator of Enablin+ project

17. Play, laugh, enjoy
18. Control over one's environment

All of these capabilities, except perhaps of the 10th, are within reach of children who have the most severe functional impairments of the severest restriction in their mode of functioning. Most of these capabilities are just the same as any child's, some even are stronger, e.g. the capability to play, enjoy and laugh, the affiliation to a family, bonding, emotions. Some are constantly under threat (e.g. health).

The quality of life criteria as forwarded by Schalock et al. within the IASSIDD are now well known in the professional world, but perhaps not so much to policy makers, by the public and people working in daily support.

QOL Factor	*QOL Domain*	*Exemplary QOL Indicators*
Independence	Personal Development	Education status, personal skills, adaptive behaviour (ADLs, IADLs)*
	Self-Determination	Choices/decisions, autonomy, personal control, personal goals
Social Participation	Interpersonal Relations	Social networks, friendships, social activities, relationships
	Social Inclusion	Community integration/participation, community roles
	Rights	Human (respect, dignity, equality), Legal (legal access, due process)
Well-Being	Emotional Well-Being	Safety & security, positive experiences, contentment, self-concept, lack of stress
	Physical Well-Being	Health status, nutritional status, recreation/physical exertion
	Material Well-Being	Financial status, employment status, housing status, possessions

*ADLs = Activities of Daily Living: IADLs =Instrumental Activities of Daily Living
(From Claes, 2015)

Professionals dealing with these children – from the ones giving daily support and education to the health care professionals – need to become thoroughly acquainted with these principles, and, more importantly, put these into daily practice.

Adapting training to the educational needs of children with CISN

There remains a lot to do in realizing a "life of quality" for children with CISN. Research has shown that children with CISN suffer from a lack of activity. This is not only understandable because of the degree of bodily impairments, but also to a lack of belief by the staff in the possibility of feasibility. In their daily schedule are too many "empty" hours; they do not move enough; there is a lack of participation in family activities, school and society (Maes, 2014). This of course has to do with their limited communication and interaction capacities, although recent research has shown they do interact if one gives them sufficient time (Neerinckx et al., 2013).

Many children are actually well taken care of, but hardly receive education. It should be defined what good education is. That requires a reflection on the basic conceptualisation of how we look at children's educational needs and potential.

Participation in society is also not ensured, often because the child has many difficulties, or there is a lack of support to enable inclusion and a lack of belief that it is necessary and that it is possible.

Hence, professionals should be trained in a mind shift, so that they actually will do it differently when arriving at the work floor. A good quality support consists of:

- Creating optimal spatial conditions allowing peer interaction
- Choosing adapted activities
- using technical aids allowing for better activities
- Systematic planning based on careful observation, not only focusing on the child's deficiencies, but more importantly on the signs of potential, what the child would be capable to do, despite impairments
- Leaving room for choice and interaction
- Have an attitude of respect, dignity, warm-heartedness

Professionals should be "scaffolded" to develop these right attitudes.

A wide variety of training

Actual vocational training insufficiently prepares professionals to deal with these issues. Training varies widely in Europe. Some countries hardly have anything; others have developed a staged system of training.

Fortunately, things are changing. Several initiatives have been taken in recent years, many of them meet each other in the IASSIDD special interest group. Within the Enablin+ project, we have been developing a common core training and various training models, which we have been trying out in the past year. Many of these experiences will be presented during these workshops and conference.

What topics should be part of a training of people working with children with intensive and complex support needs?

In one our partner meetings we discussed some ideas on which a good training should be based:

1. Change attitudes and mind-sets of everyone involved: mind-set about capability, about inclusion, rights, quality of life.
2. Become acquainted with the notion of accessibility and the use of technology to enable activity, mobility, communication, interaction, play, etc.
3. Understand the difference between giving specialist support and giving support to live in an inclusive environment.
4. Examples of good practice: how children can participate in the classroom
5. How to integrate education and care, in inclusive settings
6. How to involve families – they are the main support, they deal with daily life and care
7. Provide opportunity to experience “things of life”, besides getting support; support each other in a natural way.
8. Enabling communication
9. Enabling eating in an enjoyable way
10. Dealing with challenging behaviour
11. Use movie examples of good practices, as a trigger to discuss possible approaches
12. Have a notion of Bronfenbrenner theory of ecology of development
13. Enable children to become active
14. Learning to set small goals
15. Learning how to create a supportive environment
16. Avoiding burn-out
17. Awareness of our skills
18. (special) tools for learning (+evaluation) methods
19. Interdisciplinary learning; learn from each other. Inspire each other
20. Careful observation : knowledge of CISN is the basis education for every discipline; look for talents and interests
21. An ethics-of-care approach should be central

A big challenge will be to combine high quality support with inclusive education. Italy and Portugal have experience with inclusive education, but it remains to be seen where are the examples of really good practice of inclusive education for children with very high challenges on all areas. Some of the pioneering experiences will be shown during this training and conference. Besides education, other topics will be highlighted and ways will be sought how to train people to become familiar with them.

References

Buntinx, W.H.E, Schalock, R. (2010), Models of Disability, Quality of Life, and Individualized Supports: Implications for Professional Practice in Intellectual Disability, *Journal of Policy and Practice in Intellectual Disabilities*, 7 (4): 283–294

Claes, C. (2015), Quality of Life in Supporting Children with Multiple and Profound Disability; a Promising Concept, in: Lebeer, Jo (Ed). *Who are they? Assessing the needs of children with intensive and complex support needs in eight European regions*, Antwerp: University of Antwerp, 2015, pp. 33-40

Lebeer, J. (Ed.) (2015), *Who are they? Assessing the needs of children with intensive and complex support needs in eight Euroepan regions. Antwerp* (BE): University of Antwerp Enablin+ Research Group

Le Fanu, G. (2014) International development, disability, and education: Towards a capabilities-focused discourse and praxis, *International Journal of Educational Development*, 38,:69-79

Maes, B. (2014), Activity &participation of people with profound and multiple disability, in Vandermeulen, B.F et al*., Sporen van de reiziger [Traces of a traveler],* Antwerpen: Garant

Neerinckx, H., Vos, P., Van Den Noortgate, W. and Maes, B. (2014), Temporal analysis of attentional processes in spontaneous interactions between people with profound intellectual and multiple disabilities and their support workers. *Journal of Intellectual Disability Research*, 58: 721–733. doi: 10.1111/jir.12067

Nussbaum, M.C. (2006) *Frontiers of Justice: Disability, Nationality, and Species Membership, Harvard University Press*, 2006

Children with complex and intensive support needs: the Italian reality

Marina Rodocanachi[2] & Anna Dal Brun, Don Gnocchi Foundation IRCCS Santa Maria Nascente, Milan

The process of school inclusion of children with disabilities was established in Italy in 1971 with Law 118, and was developed throughout the following years, by establishing the right to mainstream education for students with disabilities and abolishing, in fact, special schools.[3]

On the occasion of the International Day of People with Disabilities, on December 3rd, 2015, the Ministry of Education, University and Research (MIUR) announced that the number of students with disabilities included in the national school system is 235,000 students, accounting for 2.7% of all students attending, and with an increase of almost 40% in the last 10 years.[4]

In the 2014/2015 school year, support teachers were 119,384 (15.1% of the total number of teachers).

Data on the types of disabilities however are collected starting from a diagnostic and functional concept, that groups together the different types of disabilities, according to categories that do not represent the concept of PIMD (Profound and Intellectual Multiple Disabilities), international term to define children with complex and intensive support needs and which has been adopted by the Enablin+ European Project.

The data of the Ministry of Education concerning the types of disabled children in mainstream education for the school year 2014-2015, reports that 95.8% of students and have psychophysical disabilities.
Of these:

- 65.3% (152,551 pupils) has an intellectual disability
- 3.5% (8,080 students) a motor disability
- 27% (62,991 students) is a carrier of another type of disability (a category that includes early psychiatric problems, specific learning disorders in co-morbidity with other disorders and attention deficit and hyperactivity syndromes - ADHD)
- 1.6% (3,638 students) has a visual impairment
- 2.7 % (6,217 students) has a hearing disability

The most recent statistics collected by the Ministry of Education give particular attention to the situation of children with specific learning disability included in normal schools, but without support teachers and who need specific educational attentions (Special Educational Needs).

The ISTAT[5] recently investigated the presence of students with complex disabilities, taking into account three functional parameters:

---

[2] M.D.Neurologist & specialist in Physical Rehabilitation Medicine; Fondazione Don Gnocchi, Unit of Child Neurology & Psychiatry and Rehabilitation, Via Capecelatro 66 MILANO, Tel: ++39 02 40308385; mrodocanachi@dongnocchi.it

[3] Law No. 30, March 1971, n. 118 - L. 517/77 - Integration of persons with disabilities in public schools - Law 104/92 - Framework Law for the assistance, social integration and rights of disabled persons.

[4] Statistical Service of the Ministry of Education: Inclusive education of students with disabilities for the 2014 / 2015 school year (November 2015)

[5] http://www.istat.it/it/archivio/disabili
Disabled pupils in schools
The survey finds resources and school instruments for school integration of students with disabilities. Period of reference: school year 2015-2016. Date of publication: Thursday, April 7, 2016

- independence in moving and displacement
- Independence in eating
- independence in going to the bathroom
-

The result of this investigation was that:

- in primary school, 21% of the students with disabilities is not autonomous in at least one of the investigated activities (moving, eating or going to the bathroom by themselves) and 8% is not autonomous in all three activities.
- in the secondary school level, the percentages are respectively 15% and 5%.

On a national level, there is no data concerning the few special schools still existing on national territory. These are leftover realities where children, often with multiple disabilities and complex needs, attend special classes. These schools strive to develop individual inclusive projects, but they are having a hard time in activating innovative courses for children with severe disabilities, also because of lack of specific rules and of training opportunities for teachers and professionals who deal with this type of disability.

The Italian law, which was in forefront in the 1970's, developed excellent practices regarding mainstream education for children with disabilities in Italy. But inclusion of the most frail and complex children in normal schools is not always easy. There are examples of good practices, especially in kindergarten and primary school, but these examples are not generalized. We are still lacking training courses for professionals. Families often feel alone and in conflict between a law that guarantees the inclusion and the human resources offered that are not always enough or not sufficiently specialized.

The professionals involved in education and care for these children and their families feel a strong need to find some more specific inclusive models. Starting from experiences of good practices and taking into account all aspects of complexity the model should integrate education, assistance and healthcare for a better school and social inclusion to improve the quality of life.

Training needs in Romania of staff working with children with multiple disabilities

Eniko Batiz[6], Reka Orban[7], Istvan Szamoskozi[8]

In Romania the law on the rights of people with disabilities is converging the European legislation. If interpreting word-by-word the legislation, it is some kind of „pink world" for the disabled persons.

In reality the majority of these people are living in families with minimal professional support of any kind. In the care centers educational or some supportive services (except for the minimal social welfare and medical) are not enough or are totally missing (e.g. cultural or leisure programs, events).

The finances for life and education of people with intense support needs is not enough for a decent daily life.

The actual training offer - even for the participants of the specialist's team - is very global, tangential.

Only the students who are trained as special teachers or speech therapist at the University are attending a one semester course on these complex needs and the possibilities of education for the SEN people.

There are some postgraduate method-specific courses for those who work with these persons and for the parents of children with intense and complex support and needs.

Educators and teachers are benefiting from the information on inclusive education only at master level courses – if they attend this secondary level of higher education -, and this course is mainly about the adolescent with SEN, who are included in mainstream school.

What are the needs?

Both the specialists and parents need training courses in this field.

The specialists are considering that their theoretically knowledge is enough, but they are receptive for postgraduate training in effective supportive methods. They should experience during the course that team work is effective and even if it seems to need extra time, it is actually time-saver in working with people with complex and intense needs.

The parents should be aware of their children's' rights, should benefit from instruction on how to help their child. The major question for them is: What will happen to my child, when I will not be able to take care of her/him?

---

[6] Psychologist, lecturer at Department of Applied Psychology at Babes-Bolyai University, Cluj-Napoca, Romania

[7] Psychologist, PhD, Department of Applied Psychology at Babes-Bolyai University, Cluj-Napoca, Romania

[8] phD, Head of department of Applied Psychology at Babes-Bolyai University, Cluj-Napoca, Romania

Presentation of the experiences with the pilot applications in The Netherlands, France, Belgium and Portugal

Belgium

Thematic week in Belgium (May 17-21, 2016): Training Integration of care and education for children and adolescents with complex and intensive support needs

Heleen Neerinckx[9] , Jo Lebeer[10], Beno Schraepen[11]

In Belgium, there is no systematic training of professionals working with children and young people with complex and intense support needs. Some professional training curricula (special needs psychology, speech and language pathology) focus on this target group for certain specific aspects, but generally, people learn how to deal with the specifics while already working on the floor. Also, in Belgium, although all children with very severe & multiple disabilities are usually well taken care of in welfare institutions, their education in a more formal educational context was not guaranteed. At the Catholic University of Leuven, an expertise centre Multiplus was created, to set up in-service training and coaching for those working already; due to contractual reasons, its scope was limited to institutional staff belonging to special educational needs of the Catholic School Board. The Belgian Enablin+ team made an alliance with Multiplus, in order to combine expertise with dissemination potential. The problem of training people already working in the field is that they cannot be missed to go on training during their working hours, and during the holidays, they don't go to trainings. Beginning of 2015 we formed a working group, composed of 4 higher education institutions and 2 service-centres having experience with children and adults with multiple disabilities and complex care[12]. We decided that the best way to create awareness for the target group, while at the same time giving a higher number of people a broad introduction to innovative aspects, was to organize a thematic week, where people could take part in at least one of the activities of their choice.

Target group of the training week

The thematic week was destined at professionals, students and parents, who have to deal with children and adolescents (0-25 years) with complex and intensive support needs, i.e.: children with multiple impairments and severe limitations regarding to activities and participation in daily care, education, communication, mobility, and leisure activities. All activities were open to everyone. The week offered activities which could be relevant for school directors (special and regular education), special needs teachers, regular teachers, therapists in rehabilitation, educational psychologists, nurses, doctors, educators, policy makers, researchers, etc.

Purpose

The main aim of the thematic week was to create higher awareness about the integration of care and education for children and adolescents with complex and intensive support needs. We wanted to investigate the concrete implication of the UN Convention about the Rights of People with disabilities, with its stress on inclusion, participation, full citizenship, education & autonomy. These are also criteria of quality of life as formulated by Schalock et al., which form the basic ingredients of the "common core training" developed in the international Enablin+ team. Furthermore, we wanted to raise awareness among policy makers as well as the broader society about the need for a life of quality of these vulnerable children and adolescents, focusing on the need for education, a need to take part in a variety of activities, to be welcomed, to belong, to relate, to participate. We wanted to introduce specific topics and present more in-depth in-service trainings about relevant themes, such as activation, mediated learning, modifiability, play, inclusive education, communication, basal stimulation, eating, dealing with challenging behavior, etc..

---

[9] Post-doc researcher at Catholic Univesity of Leuven and University of Antwerp

[10] Coordinator of Enablin+ project, associate professor at University of Antwerp, Faculty of Medicine, Disability Studies

[11] Lecturer at AP University College of Special Needs Education

[12] Catholic University of Leuven, University of Antwerp, AP University College of Special Needs Pedagogy of Antwerp, University College of Ghent of Special Needs Pedagogy, De Lovie (Poperinge) and Zevenbergen (Ranst)

Week programme

The start of the thematic week was given during an introductory conference at the Catholic University of Leuven on Tuesday May 17. The Minister of Welfare presented the ideas of the reform in the welfare landscape, which is more in line with the UN Convention, and operationalizes principles such as community care, inclusion, staged care, person-following budget. Prof. Dr. Bea Maes presented the report about Education Policies for children and adolescents with complex and intensive support needs. She gave an overview of the UN convention and the Quality of Life Criteria, and linked these topics to the actual situation of children with complex and intensive support needs without education in Belgium. The report formulated recommendations of the Ministerial Commission to realize the right of education for all children. Dr. Katrijn Vastmans presented research about “what is good education” for children with CISN. After an overview of different conceptual frameworks some parents and professionals gave a few testimonies of inclusion and activation. To finish the day, a round table was organized, with representatives from different institutions and associations (e.g. ministry of education, parents’ association, education institutions,…).

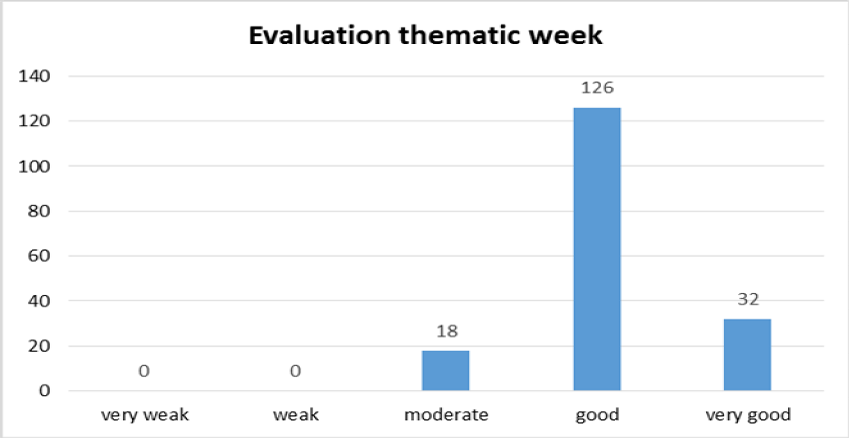
During the following days, participants were able to choose a number of workshops and site visits. ‘Real practice experts’ presented methods, techniques and more general approaches which have been proven their effectiveness, based on cases and by using lots of video material. The workshops were organized every day in every province in the country, and in principle they lasted ½ day. The visits in small groups (5-8 people) were organized to get people introduced into innovative projects with regard to integration of care and education. Both the workshops and the visits were inter-professional and were open to everyone working with children with complex and intensive support needs, so everyone could make a choice according the needs. There was one evening activity in Ghent, with a “stand-up comedian Ad Goos, who is a former educator of children with CISN, who told a number of stories of children with severe multiple disabilities, with the title “Put a comma in your ear”.

To finish the thematic week, we organized an inter-professional case conference, where cases with complex support needs were discussed.

Results

About 80 participants attended the first introductory day. During the rest of the week a total of 132 persons took part in at least one of the 13 workshops or visits. More than 300 participants came to the stand-up comedian evening show. In general, the thematic week was positively evaluated (see graph). The following quote of one of the participants reflects the opinion of multiple participants of the week: “ It is always interesting to look beyond the own walls. On the one hand it helps to feel recognition and confirmation of your own work, on the other hand it gives the chance to learn about small (but important!) things to integrate in your own practice.”

Figure 1 Quantitative evaluation of thematic week in Belgium 17-21 May 2016 (N=176)



As a result of one of the workshops (together to school classes), a group of participants gathered to make a working group, to introduce the same concept in Belgium. People also had the opportunity to formulate request and suggestions for future workshops and seminars. People working with children with complex and intensive support needs, especially want to know more about how to interact with these children, to improve communication, to know more about (inclusive) education, and to learn more about basal and sensory stimulation.

Discussion

Putting children with complex and intensive support needs into the spotlights during a whole week was a unique concept in Belgium and was strongly supported by people who are involved to this target group. Especially the broad panoply of activities we offered was a strength of the thematic week, so people could make a choice according their individual interests and needs. The impact of this awareness-raising week was in quantitative terms not small, for a small country like Belgium: we reached more than 500 people. It is too early to estimate the impact regarding the introduction of innovations or the change of long-standing habits, towards more inclusion, activity and education. The implications of the UN convention, which was signed by Belgium, are hardly known to field workers neither to professionals in managing situations. People working on a daily basis have very little time to spend to in-service training, therefore they tend to choose for instrumental workshops, rather than for reflective workshops. The thematic week showed that innovations such as inclusive education and care, are on the one hand attractive, but on the other hand create a lot of resistance. Some call it an impossible utopia, while others are striving to realize it. Showing examples of practice where these innovations are put into practice might create a double effect: they can be powerful inspirers of innovative action, but they could be blocking initiative and even create anger like "this is nothing for me". Resistance will need to be taken seriously if these innovations need to be implemented. The most important mission seems to be to open the mind-sets of professionals as well as parents. In this sense, a one-time awareness-raising event such as this thematic week is not enough. A project like Enablin+ can light a spark, but the fire needs to be maintained during many years to come. Further training in these topics will have to be organized in the coming years. It is a sign of hope that important training institutions are now introducing these new mind-sets to their students.

Acknowledgements

We thank the members of the organizing committee: Prof. Bea Maes (Catholic University of Leuven and director of Multiplus); Anneleen Penne, (Multiplus); Claudia Claes & Marie-Rose Pauwels, (Hogeschool Gent & University of Gent, and Dept. Of Special Needs) ; Boelina Sikma (De Lovie, Poperinge) ; Brigit Vermeulen (Zevenbergen, Ranst); the hosting institutions and the people who made their time available to host visits and workshops (see table 1)

Table 1 Week programme of thematic week "Integration of care and education of children with multiple disabilities" in Flanders, Belgium 17-21st May 2016

	Workshop /visit	Workshop leader	Location	Duration (h)	# Participants
Tuesday, May 17th 2016	Conference		University of Leuven	6	80
Wednesday May 18th 2016					
'Sense city' - sensory stimulation	Workshop	Jan Pauwels, Sint Oda –	St Oda, Overpelt	3	12
Behavioral problems in children with CISN -	Workshop	Herman Wouters, BE	University of Leuven	3	11
Kanguroo classes mixed-ability classes -	Workshop	Team De Kindervriend, Rollegem	De Kindervriend, Rollegem	2	8
Feeding and swallowing problems in children with CISN–	Workshop	Marleen Dhondt, prof. speech therapy, Arteveldehogeschool, Ghent	Vives University College- Kortrijk	3	7
The Moving Class: promoting activity & movement in children with CISN —	Workshop	M.Romme- Cello Training Centre for People with CISN, Rosmalen, NL	postponed until 2016-17	3	
Early care planning –	Workshop	Boulina Sikma – De Lovie, Poperinge	postponed until 2016-17	2	

Thursday May 19th 2016					
LACCS - Personal project planning physical well-being, alertness, contact, communication, stimulating leisure activities	Workshop	De Geeter & Munsterman, NL	postponed until 2016-17	3	
Basal stimulation – Fröhlich approach	Workshop	Philip Van Maeckelbergh, BE	DVC Deinze	3	14
Communication & Interaction –	Workshop	Katrijn Vastmans, UCLL, Leuven	University College Leuven campus Heverlee	3	3
Class on wheels: including a class of children with CISN in a regular school –	Workshop	Roeland Vollaard – Alkmaar-NL	MFC Zevenbergen, Ranst	2	8
Project of integration of care and education in special education setting for children with CISN-	Visit	Brigitte Vermeulen	Ranst, BE	2	18
Experience it! a methodical approach to stimulate motor, sensory and communication development in children with CISN –	workshop	Thyra Koeleman	University College of Leuven, Campus Diepenbeek, Hasselt	3	13
Inclusive nursery - 'Villa Clementina': for young children with and without disabilities -	Visit	Katleen Ballon & Mieke Destrooper	Zemst, BE	2	5
Inclusive classes – visit ZON –	Visit		Bergen-op-Zoom, NL	2	5
"Put a comma in your ear" Stories of children with severe multiple disabilities-	Artistic/poetic / humorous evening	Ad Goos	*University College Ghent*	2	300
Friday May 20th 2016					
Mobile teams – how to set up support in inclusive schools" -	Workshop & visit	Dries Cautreels & team DVC Sint Jozef	DVC St Jozef, Antwerpen	3	6
Communication in children with CISN' –	Workshop	Heleen Neerinckx & Sarah Nijs, University of Leuven, department of special needs education	University of Leuven	2,5	11
Project of practical integration of care and education in a special education setting	visit		'Sint Fransiscus'Roosdaal near Brussels	2	5
Project of practical integration of care and education in a special education setting	Visit		Ter Heide'Genk, BE	2	6
Project of practical integration of care and education in a special education setting	Visit		Emilius school Eindhoven, the Netherlands	3	5
Saturday May 21, 2016					
Inter-professional case conference	Interdisciplinary seminar	Team Ganspoel, Villa Clementina & Het Veer	Het Veer, St Niklaas	2,5	25

France

Presentation of the experiences with the pilot training in France

Christine Plivard[13]

The Project

For several years, CESAP has put in place a one–day introductory training for the new managerial staff. It takes place every two years. The association wishes to extend this type of approach by allowing all employees to access. The introductory day for specific CESAP directors will remain as such.

With this new project, all institutional staff, from executives to staff being in contact with the clients on the work floor, with contracts limited or unlimited in time, will spend a « welcoming time » in the institution, followed by a "common core" training on key aspects of our mission to the people in a situation of multiple disabilities.

During these « integration days », one of the goals is to see what kind of training courses participants are likely to ask from their direction, in order to enhance their job-related skills and develop new skills (a personal development plan). These integration days will take place as part of the plan developed with our European Enablin+ partners.

The maximum number of participants is 20 per session (possibly more, in function of needs)
The introductory course is open to people newly employed by CESAP, with a contract of unlimited duration (and if the number of participants allows, also newly employed professionals for a limited time of at least 1 year)

Calendar 2016

- Session 1 – **Monday 21 & Tuesday 22 March 2016**
- Session 2 – **Tuesday 31 May & Wednesday June 1st 2016**
- Session 3 – **Wednesday 21 Sept. & Thursday i 22 Sept. 2016**
- Session 4 – **Thursday 8 & Friday 9 December 2016**

Programme of the « Integration days »

1st Day

Day 1 – morning session (first half)

Welcoming new employees

Welcome word by a representative of CESAP
Presentation of the two days
Presentation of CESAP :

- Its history
- Its association project
- Its values
- Its functioning
- its orientations

The concept of « personal training plan »

Day 1 – Morning session (second half) and afternoon

Common core training « discover or re-discover multiple disability (polyhandicap)»

Part 1 –
About polyhandicap and taking care

- What does it mean « polyhandicap »
- Theoretical insights about the person with multiple disabilities
- From a professional viewpoint
- The person with multiple disabilities
- An individualized project
- Accompanying (supporting) the family

---

[13] Trained as a psychomotor therapist, she is now directing CESAP Formation, the training organisation linked to CESAP

2nd Day 2

Day 2 – morning

Common core training « discover or re-discover multiple disability (polyhandicap)»

Part 2 – The core of « taking care »

- Medical aspects
- Accompanying daily life

Day 2 – afternoon

Common core training « discover or re-discover multiple disability (polyhandicap)»

Part 2 (cont.) – The core of « taking care »

- An individualized project
- Prevention of psychosocial risks
- Conclusion and evaluation of the two days

Proposal for a training trajectory

CESAP FORMATION
DOCUMENTATION · RESSOURCES

1st year: discover or re-discover multiple disability (polyhandicap) (Duration: 2 days

The reality of the concept of multiple disability (polyhandicap) remains, for all practitioners, a source of multiple questions. This module proposes elements of an answer and reflection pathways.

Day 1: About polyhandicap and taking care

Welcoming PARTICIPANTS:
Presentation of the two days
Presentation of CESAP:

- Its history
- Its association project
- Its values
- Its functioning
- Running projects
- its orientations

Objectives of the training

1. Share common values
2. situate and identify multiple disabilities (polyhandicap) among other forms of disability
3. identify the impact of multiple disabilities in the development of the person
4. having a comprehensive approach of the subject, by virtue of entanglement of somatic and psychic problems specific to this population
5. take into account the comfort of the person in the course of the day
6. recognize and implement support which is adapted to the needs of the person
7. the question of intimacy and sexuality
8. relating to the person with multiple disabilities
9. think about relations with the families and loved ones
10. give all importance and meaning to an individualized project
11. assert one's professional identity in a mission of accompaniment to these people

❖ ***About multiple disabilities (polyhandicap)***

- History of polyhandicap (multiple disabilities)
- Question of terminology and definition
- To be disabled or to have disabilities?
- Be connected to, to be in relationship with, the person with disabilities

❖ ***Work on theoretical knowledge concerning the person with multiple disabilities***

- his development
- his somatic skills: sensory, physical, motor, functional
- his psychological skills: mental, emotional, cognitive, intellectual

❖ ***From a professional point of view***

- ✓ Ethics and deontology at the heart of the accompaniment
- ✓ Mission and roles of everyone: to situate one's function in the system
- ✓ From theory (one's previous training) to practice (working with the person)
- ✓ multidisciplinary, great source of enrichment, but also of conflict

❖ ***The person with multiple disability***

- ✓ Who is « this person » with multiple disabilities?
- ✓ What are his expectations, his needs?
- ✓ Intimacy and sexuality: issues to arise
- ✓ the notion of quality of life

❖ ***The individualized project***

- ✓ Give meaning to accompaniment or support
- ✓ The importance of relationships in the project
- ✓ Different activities
- ✓ Shared values
- ✓ make sure that the project is actually really the person's
- ✓ well-being and quality of life in the heart of the project
- ✓ the tools of CESAP (e-file, reference frameworks for observation, P2CJP – evaluation of cognition of R. Scelles)
- ✓ The development of cognitive skills
- ✓ Learning and activities adapted to the different ages of people with multiple disabilities

❖ ***Supporting the family***

- ✓ Family dynamics and multiple disability
- ✓ relations with the families and loved ones: how to hear them without judging them

- ✓ towards a real partnership
- ✓ rights of users and legal representatives
- ✓ medical secret, shared secret

2nd day: the core of care

OBJECTIVES

- ➢ Understand the health issues related to multiple disability
- ➢ know how to observe and transfer observations to daily life
- ➢ a process of constant prevention
- ➢ understand how the gestures of everyday life improve the quality of life
- ➢ improve everybody's ability to create appropriate solutions, to find more appropriate interventions, to adapt one's behaviour depending on the needs of the people with multiple disabilities
- ➢ to acquire knowledge on the physiology of the various functions used by humans for feeding and nutrition
- ➢ ensure secure and comfortable transfers for all, in order to prevent work-related musculoskeletal disorders (MSDS)

CONTENT

- ❖ ***Medical aspects***
  - ✓ Maturation and brain development
  - ✓ Neuro-motor disorders and their orthopaedic complications: prevention and support
  - ✓ sensory disorders: Physiology and pathology
  - ✓ respiratory disorders
  - ✓ Feeding and Digestive Disorders
  - ✓ Epilepsy
  - ✓ pain: the importance to assess, the obligation to treat
  - ✓ ageing and palliative care

- ❖ ***Daily living support***
  - ✓ Taking care of the body & hygiene
  - ✓ Meal times: their importance, their objectives and
  - ✓ The swallowing process and its disorders
  - ✓ Digestion and its disorders
  - ✓ daily structure & reference points and their meanings
  - ✓ equipment, gestures to avoid, and modalities to put in place
  - ✓ being sensitized to the pain of the other on a daily basis

- ❖ ***The individualized project***
  - ✓ The proportion of care in the individualized project
  - ✓ the place of nutrition
  - ✓ towards a maximum of autonomy
  - ✓ autonomy and dependence: human and technical aid
  - ✓ comfort
  - ✓ facilities, postures and positioning
  - ✓ mobility, changing places
  - ✓ motor aspects, movement
  - ✓ pain and palliative care

- ***Prevention of psycho-social risks***
  - ✓ Taking care of oneself in order to take care of others
  - ✓ the importance of working in a team
  - ✓ Communication and access to information

CONCLUSION & EVALUATION

- Share corporate values
- expected qualifications
- to design a real training trajectory

DIDACTIC METHODS

- Theoretical contributions and skills
- Practical work on the technical actions essential to the comfort and safety in daily life (meals, mobility...)
- Analysis of the practice and study of concrete cases brought by the participants and / or trainer
- looking for appropriate responses to the cases presented by students
- development of reflection and working tools corresponding to the needs of the trainees

2nd year: clarifying one's role and function

According to the profession, we propose specific workshops:

- Discover and rediscover multiple disability –an in-depth course (: 4 days)
- The function of the daily life support assistant working with people with multiple disabilities (: 3 days)
- The specificity of a specialized educator working with people with multiple disabilities (: 3 days)
- To be a physiotherapist working with people with multiple disabilities (4 days)
- To be an occupational therapist working with people with multiple disabilities (4 days)
- To be a nurse working with people with multiple disabilities (7 days)
- To be a medical doctor working with people with multiple disabilities (3 days)
- To be a speech therapist working with people with multiple disabilities (3 days)
- To be a psychologist working with people with multiple disabilities (4 days)
- To be a director of an institution dealing with people with multiple disabilities (3 days)
- To work as an executive in an institution dealing with people with multiple disabilities (3 days)
- The specificity of an administrative job and a reception desk job
- The specificity of general maintenance jobs
- Cooking art adapted to the needs of people with multiple disabilities

3rd and following years: to refine one's professional practice, or how to become an expert

CESAP FORMATION DOCUMENTATION RESOURCES offers trainings that will help to learn new skills: study days, vocational training, medical days, conferences, thematic days… We invite you to consult our training catalogue

More information

Comité d'Etudes, d'Education et de Soins Auprès des Personnes Polyhandicapées
62, rue de la Glacière – 75013 PARIS
Tél : 01 53 20 68 58 – Fax : 01 53 20 68 50
www.cesap.asso.fr – formation@cesap.asso.fr
N° d'agrément 11/75/08 582/75 – N° INSEE 775 662 00465 – Association déclarée N°65/535 Reconnue d'UTILITE PUBLIQUE décret du 3-07-70 J.O. du 12-07-70

The Netherlands

Experiences with the pilot in the Netherlands

Mia Nijland

In the Netherlands we organised a pilot of two days. The pilot consists of two modules spread over two days. The central theme is: The target group, Quality of Life (QoL), QoL for this target group, the QoL Curriculum, the common working standard for targeted support and stimulate children and (young) adults with CISN.
First trainings day: 6/09/2016
Second trainings day: 14/09/2016

Participants

There were 12 participants. The group consists of several disciplines and different school levels: middle and higher professional education and university. They all learned with each other. They came from 8 different organisations. We have divided the group into pairs. Each pair has worked with its own case during the training.

Training day 1

The first day was marked by the target audience: who are they? The focus was on the situation in the Netherlands. We have talked about the UN Convention, the capabilities of Nussbaum and the Quality of Life domains. The next step was to experience what this means for yourself. And then, what does it mean for your case? Do you see significant differences? The response was undeniable. This way of looking gives new insights. Homework after this day: write an 'holistic picture of the person' on their case.

Training day 2

Every pair did write a 'picture of the person' of their case. The couples have read this from each other and provided feedback. The trainer of this pilot (Mia Nijland) then tells about the QoL Curriculum and their application in practice.

1. A: Who is the child? Inventory and getting the picture
   B: Personal profiles
   C: Holistic picture of the person

   Day 1
2. Current day-weekprogram
3. Desired day-weekprogram
4. Goals (Perspective / main objective / work objectives)

   Day 2
5. Getting started (plan and carry out activities)
6. Getting started (monitor and evaluating of activities)

This trainings day we focused on step 2, 3 and 4.

Reactions

'It's just a good, crisp and clear product' 'It's for everyone!' 'Parents will understand this!' 'Focus on person and not on the stamp' 'Everyone gets back motivated to continue to work' 'New insights and there is still much potential' 'You can already perform tomorrow' 'It's nice that it's not whether right or wrong; You can also learn' 'an eye opener; you zoomed in on what we do and they actually .... Confrontational but good. This does stay (awareness) and encourages critical look and work. 'Curious to look after a period, how it continued in practice?'

Curriculum 'Flourish and Stimulate'

Mia Nijland - Nijland & Kroes – Enablin+ - 2016

The curriculum 'Flourish and Stimulate' is a (seven) step roadmap meant to train professional staff how to support and stimulate vulnerable persons with complex intensive support needs in their living- and learning situation. It involves persons which are (to a lesser or greater extent) dependent on the support system. Besides, it is for those where participation in local society does not take place automatically due to barriers in their living conditions.

The curriculum assumes an ecological approach. The associated approach revolves around the person with CISN as a whole person-in-context. In everyday life, vulnerable persons with (intensive) support needs are often reduced to their role as client, their diagnosis or their (hard to understand) behaviour. This curriculum avoids this by incorporating a direct link between vision and approach.

The curriculum is a roadmap (based on the methodological framework of Prof. Carla Vlaskamp) with room for individual applications. It consists of seven steps, which can be taken by the person himself (and parents) together with a relevant professional (family coach, advisor, lifestyle coach, health coordinator, etc.). It involves the following steps: how do we perceive the person, current 24/7 arrangement, desirable 24/7 arrangement, long and short-term goals, execution of (lifestyle) program, evaluation and finally, documentation. The seven main questions alongside each step should be answered and elaborated by following the corresponding instructions (see table below).

Process	Steps	Main question per step
1. Broad Diagnosis	Image	Who is the person in his or her current living situation (holistic)?
2. Design	Current arrangement	What conditions and requirements are associated with a suitable 24/7 arrangement (integral)?
3. Concretisation	Desired arrangement	What does the 24/7 arrangement look like if the conditions are met?
4. Prioritizing	Goals	What goals are set for the (lifestyle) plan and (lifestyle) program?
5. Application	Application	What is the day-week program, and how do we achieve this?
6. Evaluation	Monitor and review	How will the implementation be assessed and how are the results measured?
7. Documentation	Lifestyle plan	Is everything documented?

Central pillars in the curriculum are step 1 and 4, which are based on the support program of C. Vlaskamp (Vlaskamp & Vanderputten, 2009). In addition to this, the steps are also based on domains and principles like Nussbaum's Capability Approach (Nussbaum, 2011), the Quality of Life concepts of the IASSIDD (Schalock & Verdugo), UN Convention of the Rights of People with Disability and the ICF framework of the World Health Organisation. Furthermore, additional knowledge resources are used: learnability and modifiability (Feuerstein, 1991), criteria for person-centred planning processes (Schwartz, Holburn and Jacobson, 2000), and existing care and education curricula. In the lifestyle plan (step 7), information is translated and summarized by means of nine lifestyle domains related to the development tasks which are associated to the calendar age and different life events of the person that could be going on (JGZ - Youth Health in the Netherlands).

The roadmap facilitates the person and those in the support system. The roadmap is more than a support plan. The roadmap linked to a database coupled with information (see infographic: toolbox). You choose from a wide range of applications by each step (which are available for health care and education). The toolbox provides (grounded) information for all steps (for example a list of profiles in step 1b or activity programs in step 5). A plurality of orderly information and inspiration for the support and learning questions of for both the target and the individual. It helps to achieve balance and custom care in everyday life at home, leisure, school, daily activities and work.

The roadmap has three functions:

1. Advisory system for professionals - The roadmap helps professionals in assessment, arranging, imaging, diagnostics for healthcare, education, care, treatment and rehabilitation. For example, of municipalities or allocation committees are potential users.

2. Individual roadmap - For individual application the roadmap provides guidelines for a (lifestyle) program with fixed steps, always with a personal interpretation. It helps:

a. Completing and directing daily life
b. In choosing and tracking their own (healthy) lifestyle
c. in the creation and tracking their own lifestyle plan

The degree of self-management and lifestyle of a person are inextricably linked. The roadmap brings both together and provides advice for an adequate and appropriate lifestyle. A personal lifestyle program is central in this, from design until evaluation. By assessing someone's lifestyle (adjust and guide if necessary), a contribution is made to (a better) quality of life of the person. It guarantees the necessary balance between, for example physical and psychological approaches to certain questions or problems. The personal roadmap could be managed by the individual (or his most relevant mentor) through the use an electronic environment. The individual can do this with parents and family coach, process coordinator, mentor or these representatives do on behalf of him or her. Through an electronic (cooperation) platform can everyone be involved. Professionals have such access and can connect and add things. In this way, the person does not insert in various professional sub-plans but he or she manages their own (lifestyle) process and plan.

3. Systematic work for professionals - The roadmap provides support for professionals in care, treatment and education in the form of a work standard and (remote) monitoring system, which helps to design, facilitate and achieve an appropriate (lifestyle) program. Not the organization is in control but the person himself (or his parents or mentor).

Integrating care and education
The roadmap helps establish cooperation between different disciplines. It will be suitable to achieve integration and cooperation between care and education for the target group (on target group, group and individual level). The roadmap provides opportunities to bring the best of both worlds together, through combining (existing and evidence based) methodical framework and existing didactic framework.

References

Feuerstein, R. & Feuerstein, S. (1991) 'Mediated learning experience: a theoretical review.' In R. Feuerstein, P. Klein & A. Tannenbaum (eds), *Mediated Learning Experience: Theoretical, Psychosocial and Learning Implications*, pp. 3–52. London: Freund Publishing House.

Nussbaum, M. (2011), *Creating Capabilities. The Human development approach.* Cambridge (MA): Harvard University Press

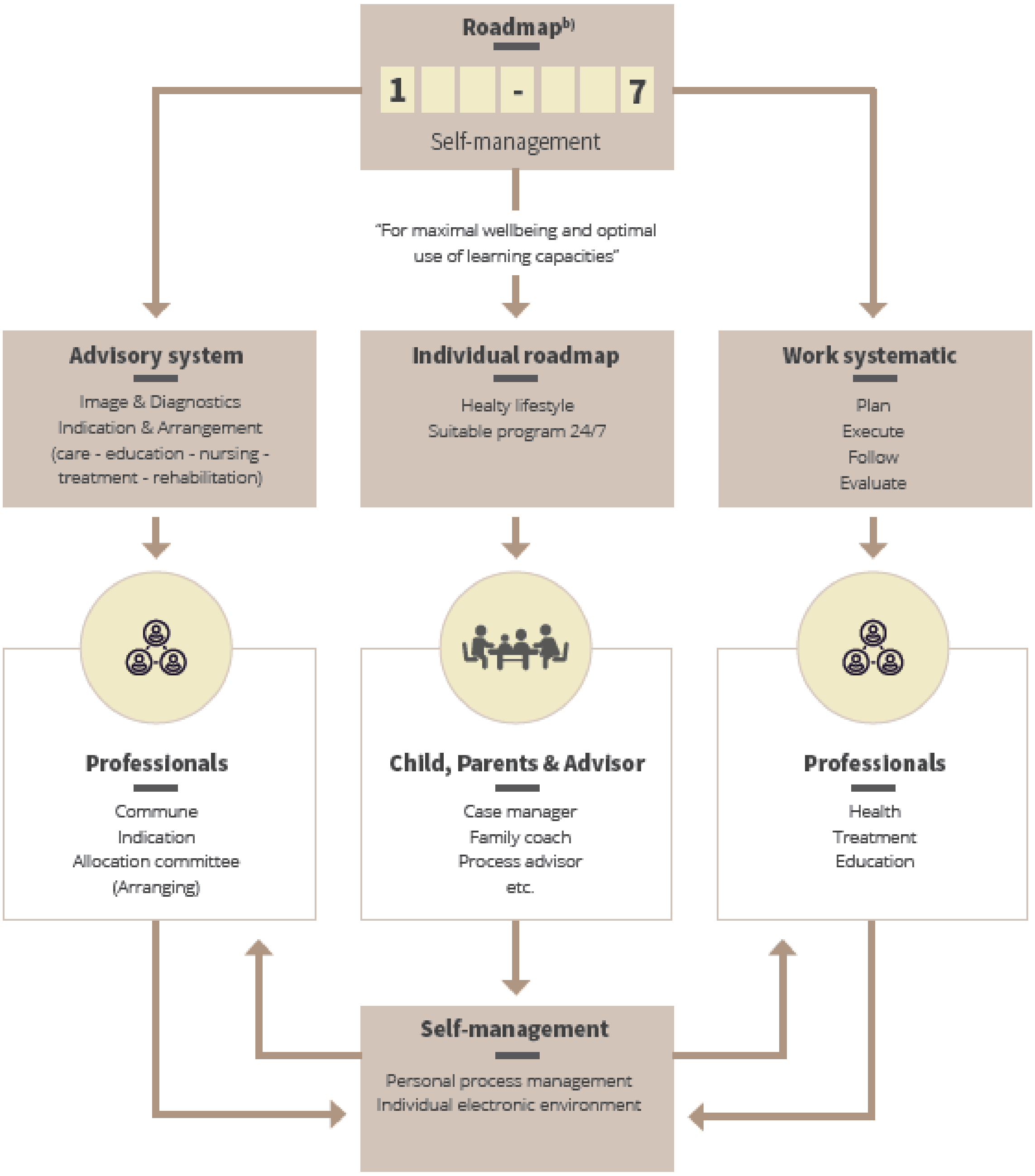
Schalock, R.L, Verdugo, M.A. (2002) *Handbook on Quality of Life for Human Service Practitioners*. Washington, DC, USA: American Association on Mental Retardation

Schwartz, A.A., Holburn, S.C. and Jacobson, J.W.(2000) Defining Person Centeredness: Results of Two Consensus Methods , *Education and Training in Mental Retardation and Developmental Disabilities*, 35 (3): 235-249

Vlaskamp, C., & van der Putten, A. (2009). ***Focus on interaction: The use of an Individualized Support Program for persons with profound intellectual and multiple disabilities****. Research in Developmental Disabilities*, *30*(5), 873-883. DOI: 10.1016/j.ridd.2008.12.005

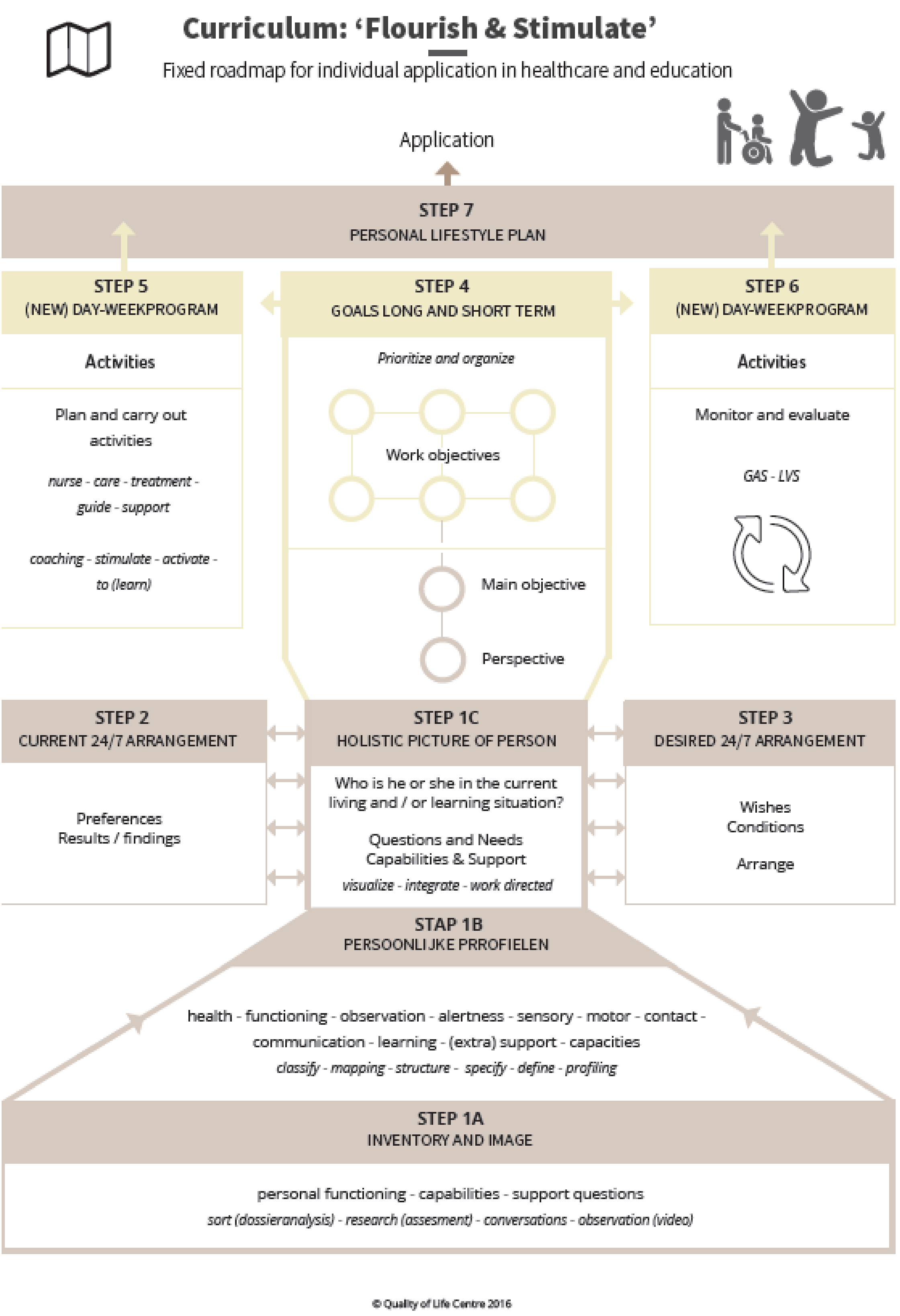
Curriculum: 'Flourish & Stimulate'

For balance and custom care[a] at home - leisure - school - day care
(For children and youth with complex intensive support needs)



[a] Advice, Profile, Arrangement & Program

[b] Fixed roadmap for individual application based on support programs C. Vlaskamp



Curriculum: 'Flourish & Stimulate'

Fixed roadmap for individual application in healthcare and education

Application

STEP 7
PERSONAL LIFESTYLE PLAN

STEP 5
(NEW) DAY-WEEKPROGRAM

Activities

Plan and carry out activities

nurse - care - treatment - guide - support

coaching - stimulate - activate - to (learn)

STEP 4
GOALS LONG AND SHORT TERM

Prioritize and organize

Work objectives

Main objective

Perspective

STEP 6
(NEW) DAY-WEEKPROGRAM

Activities

Monitor and evaluate

GAS - LVS

STEP 2
CURRENT 24/7 ARRANGEMENT

Preferences
Results / findings

STEP 1C
HOLISTIC PICTURE OF PERSON

Who is he or she in the current living and / or learning situation?

Questions and Needs
Capabilities & Support

visualize - integrate - work directed

STEP 3
DESIRED 24/7 ARRANGEMENT

Wishes
Conditions

Arrange

STAP 1B
PERSOONLIJKE PRROFIELEN

health - functioning - observation - alertness - sensory - motor - contact - communication - learning - (extra) support - capacities

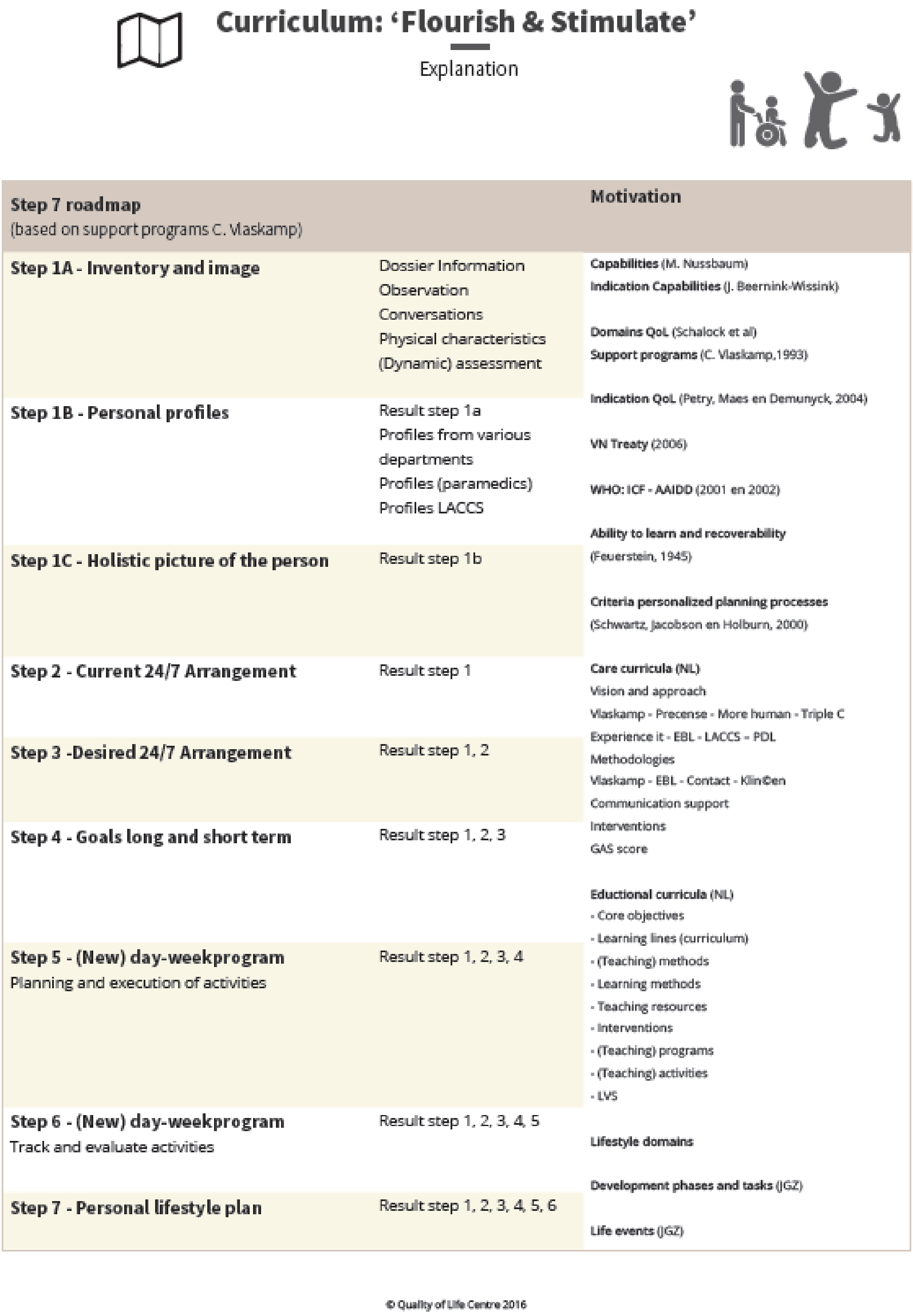
classify - mapping - structure - specify - define - profiling

STEP 1A
INVENTORY AND IMAGE

personal functioning - capabilities - support questions

sort (dossieranalysis) - research (assesment) - conversations - observation (video)

© Quality of Life Centre 2016



Curriculum: ‘Flourish & Stimulate’

Explanation

Step 7 roadmap (based on support programs C. Vlaskamp)		**Motivation**
Step 1A - Inventory and image	Dossier Information Observation Conversations Physical characteristics (Dynamic) assessment	**Capabilities** (M. Nussbaum) **Indication Capabilities** (J. Beernink-Wissink) **Domains QoL** (Schalock et al) **Support programs** (C. Vlaskamp,1993) **Indication QoL** (Petry, Maes en Demunyck, 2004) **VN Treaty** (2006) **WHO: ICF - AAIDD** (2001 en 2002) **Ability to learn and recoverability** (Feuerstein, 1945) **Criteria personalized planning processes** (Schwartz, Jacobson en Holburn, 2000) **Care curricula (NL)** Vision and approach Vlaskamp - Precense - More human - Triple C Experience it - EBL - LACCS - PDL Methodologies Vlaskamp - EBL - Contact - Klin©en Communication support Interventions GAS score **Eductional curricula** (NL) - Core objectives - Learning lines (curriculum) - (Teaching) methods - Learning methods - Teaching resources - Interventions - (Teaching) programs - (Teaching) activities - LVS **Lifestyle domains** **Development phases and tasks** (JGZ) **Life events** (JGZ)
Step 1B - Personal profiles	Result step 1a Profiles from various departments Profiles (paramedics) Profiles LACCS	
Step 1C - Holistic picture of the person	Result step 1b	
Step 2 - Current 24/7 Arrangement	Result step 1	
Step 3 -Desired 24/7 Arrangement	Result step 1, 2	
Step 4 - Goals long and short term	Result step 1, 2, 3	
Step 5 - (New) day-weekprogram Planning and execution of activities	Result step 1, 2, 3, 4	
Step 6 - (New) day-weekprogram Track and evaluate activities	Result step 1, 2, 3, 4, 5	
Step 7 - Personal lifestyle plan	Result step 1, 2, 3, 4, 5, 6	

Enablin Quality of Life through meaningful learning :

Common Core Training for parents and professionals supporting children with complex and intensive support needs

Mia Nijland, NL

Why this training?

During the needs assessment research (Work package 1 – see Lebeer et al., 2015), it became clear that children and young people with very complex and intense support needs, including those with PIMD (profound intellectual and multiples disabilities), are too often too passive and rarely involved in participation in ordinary education or life in general.

This happens because people don't believe it is possible nor feasible. That is why mind-sets have to be tackled in the first place. Research has shown (Maes, 2014) that children with very few exceptions, are capable to learn, and could be activated more. The staff should learn better what it means "to activate" and "to learn" in this case, and how to do this in practice. This has to do with know-how, learning from examples, becoming creative, etc. The support staff needs more time to reflect on their own actions and how children can be supported in this way. Recent research showed that supporting staff should be encouraged to have more time and attention to interaction and the learning processes of children (Neerinckx, 2015). This has to do with creating the time, believing it is possible, and making it organizationally possible.

Professionals, in experiencing time pressure, run a risk of becoming overburdened, and becoming burn-out. Therefore, they need more suggestions, in order to know more concretely how they can deal with children in a different way and organize their work differently. The training wants to empower support people by reinforcing their belief system that they are capable in supporting children with CISN to facilitate meaningful learning, and to set up meaningful learning environments, which facilitate maximally participation to society. We want to elicit capacities and values, in order to fulfil their work with an even greater motivation.

The training is based on three frameworks:
(1) The principles of the UN Convention on the Rights of People with Disability (UNCRPD);
(2) Quality of Life principles of Schalock (Schalock Petry, Maes & Vlaskamp)
(3) The Capability approach (Nussbaum).

Target group students

- Mainstream and special education staff
- personal assistants daily living (professional assistants, educators, volunteers)
- Support staff (.e.g. educational psychologists,
- parents,
- medical & rehabilitation staff (e.g. nurses doctors, physiotherapists, speech therapists, occupational therapists, psychologists
- representative organizations for the disabled,
- vocational training staff at secondary and continuous professional development level

… in short: everybody who is involved with children with complex and intensive support needs[14]. When the term "*support people*" or "support staff" is used in the following text, we mean professionals of all professions or parents, unless otherwise specified.

---

[14] In Anglosaxon literature mostly called "PIMD" (profound intellectual and multiple disabilities); in French "polyhandicapés"; we want to introduce the term CISN to stress the needs side and the potential.

Entry requirements

We want to take into account the following requirements:

- Motivation for learning
- Feeling involved or having an interest in supporting children and young adults with CISN
- Being able to apply or practice the training content

The level of education or degree of the students is not part of the requirements because an interdisciplinary context is the ideal learning context. An inclusive learning approach is an essential part of the course. Learning tasks will be differentiated based on learning styles of the students. For example: for the preparation assignment the students can choose between an observation of a child, watch and reflect on a video, read an article, …. During the following contact sessions, students can give feedback in learning groups to each other, or the assignment can be discussed in the group.

General objectives

1. To raise awareness in *support people*, that it is possible and worthwhile to activate children with complex and intensive support needs (CISN).
2. To train *support people* to become aware of their own mind-sets (belief systems) regarding the possibilities of this target group regarding learning and participation
3. To train *support people* in implementing the quality of life-framework in supporting the development and participation of children and young adults with complex intensive support needs (CISN)
4. To enhance the quality of support in important aspects of daily living, such as feeding, hygiene, communication, relationships, learning ,play, etc.
5. Raise awareness that children with CISN, even those with the most severe impairments and restrictions in participation, are entitled to become recognized as full members of the community; hence the course will contribute to the transformation of "classic" institutions towards service-centres oriented at inclusion
6. To train *support people* in facilitating social and educational participation, activities and learning;
7. To increase self-efficacy of parents and professionals supporting children and young adults with CISN
8. Increase the motivation, fun, satisfaction and inspiration in supporting children with CISN, in order to prevent burnout and empowering professionals and parents
9. To enable QOL of children with CISN through the focus on meaningful learning.
10. To explore and create individually adapted and supported learning curricula for children with CISN
11. To provide a framework, plan for action and toolbox for professionals in special and mainstream schools or care centres for children with CISN
12. To promote a standard for guidance/support which provides enough space for individual differences and approach

Day 1:

"Who are the children with CISN and what are their needs?"
"Quality of Life (QOL) and participation"
Directions for a good life

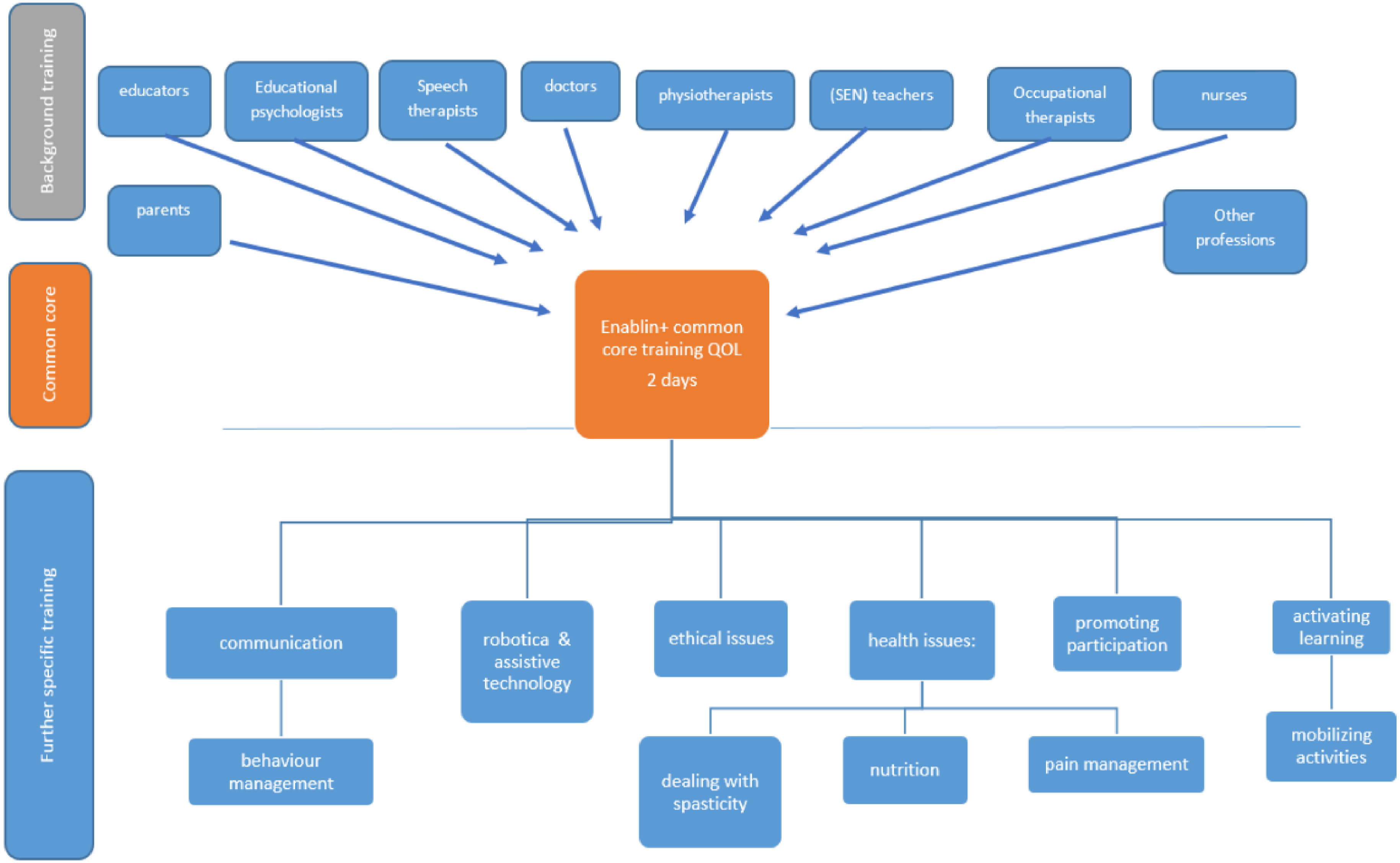
Day 2:

Flourishing and stimuLEARNING"
Curriculum for integrated care & education
Getting organized with a methodical and didactic framework

After:

"A glimpse of various teaching methods and tools''

Competences are described for each module:


Background training
educators
Educational psychologists
Speech therapists
doctors
physiotherapists
(SEN) teachers
Occupational therapists
nurses
parents
Other professions
Common core
Enablin+ common core training QOL
2 days
Further specific training
communication
behaviour management
robotica & assistive technology
ethical issues
health issues:
dealing with spasticity
nutrition
pain management
promoting participation
activating learning
mobilizing activities

Abstracts of Workshops

Workshop 1
How to train behaviour management

Moderator: Giorgio Seragni (Don Gnocchi Foundation, Pessano)
Discussant: Petra Poppes (‘s Heeren Loo & Skils bv, NL)

Case 1:
How to train behaviour management

Petra Poppes[15] (‘s Heeren Loo, NL)

Case description: Eva

Eva is 27 years old. Eva is described by her parents and staff as a cheerful lady who likes to be around others. According to all those involved Eva enjoys listening to music, playing with soft materials, swimming and being outside (no matter what the weather is like).
Eva has a profound intellectual and multiple disability. She has microcephaly, epilepsy (seizures don’t occur because of the medication she is taking) and diabetes. Eva has a visual impairment. She has trouble seeing contrasts. A yellow cup on a white table is difficult to see for her. Colour contrasts are important. There does not appear to be a hearing problem. Eva cannot walk and is in a wheelchair. Eva can hold objects, explores them with her mouth but according to staff she mostly throws the objects on the ground. Staff say it is difficult to capture Eva’s attention and they fear she gets bored.

Eva appears to be able to make small associative connections. For example when staff puts on her coat, she knows she is going outside. Eva’s parents indicate that they think Eva has little understanding of the world around her. Eva appears to recognize her family and familiar staff. She appears to have a preference for staff she knows well. Staff indicate that Eva does not need others to get involved in activities. Her parents find, however, that she needs a lot of stimulation and support to be able to get involved in activities. Staff and parents do not think Eva can make choices.

According to staff and parents, Eva expresses pleasure and displeasure through posture, sounds and facial expressions. She knows, according to staff, how to draw attention. She appears to do this through laughter, taking someone’s hand, pulling someone’s finger or Jersey. When Eva feels happy she laughs, is focused on the environment and reacts to contact. When she is exited she moves her arms up and down and stomps her feet. Eva rarely cries. This is only seen when she has a doctor’s appointment or is in pain. When Eva is not feeling well or does not like something, she tends to scream. This behaviour is seen daily and in several situations. Parents indicate that Eva used to scream for hours on end when she was still living at home (it started at a very young age). They say that the screaming still occurs on a regular basis when Eva is at home during the weekends. There does not appear to be a medical reason for the behaviour. Both parents and staff find it difficult to understand this behaviour and don’t know how to reduce or prevent it.
I will present further data on Eva during the session and will illustrate with a short videoclip.

After discussion on how to go about the support of Eva and the case that will presented by a participant, I will explain in detail how we used an individualized support program developed by Carla Vlaskamp to better understand the behaviour Eva shows.

---

[15] Petra Poppes is health care psychologist at the‘s Heeren Loo Zorggroep in The Netherlands and works as researcher/teacher at the University of Groningen.Petra Poppes has worked as a health care psychologist since 1997 and has specialized in the support of children and adults with a profound intellectual and multiple disability. She has completed her PHD project last year on challenging behaviour in people with PIMD.

Resources

General – film about individualized support program

Vlaskamp, C., & Van Der Putten, A. (2009). Focus on interaction: The use of an individualized support program for persons with profound intellectual and multiple disabilities. *Research in developmental disabilities*, *30*(5), 873-883.

Links:

www.rug.nl/news-and-events/video/archive/unifocus/0525-unifocuspoppes

www.rug.nl/news-and-events/video/1021-unifocusvandenbosch

Case 2:

School inclusion in reference to behavioral features

M. Cometa[16], F. Sacchi[17], MT. Giordano[18] (Don Gnocchi Foundation, Legnano)

To develop the theme of school inclusion, with reference to behavioural traits, we will present two clinical case studies that describe, on one hand, the success of inclusion at school, on the other, the failure to include a disabled child in a classroom.

M. is a 14-year-old girl with Epidermal Nevus Syndrome with severe intellectual disability and dyspraxia. She had good communication skills, although she is non-verbal. Interpersonal and cognitive competences are poor and she suffers from attachment disorder. She pays attention to others, but is not empathic and often has provocative behaviour to attract attention.
She attended nursery school and Kindergarten with the aid of a support teacher, but she had to subsequently stop her schooling.

In 2010 our Day Care Rehabilitation Unit for children with disabilities took charge of her and only in 2012, at the age of 10, did she start attending regular primary school with normal children, thanks to the educational work carried on by our unit which aimed to reduce problematic behaviour.
At present, she attends primary school on a daily basis for a total of 10 hours weekly. At the same time, she also attends the Day Care Unit for a total of 20 hours weekly.

Her inclusion at school gave good results thanks to the collaboration between teachers, our service and the family.
In the course of time, the educational intervention was oriented towards socialization opportunities, school inclusion and a sense of belonging towards her class. M. has, thus, the possibility of participating in the whole school life.

E. is a 12-year-old boy with Down syndrome, severe intellectual disability and motor problems. Spoken language is just now emerging, characterized by verbal imitation with no communicative intent. He understands simple and contextual orders and intentional communication intentionality is present.

His behaviour, not always appropriate for the context, is characterized by provocative attitudes often aimed at the adult who is his reference point. He behaves this way to avoid frustration or it is his answer to what he perceives to be the expectations of the adult.

He attended both nursery school and Kindergarten always with the same support teacher. He attended primary school at regular age, before the Day Care Rehabilitation Unit took charge of him in 2013.

---

[16] MD Child Neuropsychiatrist, Don Gnocchi Foundation
[17] Professional Educator, Don Gnocchi Foundation
[18] Psycologist, Don Gnocch Foundationi

He attended primary school for a total of 10 hours weekly. At the same time, he also attended the Day Care Unit for a total of 20 hours weekly.

The lack of collaboration and sharing of our project on behalf of the school and the family did not permit the transfer of the educational intervention, therefore, the child uses behavioural attitudes differently, not always in a functional way and according to the context he finds himself in.

E. spent very little time in regular class with his peer also during not structured activities and play. On the contrary, to what usually happens, his mainstream school educational process finished with grade 5, without taking into consideration the possibility of giving him a transitional extra year.

In conclusion, we can assess that factors that mainly determine or help school inclusion and behaviour management of the child are:

- Sharing the educational project (PEI) with the family, the school and the Day Care Unit:
    - ✓ Scheduled meetings before and after filling out the PEI, along with regular meetings, or sporadic meetings when necessary, during the year
    - ✓ Having teachers observe the child when he attends the Day Care Unit
    - ✓ Having professional educators observe the child at school
- Compliance between family and school
- Compliance between family and Day care Unit
- Compliance between school and Day Care Unit
- Meetings to introduce the child between Day care Unit and the teachers of the elementary school
- Collaboration and advice from the Day Care Unit regarding the use of educational tools (communication tables, agendas, visual material to support school activities)
- To establish in advance who will be the support teacher throughout the child’s entire schooling
- Support teachers and teaching staff’s psycho-pedagogic preparation to improve the welcoming of the disabled child’s entrance in the classroom
- School flexibility regarding the child’s attendance
- School inclusion in the home territory

Workshop 2

How to train physical/health wellbeing aspects

Moderator: Odoardo Picciolini (Policlinico of Milan Foundation)
Discussant: Paolo Banfi – Carlo Bianchi (Fondazione Don Gnocchi, IT &
Anne-Marie Boutin CESAP, FR)

Case 1: Game, learning and integration: having a good time being together in a clever way

Roberta Mapelli, Flavio Cimorelli (Don Carlo Gnocchi Foundation, Centro Santa Maria al Castello, Pessano con Bornago)

ACCANTO ALLA
VITA. SEMPRE

Fondazione Don Carlo Gnocchi
Onlus
Istituto di Ricovero e Cura a Carattere Scientifico

ABSTRACT:
Federico, born May 10th 2005, attends our Rehabilitation Centre as a day inpatient since September 2008.

The child is affected by spastic quadriplegia, partial epilepsy, and mental retardation.
Federico has epileptic seizures since he was 12 hours old, only partially controlled in the first few years of his life. The MRI scan showed several malformations: unilateral polymicrogiria on the right side of the brain and a dysmorphic corpus callosum. Since he was 9 months old, he was inserted in a physical therapy program at our institute, twice a week, for psychomotor retardation and trunk hypotonia, hyperreflexia and strabismus.

Since September 2010, after his mother's death, the child is taken care of and lives with his maternal grandparents. His father goes to visit him every day and handles the medical situation.
In June 2012, he underwent a tenotomy. His seizures are now under control.

These past few years Federico has achieved important results regarding his communication skills and his relationship with others. He is now more interested in his environment, which he explores with more attention, he eats his snack by himself, his meal is made of blended food, he has more control in keeping his head up. He still does not have sphincter control.
The comprehension of his verbal speech appears to be good and this let him to get involved with social activities outside of the day-care centre. He is able to choose from two items (his favourite snack, the game he wants to play, the song he wants to listen to, the video he wants to see, etc…).

To engage his emotional and relational development, Federico was included into a normal class with success. He recognizes his classmates and other students whom he likes very much. He knows how to relate to adults adequately. He loves playing with unstructured sensory material. We use the CAA (Alternative Augmentative Communication) to communicate with him and Federico is able to indicate symbols by gaze and to make simple choices that permit him to communicate and make himself understood and, therefore, to satisfy his personal needs.

In 2014 the child was included in a welfare continuity project to promote social and health care for children with severe disabilities of our day care unit.

The project is born to fight the increasing difficulty that our children and their families encounter when they try to build relationships with others and to support the development of a network for families with children with intensive support needs.

The specific objectives of the project are, therefore, aimed at helping both the child and his/her family. They consist in:

- promoting inclusion in a normal environment
- providing the child with means to get to know new environments
- allowing the parents to share relieve moments with other parents
- assisting and helping parents to think at their sons and daughter out of their homes and institute and into the outside world

Case 2:
How to take care of a child with disability's health and deal with school inclusion, when body structures and functions are severely compromised: the case of E. and her family's fight for her rights

M. Rodocanachi, AM Sanchez, K. Toshimori, V. Gestra,T. Lopez, A. Dal Brun (Don Gnocchi Foundation, Vismara)

We would like to present the case of E. a 7 year old girl, whose rehabilitation care dates back to her birth. E. was born with a mild prematurity (35.5 weeks) after having had a cardiac arrest when still in her mother's womb. Her mother underwent an emergency Cesarean section, after a uterine rupture.

The clinical situation of E. proves to be immediately complex with body structures and functions extremely damaged (cortical-subcortical central nervous system damage with seizures, sucking and swallowing deficit, respiratory problems resulting in 14 days of intubation, anaemia).

An early diagnosis of cerebral palsy, tetraparetic form is formulated. Further development occurs with major health barriers: seizures with EEG hypsarrhythmia at 6 months of age; central visual impairment; chronic pain with acute fever episodes classified as "neurovegetative storm or autonomic storm"; failure to thrive, gastroesophageal reflux and recently PEG tube placement, microfractures due to hypertonia and dystonic contractions. Recently E. undergone gradual orthopaedic multifunctional fibrotomy surgery.

Rehabilitation starts immediately at the neonatal unit with the involvement of the family. When the baby was six months old E. rehabilitation project was transferred from the Neonatal Follow-up Unit of Policlinico Hospital Foundation to the Vismara outpatient rehabilitation service centre. Rehabilitation objectives were shared between the two services.

E. is still followed at Vismara Centre for her rehabilitation project, though along these years her family went in search of other rehabilitative approaches, in the hope of offering the best medical and rehabilitative care for E. Nevertheless parents were always keeping our professionals informed about their different choices, maintaining a relationship of confidence with Vismara's professionals.

E.'s evolution (between health barriers and resources emerged during the developmental course) has allowed the rehabilitation team to collect many signals of participation and intentionality that appeared within the physiotherapy and communication therapy sessions, as well as during music therapy sessions, but also at school and in the family. These signals were shared between professionals. A strong-willed and determined personality of the child emerged, both when she manifests pleasure in participating in activities with adults and peers, as well as to communicate critical moments, often related to health troubles. When E. feels good, one can clearly recognize and interpret her communicative body signals. She pays attention, she waits for her turn to communicate, she has the ability to choose between objects or large figures, she has intentional use of the VOCA, she uses voice modulation if she is happy and participates showing enthusiasm and laughing. If she doesn't feel well, she is able to defend herself with messages such as "leave me alone" accompanied by a whole body reaction with a reduction or an increase of muscle tone and she withdraws into herself.

Currently E. has concluded her inclusive course at kindergarten and is starting primary school. In spite of E.’s critical underlying health factor, her parents have always applied for mainstream school inclusion and have fought to overcome barriers related to her health problems, demonstrating just how essential interaction is among peers, and highlighting important and positive elements for their child and her peers.

The influence of E.’s state of health on activity and participation during the rehabilitation course is analysed as well as the training required for different professionals dealing with her.

Workshop 3

How to train integration of education & support/ aspects of participation/ aspects of learning & activities; design action plans based on observation

Moderator: Jael Kopciowski (Una chiave per la mente, Trieste)
Discussant: Mia Nijland (Expert Centre for Integration & Care, Wijhe, NL

Case 1: Inclusion is possible: presentation of a model of intervention through the experience of a girl with Rett Syndrome

Gabriele Baldo[19], Barbara Bettini[20] (ODFlab-University of Trento and "Il Ponte" Cooperative Association)

The objective of the conference is to illustrate, with the presentation of a case study, a network model to facilitate the participation and the inclusion of students with special educational needs within the classroom setting. Therefore, we will start with the description of the institutional network, which made it possible to find a way to include Stefania, a little girl affected by Rett Syndrome. This network involves the school, the Independent Province of Trento, the Observation Diagnosis and Training Laboratory at the University of Trento, the Provincial Institute for Updating Research and Educational Experimentation, as well as a Social Cooperative Association ("Il Ponte" Cooperative Association in Rovereto). The network has given life to the "Autism Project" (created with the aim to manage the inclusion and the participation to scholastic life of children having autistic spectrum disorders and correlated diseases). The project, which took place in different phases, first consisted in building a relationship between the educator and the child. Then there was an observation stage, which was more systematic in order to identify critical and positive points. The following phase was on how to structure environment. We then proceeded to the next phase: how to define the didactic objectives. We will show how the girl improved at various levels and much importance will be given to the active participation on behalf of her classmates, who facilitated reciprocal exchanges and motivated the little girl to participate and to learn and how this feature determined the success of the project.

---

[19] psychologist and psychotherapist at the ODF lab, University of Trento and "Il Ponte" Cooperative Association
[20] educator at the "Il Ponte" Cooperative Association

Case 2: The "Hinkelpad" [the Hopping Path]: a case of inclusive education involving a child with CISN

Jo Lebeer[21], Beno Schraepen[22], Inge Wagemakers[23] & Luk Dewulf[24] (Antwerp University, Belgium)

Although inclusion in regular schools of children with impairments, who are capable to follow the regular school programme, with minimal adaptations, is quite common in Belgium, inclusive education of children with serious learning difficulties and/or with intellectual disability is much rarer (see part I). There are now about 100 "inclusive education projects" going on. Regular schools, which welcome children with very severe and complex disability, or with complex and intensive support needs, are even rarer. It requires a mind shift towards an inclusive orientation of the school, a willingness to "think flexibly", to create an inclusive culture, to professionalize staff to make a mind shift and create inclusive practices, and a strong networking and teamwork orientation. These pioneering schools have not awaited the change of law of September 2015.

One of these pioneers is the school "Het Hinkelpad" ["The hopping path"] in Antwerp[25], a regular primary school which includes many different children, coming from different cultures and backgrounds; having a wide variety of abilities, some have been diagnosed with a developmental disability; one of the children has multiple disabilities and will be the focus of the present presentation and article.

> K. is a boy of 5 years. He is sociable, loves to play with other children, and loves action. His favourite games are football, hide and seek, playing with building blocks ... What he likes the most is sliding down the slide. He is a fan of Captain Winokio (a children's music project), the children's programme on the Radio, St Nicholas songs and songs from school ... and he loves to dance. This sounds almost like a normal toddler, and that is what he is. Therefore, K. goes to a regular school. What is different is that K. has CP (Cerebral Palsy) and multiple disabilities. He has severe difficulties in language expression (he understands, he speaks a few words and uses gestures to make himself clear), in mobility (he cannot walk alone; he is able to sit and stand with support; he has severe difficulties in hand coordination so that drawing, eating, playing are difficult); he is dependent for all daily activities and needs permanent support.

It was not easy, but the parents found a school nearby. Three years ago, K. was warmly welcomed. At that school, K. learns a lot and he is challenged. The school is also the place where K. is "receiving" all his therapies. In Flanders, it is still exceptional that so much therapy is organized in a regular school, but the inclusion of K's trajectory proves that it is feasible.

His parents constructed an extensive network around K. The teacher works closely with the internal care team of the school, such as the S.E.N. coordinator and the principal. In addition, many external partners are brought to the classroom. Those counsellors or 'special teachers' regularly come along to support the teacher in the classroom. There are co-teachers such as "a mobile assistant teacher" (employed by the multifunctional service centre) who regularly comes to support K for group activities. Students in special needs pedagogy help the teacher several times a week and serve as co-teacher. They are working with the teacher so that K. can participate as much as possible with the other children. Then there are also two external support professionals from the Special Education Needs support centre. One focuses on the visual capabilities of K. and encourages him to focus, the other counsellor looks at the movement functions. A private physiotherapist visits the school four times a week, one of which is during gym class. He helps the teacher and other support staff to move in a good way with K., to help him to walk and perform actions. The speech therapist visits once a week and works on communication and eating, which is an

---

[21] MD PhD, associate professor in disability studies, University of Antwerp, Faculty of Medicine & Health Sciences, Department of Primary & Interdisciplinary Care, Antwerp, Belgium. Coordinator of Enablin+ project jo.lebeer@uantwerpen.be

[22] MA in SEN, lecturer at University College AP, in disability matters; scientific collaborator at University of Antwerp, coordinator of INCENA, study centre for inclusion & enablement.

[23] PhD in Development Studies, researcher and expert equal education opportunities, investigative journalist for broadcast media

[24] Investigative journalist and director for broadcast media and print

[25] www.hethinkelpad.be/Hinkelpad/index.php

important link. The speech therapist provides input to the teacher and other support staff. During team meetings, K's learning objectives are being discussed and agreed so that everyone is working towards the same goals.

K. is supported in many activities, and because he can participate, he is constantly challenged by the group. He does not only look at what others do, he does it himself and that stimulates development. K. likes to learn new things and he is always very proud and happy if he can show what he is able to do.

For everyone, this was a big challenge. It is the first child with this degree of complex needs in that school. The teachers adapted the activities so that he could join in with the group. Children spontaneously help each other, play together, help him with eating, with pushing a wheelchair, etc. A lot of the school time there was an extra adult to give support, professionals, students and volunteers. Parents were very much involved; they made a communication booklet. A student in Special Needs Pedagogy made a kind of "instruction manual", which is updated every year.

A DVD has been made[26] of the first three years of kindergarten, showing various situations in the class (welcoming, play, mealtimes, gym lesson, staff meetings, and a day at the seaside).

The DVD is very useful for training purposes, for all professions, accompanied by a series of guiding questions. It illustrates the following topics: learning together (how to differentiate tasks, how to ensure full participation), playing together, how to give support in the classroom (with subcategories according to the persons giving support e.g. peers, co-teacher, educator, speech therapist, physiotherapist, students; and according to the goal of giving support: to enable mobility, communication, eating, peer interaction, participation), support by an external multifunctional team; integrating care & education; how to set up teamwork.

---

[26] Production: Luk Dewulf & Inge Wagemakers (production house De Seizoenen), Antwerp, Belgium

Case 3:

A Case of Bulgarian twins with Cerebral palsy

Zvezdelina Atanasova[27], Andreas Andreou[28], Nikoleta Yoncheva[29] (Karin Dom Foundation, Varna, BG)

Ana and Teodora are happy and friendly little twin girls who were born after 10-year sterility treatment from a 6-th high-risk pregnancy. They were born in 32 gestational week with extremely low birth weight.

Ana is the first twin diagnosed with cerebral palsy and strabismus. Teodora is the second twin, born with severe infection, internal hydrocephaly, polymorphic seizures, and multiple hemangiomas. At the age of 1 year 2 months she was consulted with a gastroenterologist because of her low weight gain. She was found to have severe protein calorie malnutrition and had to follow enriched diet. She is currently with a Hydrocephaly and Ventricular peritoneal anastomosis.

The twins were 4-month old when they were referred to Karin Dom's Early Intervention Program. On the regular home visits parents received advice and suggestions on care and stimulation of their children development. At the age of 2 years 10 months the girls were enrolled in Karin Dom Centre based service for more intensive therapy treatment.

At entry to the Centre Teodora weighted only 5150 grams. Her physiological age responded to a 7-8 month baby. She had physical therapy, speech therapy and participated in communication group biweekly. The goals set in her individual plan were connected to her cognitive development, passive and active vocabulary, on chewing skills and getting independence in feeding, drinking and dressing; on her fine motor skills and body orientation, and towards reaching the gross motor milestones corresponding to her level of development.

Ani had also low for her age height and weight – 950o grams. She had significant delay in her gross motor development and self-help skills. Ani received physical therapy and attended Montessori class room at Karin Dom as well as communication group, gymnastics and art activities. The goals for her were to make her more independent and develop the skills needed for her inclusion in kindergarten.

For the girls physiotherapy we used the Bobath approach, for communication - Picture Exchange Communication System. In the communication group and elsewhere we introduced variety of sensory stimuli and appropriate organization of the environment.

After a year of intensive work both girls were enrolled in a mainstream kindergarten and continue to receive therapy at Karin Dom once a week.

---

[27] special teacher, speech therapist, senior trainer
[28] physical therapist, trainer
[29] speech therapist, trainer

Workshop 4
How to train communication, intentionality and capacity to make choices

Moderator: Anna Dal Brun (Don Gnocchi Foundation, SMNascente, IT)
Discussant: Juliet Goldbart (Professor of Developmental Disabilities, Manchester Metropolitan University, UK)

Case 1:
How to train communication, intentionality and capacity to make choices

Juliet Goldbart[30] (Professor of Developmental Disabilities, Manchester Metropolitan University, UK)

Anna is 13 years old. She has profound intellectual and motor disabilities. She also has severe nystagmus. Anna's preferred activity is putting her hand in her mouth as far as it can go. This can result in vomiting, which Anna seems to enjoy.

Anna can move independently by shuffling on her bottom and she can hold objects, though she prefers to keep her hands in her mouth. Anna seems to enjoy some types of music and flashing lights. She has learned to operate a single switch to get a music and light display in a darkened room.

Anna does not appear to understand any spoken language although she might recognise her name. She makes sounds, but they are not typical sounds of speech. She will work with any member of classroom staff but does not seem to have particular preferences or relationships with any individual staff member.

I use Anna as a case example for a final year workshop with speech and language therapy students in the UK. I will present the data on Anna's cognitive skills and her communication that the students use to plan communication assessment and therapy. I will illustrate with some short clips of video.

We will use the models and definitions below to plan for Anna, considering how this information could be used in training staff and family members.

Stages in Early Communication Development (from Coupe & Goldbart, 1998)
Level 1: *Pre-intentional – Reflexive:* The child's limited repertoire of mainly reflex behaviours can be interpreted by familiar people. Internal stimuli are as significant as external ones.

Level 2: *Pre-intentional – Reactive*: A wider range of voluntary behaviours are treated as meaningful by caregivers. The range of likely interpretations widens a little and the learner will be more responsive to affective messages from the caregiver. Iacono et al., (2009) say that it may not really be possible to distinguish between stages 1 and 2.

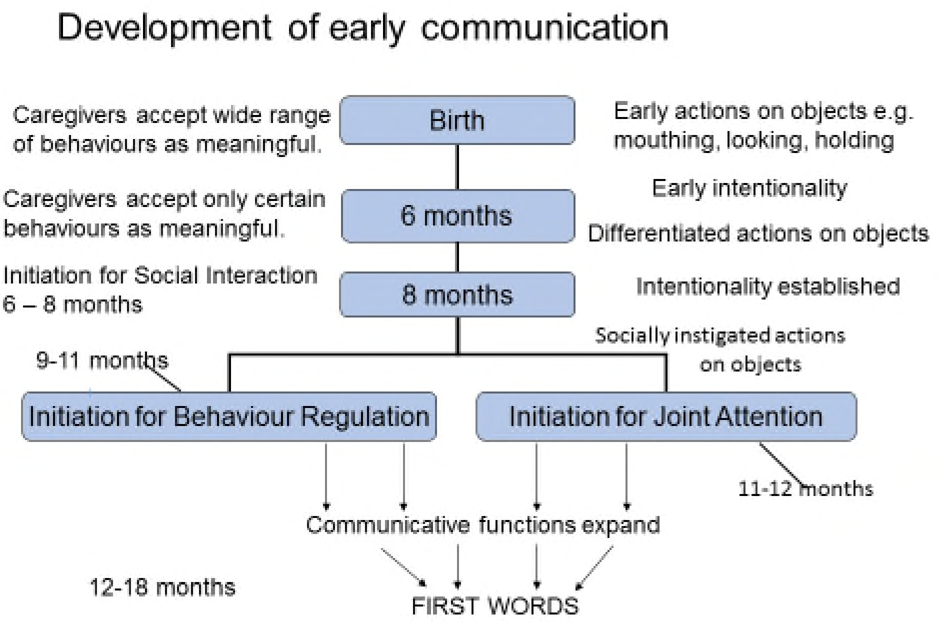
Level 3: *Pre-intentional – Proactive*: The child's behaviours are goal directed. Behaviours function as signals to others who assign communicative intent and meaning to them. The child extracts meaning from other people's intonation and facial expression.

---

[30] Juliet Goldbart PhD is professor of Developmental Disabilities and Associate Dean for Research at Manchester Metropolitan University in the UK. A psychologist by background, she has taught speech and language therapy students for over 30 years. Her research interests include communication and complex needs, and appropriate service delivery models for families in the UK and in under-served countries. She has a longstanding involvement with the Indian Institute for Cerebral Palsy, including an evaluation of innovative approaches in establishing disability services in slum areas of Kolkata.

Juliet has worked on establishing the evidence base for communication interventions for children and adults with profound intellectual disabilities (https://www.choiceforum.org/docs/compmer.pdf) and is currently part of an NIHR funded project: Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision-making.

Level 4: *Intentional – Primitive*: The child has learned to affect the environment by acting on another person. Interpreting "primitive" communicative acts relies on the context. The child understands other's nonverbal communication and starts to show situationally cued understanding.



Contingency Awareness and Intentionality
Contingency Awareness: awareness of an association between two events; the relationship between a specific action and a consequence.

Intentionality: the realization that you can have an effect on the environment – and how.

Intentionality appears to be achieved during Piaget's stage of Secondary Circular Reactions (4-6 months in typical infants), probably as a result of repeated chance experiences.

Probably the most important thing you will ever learn!

Leads on to Intentional Communication; using another person to make something happen.

Secondary Motivational Impairment
An alternative outcome is secondary motivational impairment, also called learned helplessness, which results from the failure to acquire intentionality.

This is where the child has a lack of awareness that s/he can have an effect on the world; a failure to connect actions and their consequences.

This can cause a progressive reduction in attempts to engage with objects and people, and may be associated with increased self-involvement or self-stimulatory behaviour.

Learned helplessness or secondary motivational impairment causes considerable difficulties in education and therapy as it is hard to get past the self-stimulatory behaviour and provide alternative, enjoyable experiences of making things happen.

Intervention Approaches

These could include: Communication Passports, cause and effect e.g. switch-based interventions, Intensive Interaction, Objects of Reference, staff and parent training, music and story-based approaches, others suggested by participants.

Key references

Coupe, J., Barton, L., Collins, L., Levy, D. and Murphy, D. (1985). *The Affective Communication Assessment*, Manchester: M.E.C.

Coupe-O'Kane, J. & Goldbart, J., 1998, *Communication before Speech: Development and Assessment*, London: David Fulton.

Goldbart, J. and Caton, S. (2010) *Communication and people with the most complex needs: What works and why this is essential*. London: Mencap http://www.mencap.org.uk/page.asp?id=1539.

Goldbart, J. and Ware, J., (2015). Communication. In P. Lacey, H. Lawson, and P. Jones (Eds) *Educating Learners with Severe, Profound and Multiple Learning Difficulties* London: Routledge

Hewett, D. and Nind, M. (eds.) 1998, *Interaction in Action*, London: Fulton.

Jones, F., Pring, T. and Grove, N. (2002) 'Developing communication in adults with profound and multiple learning difficulties using objects of reference', *International Journal of Language and Communication Disorders*, 37: 173–184.

Lancioni , G., O'Reilly , M., Singh , N., Oliva , D., Baccani , S., Severini , L. & Groeneweg, J. (2006a). Micro-switch programmes for students with multiple disabilities and minimal motor behaviour: Assessing response acquisition and choice. Developmental *Neurorehabilitation*, 9 (2), 137-143.

Lancioni, G., O'Reilly, M., Singh, N., Sigafoos, J., Didden, R., Doretta, O., & Severini, L. (2006b). *A microswitch-based program to enable students with multiple disabilities to choose among environmental stimuli. Journal of Visual Impairment and Blindness*, 100(8), 488-493.

Millar, S. with Aitken, S. (2003). *Personal Communication Passports: Guidelines for Good Practice*. Edinburgh: CALL Centre.

Nind, M. and Hewett, D. (2006). *Access to Communication*, (2nd Ed.). London: David Fulton.

Petry, K. and Maes, B. (2006). Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual and Developmental Disability* 31(1), 28-38.

Resources

General – online training materials produced by Department for Education, UK: http://complexneeds.org.uk

Routes for Learning documents: http://learning.gov.wales/?view=Search+results&lang=en
http://learning.gov.wales/docs/learningwales/publications/121115routeslearningposteren.pdf

Training materials on using RfL: http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/m08p010c.html

RfL Assessment Booklet: http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/downloads/m08p020c/assessment_booklet.pdf

Quest for Learning: http://www.nicurriculum.org.uk/docs/inclusion_and_sen/pmld/quest_guidance_booklet.pdf

Communication Matrix: https://www.communicationmatrix.org/

Communication Passports: http://www.communicationpassports.org.uk/About/

Intensive Interaction: http://www.intensiveinteraction.co.uk/

Case 2:

A possible challenge: an experience of school inclusion of a girl with severe communication problems

N. Schiappacassi[31], E. Bortolozzi[32], F. Restelli[33] , A. Dal Brun[34] (Don Gnocchi Foundation IRCCS SMNascente) Juliet Goldbart (Professor of Developmental Disabilities, Manchester Metropolitan University, UK)

We present the rehabilitation programme of an 8-year-old girl from when we first took charge of her starting with speech therapy, to when we introduced her to Augmentative and Alternative Communication.

As a main objective, we wanted to improve participation and inclusion in her life's environment.

We will, therefore, present an insight where strategies, competences and tools were shared and transferred to the school setting. The teachers' direct involvement was, consequently, a fundamental step to pass on the good practices to the peer group.

This guaranteed the girl's participation towards a real and possible inclusion and only through a mutual encounter, inclusion can be transformed in quality of life.

---

[31] Professional Educator

[32] Professional Educator

[33] Teacher

[34] Child rehabilitation doctor

Workshop 5
How to train aspects of assistive technology

Moderator: Elena Brazzoli (Don Gnocchi Foundation, IT)
Discussant: Ivana Olivieri & team (CARELAB & SIVALAB, Don Gnocchi Foundation IRCCS SMNascente, IT)

Case 1: Assistive technology in communication: using the device is not everything

Aurelia Rivarola, Child Neuropsychiatrist, Augmentative and Alternative Communication Service (CAA), Centro Benedetta D'Intino Onlus, Milan, Italy

Technological development, particularly voice output aids (Speech Generating Devices SGDs) and mobile technology with a lot of applications for CAA, brought unquestionable benefits to people with multiple disabilities and complex communication needs (CBC) by reducing the restrictions on participation and promoting social inclusion.

In addition to many advantages, however, as early as 1991 David Beukelman pointed out, that the revolution technology has resulted in many adverse effects; in fact the enthusiasm for new technology often has moved the CAA intervention focus exclusively on the instrument, shifting the focus and resources from what must be the objective of the intervention: the needs of the person with CBC to communicate and to participate in his/her living environment.

The access to technological solutions is not enough to make a person with CBC a competent communicator. Too often the intervention of CAA is limited to the prescription of a technological aid without an analysis of the needs, of the abilities, and of the preferences of the person, and without any training and support addressed to him/her and to all of the communication partners involved. In such a way, the failure of technology involves the default of any other CAA solution.

Some clinical situations will be presented, in which the use of simple voice output aids have been integrated in a multimodal communication system for children and teenagers with CCN, in order to improve their participation in their living environment.

Case 2: Communication using Tobii, an eye-tracking device

Marlène Gregoire[35] (Cem Sainte Suzanne, ASFA, Réunion Island)

English

The need for communication is a priority in the daily life of humans. So, it is our mission as therapists and carers to answer that need. Children with CISN (Complex and Intense support Needs) are not always capable of oral communication due to intellectual deficiencies, organic causes, etc.

So it is important to find tools that allow access to an augmentative and alternative communication. The vocal devices perform well and are efficient tools for our population even if they are expensive. In the video you will follow the procedure as it is applied to a child, Miss M (attends the CEM, ASFA, Reunion Island, France), from the beginning, her attempts, the processes and training at different levels, to enable her to use a communication device that is controlled by her eyes, the Tobii.

Français : Le besoin de communication est une priorité dans le quotidien de chaque être humain. Il est donc notre rôle en tant que thérapeute et accompagnant, de répondre à ce besoin. Nos enfants avec Besoins Intenses et Complexes n'ont pas toujours accès à de la communication orale (cause organique, déficience intellectuelle, etc.)

Il est donc primordial de trouver des outils pour permettre un accès à un mode de communication alternative augmentée. Les synthèses vocales sont un outil très performant et efficace pour notre population, malgré leur coût onéreux. Ainsi, dans la vidéo, vous allez pouvoir suivre la démarche pour une jeune du Centre d'Education Motrice (ASFA, Ile de la Réunion, France) Miss M, depuis les prémices, les essais, les démarches pour l'acquisition du matériel en passant par les phases d'apprentissage (le Tobii) qu'elle utilise grâce à une commande oculaire.

---

[35] Ergothérapeute / Occupational Therapist, Cem Sainte Suzanne / ASFA / Ile de la Réunion / France

Workshop 6

How to train ethical aspects /Quality of Life and dealing with families

Moderator: Carlo Riva (L'abilità, Milan, IT)
Discussant: Mario Mozzanica (Emer. Prof. Univ. Catt. Milano & Don Gnocchi Foundation Ethical Committee, IT)

Case 1:

Family centered intervention and parental development

Vitor Franco, Heldemerina Pires, (University of Évora PT)[36]

It is recognized that the family have a key role as promoter of the individual development of its members. This is a fundamental assumption also when we talk about the development of children with severe, intense and complex problems and needs.

Therefore, the actual perspectives and practices on early intervention in the development of children define themselves more and more as family-centred. Because it is within the family that children spend most of their time, but mainly, because it is the interaction with the significant persons within the family system that creates the basic conditions for their development.

However, to put more pressure on the family, when it is already wrapped in emotional difficulties, arising from having a child with a diagnosis, and on a mother / father whose development is threatened, is to increase the risk of family destruction and emotional imbalance of the parents.

Using a practical case, we will try to understand how a family-centred approach (and not targeted in isolated therapeutic or educational interventions) can be organized, without endanger the developmental process of the parents, but enabling them to be effectively responsive and competent in their parenthood that is affected by unexpected and undesirable factors.

Portuguese

Intervenção Centrada na Família e Desenvolvimento parental

A família é reconhecida como tendo um papel fundamental enquanto promotora do desenvolvimento individual dos seus membros. Este é igualmente um pressuposto fundamental quando nos referimos ao desenvolvimento das crianças com graves e complexos problemas de desenvolvimento.

Por isso, as perspetivas sobre a Intervenção precoce no desenvolvimento das crianças se definem, cada vez mais, como centradas na família. Porque é no contexto familiar que as crianças passam a maior parte do seu tempo, mas, principalmente, porque é a interação com as pessoas significativas do seu sistema familiar que cria as condições fundamentais para o seu desenvolvimento.

No entanto, colocar apenas mais pressão sobre a família, quando ela já está envolta em dificuldades emocionais decorrentes de ter uma criança com um diagnóstico e sobre uma mãe/pai cujo desenvolvimento se encontra ameaçado é aumentar o risco de destruturação familiar e de desequilíbrio emocional dos pais.

A partir de um caso concreto, procuraremos ver como uma abordagem centrada na família e não segmentada em intervenções terapêuticas ou educativas isoladas, se pode organizar sem colocar em causa o processo de desenvolvimento dos pais, de modo que eles sejam efetivamente responsivos e competentes na sua parentalidade que está afetada por fatores inesperados e indesejáveis.

---

[36] University of Évora, Department of Psychology

Case 2:
Case presentation : Ianis

K. Goust[37] (Relais Handicaps Rares, Île de France, FR)

Ianis and his family are part of the"Equipe Relais Handicap Rare" intervention (Ile de France). This intervention seeks to find solutions to the difficulties caused by both the rare and complex needs of the child, by the territorial dispersion of the cases and by the rarity of specialized professional resources. Our mission respects the choice of the family and promotes the quality of life and the child's rights to communicate and develop his potentialities.

When I met Ianis, the family had been living in France for 7 months. Ianis is three years old, is affected by CHARGE Syndrome, which was diagnosed when he was 6 months old. The child is at present without educational and rehabilitative medical support, his parents are looking for a strategy of intervention to resolve his problems, among which sensorial ones (Ianis is blind-deaf).

The father has contacted our center asking to be supported to build with our support a project for his son. For this family I have suggested a global intervention with different actions:

- evaluation of the impact of the syndrome on structures, functions, child's activities and on his possibilities of participation in activities with others;
- evaluation of environmental and personal factors (from an ICF point of view);
- definition of a profile of skills and potential resources as well as of his rehabilitative needs;
- information to be given to the family regarding territorial resources and various rehabilitation opportunities;
- presentation of Ianis' situation to the different suitable services at a reasonable geographical distance from Ianis' home, as well as finding a support for guidance projects;
- improving parents' awareness to pedagogical, ludic and communicative strategies suitable to Ianis' sensorial profile, while waiting for his inclusion in specialized services;
- coordination and integration of the interventions for the different actors of the education, health and social network involved with the child, before and after his inclusion in the specialized service chosen;
- building and coordination of a new collaborative partnership between the service that will takes care of the child's rehabilitative needs related to his deafness (current priority) with another service, that can offer complementary interventions with regard to his blindness;
- strengthening the professional skills of these services, involving in training actions the experts of one of the four National Resource Centers of our integrated system for rare disabilities, CRESAM (deafblindness), and the "CHARGE" family association.

La situation de Ianis et de sa famille est présentée dans le cadre de l'intervention de l'Equipe Relais Handicap Rare Ile de France qui tente de répondre aux difficultés posées par la conjugaison des besoins rares et complexes de l'enfant, de la dispersion des cas sur le territoire et de la rareté des ressources professionnelles spécialisées. Notre mission respecte le choix de la famille, et promeut la qualité de vie et le droit de l'enfant de communiquer et de développer ses potentialités.

Quand je rencontre Ianis, la famille se trouve depuis 7 mois en France, il a 3 ans et est affecté du syndrome CHARGE diagnostiqué à l'âge de 6 mois. L'enfant est actuellement «sans solutions» d'accompagnement médico éducatif et rééducatif, les parents sont à la recherche d'un parcours adapté aux problématiques, entre autres, sensorielles (surdicécité) de l'enfant.

Le père contacte notre dispositif pour demander à être soutenu dans la co-construction du parcours de son fils. Pour cette famille je propose une intervention globale avec diverses actions:

- évaluation des retentissements du syndrome sur les structures, les fonctions, les activités de l'enfant et ses possibilités de participation, évaluation des facteurs environnementaux et personnels (dans l'esprit de la CIF), définition de son profil de compétences et ressources potentielles ainsi que de ses besoins rééducatifs ;
- information de la famille sur les ressources territoriales et sur les techniques rééducatives ;
- présentation de la situation de Ianis aux différents services repérés comme compétents sur une zone géographique raisonnable et appuie des projets d'orientations ;

---

[37] Course Coordinator/Referent Psychologist

- sensibilisation des parents aux approches pédagogiques, ludiques et communicatives adaptées au profil sensoriel de Ianis dans l'attente de son insertion au sein de services spécialisés ;
- coordination et intégration des interventions des différents acteurs du réseau socio sanitaire et éducatif impliqués autour de l'enfant avant et après son insertion dans le service spécialisé choisit ;
- construction et coordination d'un nouveau partenariat de collaboration entre ce service qui couvre les besoins rééducatifs de l'enfant relatifs à la surdité (actuellement prioritaires) avec un autre service qui peut offrir des interventions complémentaires en rapport avec la cécité ;
- potentialisation des compétences des professionnels de ces services en impliquant, pour des actions formatives, les experts de l'un des quatre Centre Ressource Nationale de notre système intégré pour le handicap rare, le CRESAM (surdicécité), et l'association de famille “CHARGE”.

Case 3:

The emerging of potentialities in a child with multiple disabilities: a network between family, rehabilitative service and school

D. Raddi, A. Dal Brun, C. Guerini Rocco, P. Cartamantiglia, A. Colletti, M. Rodocanachi (Don Gnocchi Foundation, Vismara)

We present a case of a child with complex disability characterized by severe motor impairments (Cerebral Palsy) with multisensorial deficits (central visual impairment and neurosensory deafness) and prognostically a severe mental retardation (if the child had been left to himself ...).

The child arrived at our Centre when he was four months old and an intensive neuropsychomotor treatment was started. During the second year of life, the program was implemented with music therapy sessions and at the same time counselling for parents.

From a psycho-pedagogical point of view, the intervention begins with the first year of attendance at a mainstream kindergarten where he was included with a support teacher.
Speech therapy intervention started when he was three years old and mainly regarded the communicative and linguistic aspects, with particular attention given phono-articulatory processes (first words when he was around three years old after an acoustic prosthesis).

With the child's inclusion at kindergarten, several differences between school and the family's point of view emerged:

- The investment of the family in the cognitive domain was very competent and effective in identifying the potentials of the child and in seeking means and methods to make them emerge.
- the school establishment, on the other hand, set the intervention on a more holistic point of view of the child and his development, claiming he had potentials even in the complexity of his disabilities, without, however, focusing specifically on cognitive factors.

Our Centre had to intervene and act as mediator between the family and the school several times.
The rehabilitation team has constantly strengthened, along with all the rehabilitative interventions, the child's communication skills and his relationship with others, so much so that he has found his own strength in his constant intention to communicate with the outside world.
Since he was nine month of age the child is following a neurovisual rehabilitation programme at the specialized centre of neuro-ophthalmology at the Mondino Foundation in Pavia, which is in constant contact with our Centre.
The child is now starting to learn how to use the electric wheelchair to explore his surroundings, by using visual environmental reinforcement strategies. The will of the family was decisive in helping him achieve his skill, against the scepticism of the same assistive technology experts at Don Gnocchi Foundation.

Now the child uses a personal computer for school learning and the support in speech therapy of “Clicker 4”. The hearing aid is used from time to time and the child has acquired good use of the residual hearing.

This child has made us, as his medical staff, reflect on the need to have a constantly open channel to transfer information among us professionals (doctors, therapists. technical figures, teachers).

The necessity of having a professional figure who constantly maintains the relationship with the families, as well as mediating communication between the families and the institutions, has emerged. It would be appropriate and desirable to introduce the figure of a Case Manager who manages and/or organizes various interventions necessary to the child's and family’s well-being.
In the child’s rehabilitation course, the parents’ tenacity and their constant exchange of information with the professionals of the rehabilitation centre and the school, have brought to light the potentials expressed in the context of inclusive education. The parents were able to see their child not as a child to be cured, but as a person with whom they could relate to, by conversing and playing with him. In this process, the professionals of both the school and the rehabilitation centre have learned "on the field" strategies and models, transferable to other situations and in different contexts.

All the professionals who deal with complex situations, need continuous personal reflection and communication training to be able to work in multidisciplinary teams.
The taking in charge of a situation that will continue over time and will require constant changes and different interventions, is sustainable only if the team that follows this situation understands and accepts professional and ethical responsibilities.
For both the professionals and the family, it is important to work on the consciousness of their own grief, on the awareness of mourning and to allow to help themselves and to be helped to overcome them.