enablin+

Enabling & Including Young People with Complex & Intense Support Needs

Experience with a new in-service training „common core" interprofessional programme "Supporting children with intense and complex support needs: enabling quality of life through meaningful learning"

Work package - 4 - Deliverable 12

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Introduction

Children with profound and multiple disabilities, as they are called in the Anglo-Saxon literature, or "polyhandicapés" – as called in the French literature - or "with complex and intensive support needs" – as we would prefer to designate them in the Enablin+ Project – have multiple impairments and therefore multiple needs: severe intellectual impairment, often undetectable with psychometric IQ tests, physical, motor, sensory, communicative deficiencies and often also behavioural difficulties (Lyons & Arthur-Kelly, 2014). They need 24-hour support. Because of these, access to education, learning, leisure, social life, welfare, overall wellbeing is severely limited, if not inaccessible. Families, doctors, educators, specialists, communities are facing the question: *how to improve the quality of life*? (Schalock, 2010). *How do we reconcile individual student differences and needs, family preferences and systemic factors in ensuring the achievement of maximized learning outcomes for students with PIMD across their educational life*? (Lyons & Arthur-Kelly, 2014).

In many countries in the world, the needs of these children and youth with complex and intense support needs (CISN), their caregivers and supporters, are not fully met. The history of care is rather short: in the beginning of the 60-ties, care for children with PIMD was limited to basic physical wellbeing – if at all – but then specialists and parents became aware that something must be done, and something can be done. The first services for children with the most severe deficiencies and the highest needs then started and developed into nowadays sophisticated comprehensive support systems (Zucman, 2017).

These children have nowadays much more survival chances and therefore increasing demands for support and care. However, care is still often taking place in separate institutions (Lebeer et al., 2015).

In order to comply to the 2006 Convention of the United Nations on the rights of persons with disabilities (UNCRPD) with the explicit right to participating in society's life, and the compelling urge of de-institutionalization, the countries, which signed this UN Convention, agreed to take measures against discrimination and to organize the possibility of including children with a disability in normal schools & life. For children with the most severe impairments and CISN, this is far from easy. Actual vocational training insufficiently prepares professionals to deal with these issues. There is a need of transdisciplinary collaboration of all concerned, bringing together and sharing expert knowledge of parents, teachers, daily-life supporting staff, medical & rehabilitation staff and vocational training staff. Nobody can do it alone.

Whereas in the beginning, care was often confined to physical care – often designated as "the medical model", which stressed deficiencies (hence the name "defectology") - the perspective on people with a disability has been gradually broadened, perhaps under the influence of Engel's biopsychosocial model, which states that the working of the "whole" is more than the sum of its parts and that we cannot reduce the working of the whole to the co-functioning of its parts (Engel, 1980). Instead of a classifying a „list of deficiencies", diagnosis has to be oriented at inclusion. The paradigm is shifting from a static, individualistic, deficiency-oriented disability model, to a more needs- and context oriented, considering the person within his environment, function- and learning-oriented, which needs a more dynamic and interactive assessment and intervention (Lebeer, 2003).

Therefore, the Enablin+ project took upon it the task to develop an interprofessional in-service training, where professionals and parents of various professional backgrounds learn together, with the aim of improving inclusion and enhancing quality of life of the children with CISN, at various age levels.

The core training programme was submitted to the partner countries for translation and further adaptation to the specific target population, specific needs and local situations, considering that the eight partners involved in the project have different legal frames, organizational backgrounds, specialization and target population. A pilot version was tried out.

In this chapter, we report results of a preliminary experimentation with this new "common core" training programme.

Participants and methods

We designed a common core training "Enabling Quality of Life through meaningful learning" (Nijland et al., 2017) oriented at everyone involved in supporting children with CISN: special education and mainstream educational staff, personal daily living assistants (professional assistants, educators, volunteers), educational psychologists, medical & rehabilitation staff (e.g. nurses doctors, physiotherapists, speech therapists, occupational therapists, psychologists), people in management, vocational training staff at secondary and continuous professional development level, as well as parents.

The training is based on an international needs assessment survey (Lebeer et al, 2015), which concluded that:

- Children are capable to learn if placed in a more learning and challenging environment (Maes, 2014)
- Staff needs to learn how to activate, to be involved, to practice, to share expertise, knowledge and good practice (Neerinckx, 2015), and most of all how to believe, support, facilitate, encourage, reinforce and prevent burn out.

Four relatively new conceptual frameworks are underpinning the training: (1) the UN Convention on the Rights of People with Disability (UNCRPD); (2) the Quality of Life principles (Schalock & Verdugo, 2002); (3) The Capability approach (Nussbaum, 2006) and (4) the Supports Paradigm (Buntinx & Schalock, 2010). The curriculum assumes an ecological approach, in the sense of Bronfenbrenner's "ecology of development". This revolves around the person with CISN as a whole person-in-context. It is based on the principle that all children have the same rights to a decent inclusive life of quality, and that all are capable of learning and developing to some extent, in different ways and conditions, if they are offered adequate support.

Aims and goals of the training

The overall objectives of the common core training are:

1. To raise awareness that it is possible and worthwhile to stimulate and educate children with complex and intensive support needs (CISN).
2. To raise awareness of their 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), to promote inclusive schooling, inclusive lifestyle and integration into society.

Specific aims of the training concern raising awareness of and introducing participants to approaches and methods which enhance children's communication capacities, improve daily life activities,

improve self-efficacy of staff and parents as to dealing with challenging behaviour, and which activate the cognitive and non-cognitive inner resources of people with CISN to enable them to participate and learn.

We propose a 2 to 6 days training in workshop format consisting of six modules, with heterogeneous small interprofessional groups (figure 1) Whereas the training's content has common themes, its structure has been left very flexible, in order to adapt to local and national circumstances.

The suggested modules are:

Module 1	Who are the children with CISN and what are their needs?
Module 2	Quality of Life
Module 3	Basic learning, (inclusive) education
Module 4	Dealing with a quality of life plan including assistive tools and support
Module 5	Dealing with challenging behaviour
Module 6	Promoting Activities in daily life

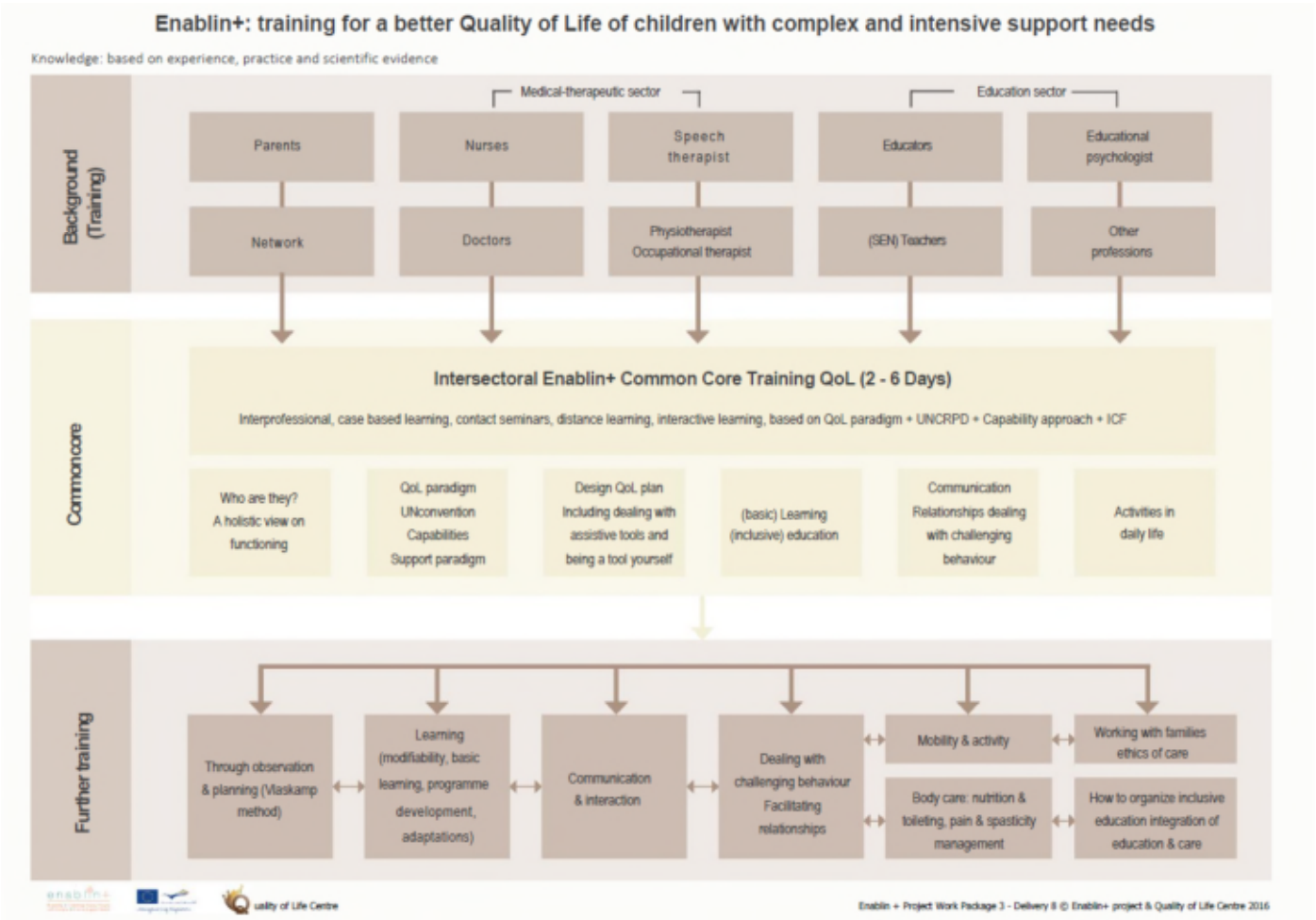

Figure 1 Training scheme for interprofessional & parents training dealing with children with complex and intensive support needs (Nijland et al., 2017)

The **teaching and learning methods** are essentially based on problem-based and case-based learning, dialogue, reflective learning, analysing videos showing concrete examples of 'best practice', feedback on self-made video recordings. In the course of the project, and still during the

training pilots, videos of “good practices” have been gathered, some of which have been selected as training materials (Lebeer et al., 2017)

Pilot courses have been tried out in the Netherlands, France, Belgium, Romania, Italy, Bulgaria and Portugal in the course of 2015-17. Participants were asked to fill out evaluation forms, electronically or on paper. Because of the lack of standardized application, no standardized evaluation of outcomes was possible.

Results

1. Quantitative results

In order to create an image on the scopes of pilot trainings, we summarized some data. Table No. 1 illustrates the overall picture of the pilot trainings in the partner institutions.

Partner Number	Country	Partner name	N° participants	Training format	N° training activities	N° trainers
1	Belgium	UAntwerpen	212/562*	Thematic week	19	16
2	Netherlands	BNK	66	workshops	9	12
3	France	CESAP	50	Thematic days	5	6
4	Romania	BBU	120	Thematic days	10	10
5	France-Réunion	ASFA	30	Thematic days	3	2
6	Bulgaria	KDC	50	Workshops, courses	6	6
7	Italy	FDG	40	3 days, non-consecutive	7	10
8	Portugal	UEvora	120/15**	Courses	5	9

*Table 1 Pilot trainings in the partner countries; *212 registered names to one or more activities during thematic week in Belgium; 562 if also the unregistered participants to the theatrical evening even are counted; **15 registered names in the pilot course in January-February 2017; 120 registered names to one or more activities during 2015-2016 in preparation and dissemination of pilot course;*

Based on the designed common core training, every partner proceeded to adapt the curriculum, considering the specificity of the already done need’s assessment and every partner’s organizational construct. This adaptation resulted in a variety of in- and out-door training sessions, which took place either in the locations of the partnering institutions, either on-line, either took the form of visits to different special schools, special institutions and/or other locations (e.g. community centres).

During the period allocated for piloting the trainings, 64 activities were organized in the partner countries within the pilot training sessions. The summary is presented in Figure No. 1 (N=64): Belgium 19, The Netherlands 9, France + Reunion 8, Italia 7, Romania 10, Portugal 5, Bulgaria 6.

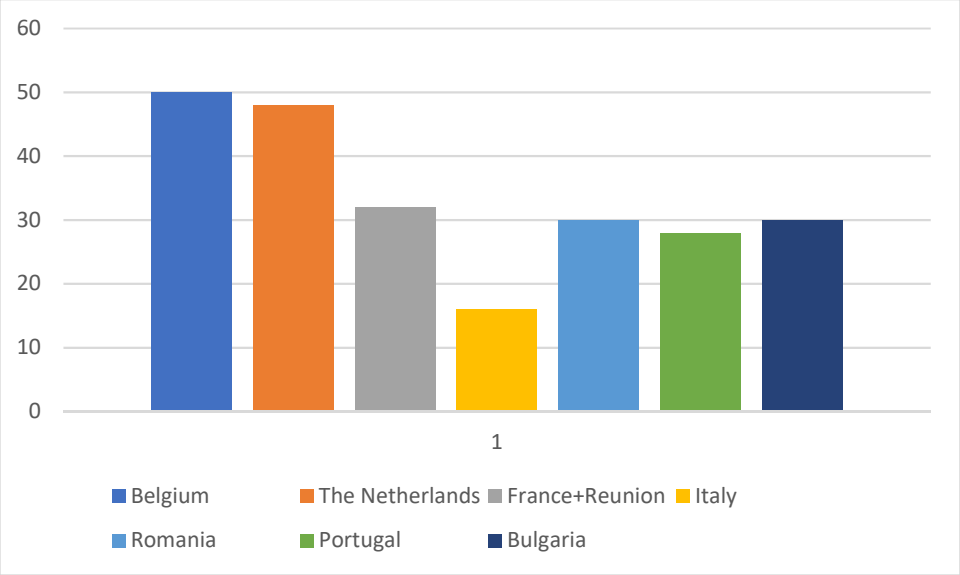

Figure 2 Number of activities within the pilot trainings

In the piloting of the custom-tailored training there were 78 professional (N=78) trainers involved, who's background came from the academic sphere (university professionals), medical doctors, different types of special trainers, policy makers, and administrative staff. The distribution per partner is presented in Figure No. 2, divided as follows: Belgium 16, The Netherlands 12, France and Reunion 15, Italy 11, Romania 10, Bulgaria 6, Portugal 9.

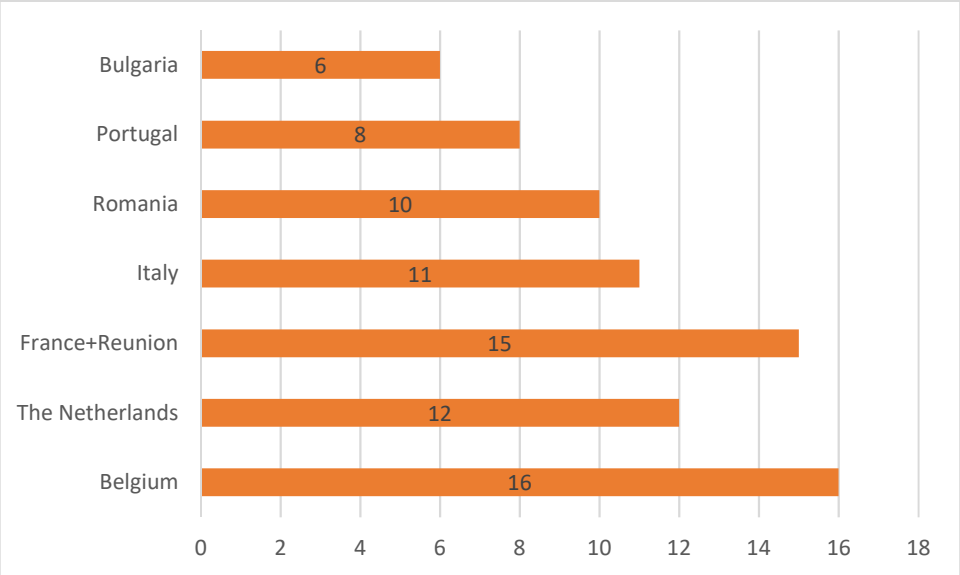

Figure 3 Professional trainers involved in the pilot trainings

Regarding the time spent for the 64 training activities organized during the piloting, we estimate that over 234 hours (N= 234) were spent for the in- and outdoor training sessions (Figure No.3), workshops organized loco or in different locations in the partner countries. We can only estimate the hours, regarding that the different sessions, presentation, workshops, meetings and other pilot training related activities had a previously established

timetable, but, in every case, the organizers and partners reported over-timing in some activities, due to the interest manifested for some topics, or the questions and reflections related to certain presented cases or issues.

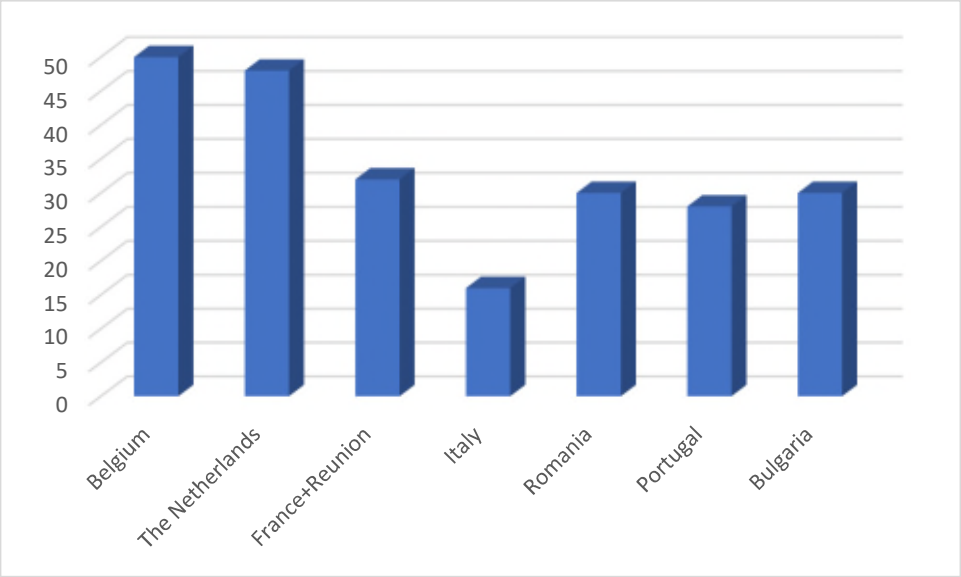

Figure 4 Hours spent on training activities

The overall number of participants at the training activities could not be accurately calculated, due to the fluctuation of the attendants and due to the free mobility in between some of the scheduled training activities, but we was able to make a preliminary counting on the training capacity of the announced trainings by the different partners.

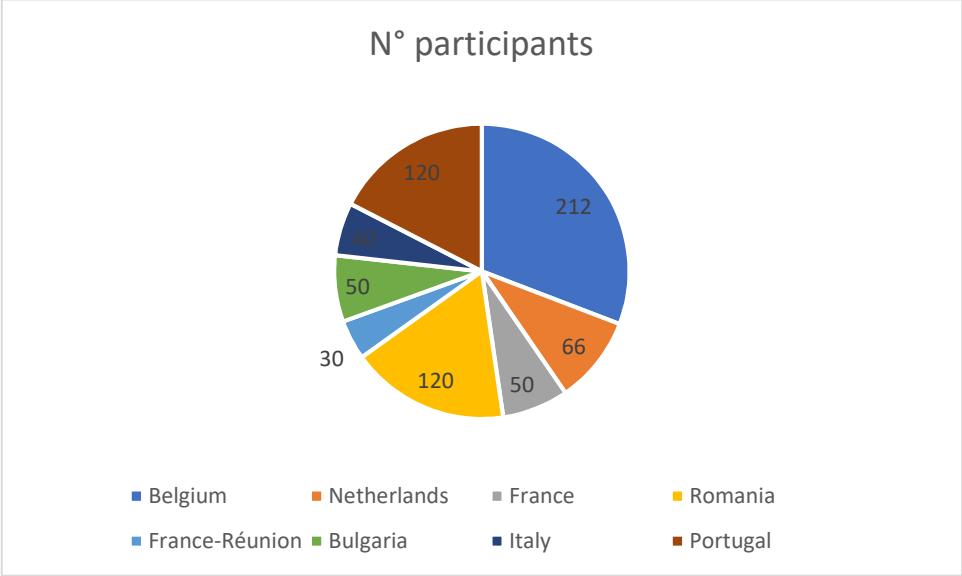

Figure 5 Estimated number of participants at the pilot trainings

We estimate that almost 700 participants have taken part in one or more announced training activities (N= 688), and as shown in Figure No.4. To this number, the 350 participants to a special "theatre evening" in Belgium should be added. This evening was

organized during the Enablin+ thematic pilot week, with a stand-up comedy about attitudes towards people with serious disability, organized to awaken awareness to the topics within the Enabling+ project. The large number of participants to this theatre event can be considered as a benefit of the project.

2. Participants in the pilot trainings

Based on the need's assessment analysis made by the partners and based on the groups targeted of the designed common core training program, the direct and indirect target groups of common core the training activities is very broad: there is a multitude of persons involved in the daily life of the children with complex and intensive support needs, who were identified as playing key roles in the education and overall QoL – of the children. Our aim was to involve indeed everyone, from "highly" to "low educated" professionals, whereby "high" or "low" are commonly defined in terms of the number of years trained in higher education. However, we learnt from the needs' assessment study that everyone has to learn when it comes to dealing with children with CISN.

During the pilot trainings, we managed to obtain participation of all the involved professions and parents. This was made possible thanks to a very flexible, locally adaptable format of the pilot courses, with the emphasis on "low threshold" to participate.

First, there were teaching staff members (Figure No.5): teachers, special needs teachers, professional educators, kindergarten teachers, teaching assistants. Teaching assistants are mentioned here as part of the educational staff. Although in some countries they have no basic teaching degree and formally have tasks without direct link with the teaching and learning process, we know from practice and from the needs' assessment study that they are also involved in helping with the education process and that there is not strict separation between "educational and non-educational" tasks in this case.

Figure 6 Teaching staff target group

The second major group directly involved (Figure No.6) are those performing therapy sessions or consultancies, on a daily or weekly basis.

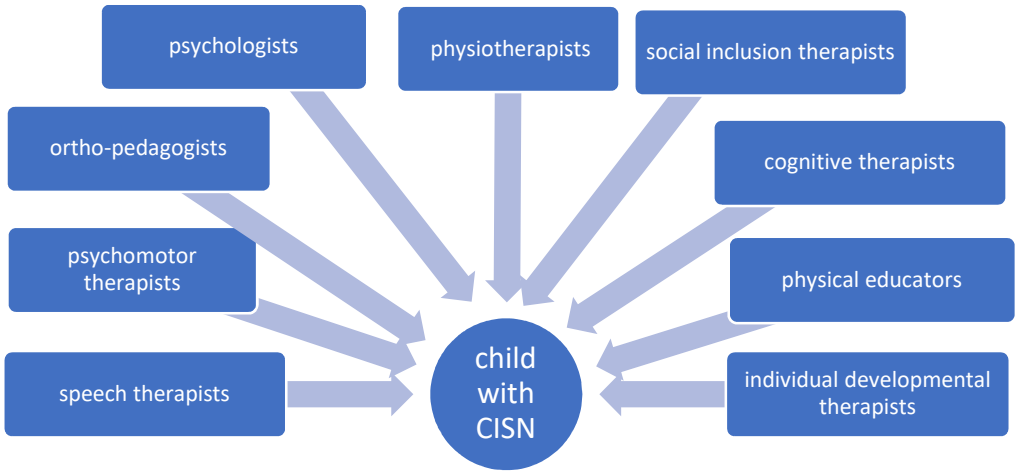

Figure 7 Specialists/therapists target group

General and professional medical personnel (Figure No. 7) who are primary dealing with the physical health and its support were also targeted and reached by the pilot studies. The need assessment study performed in the Enablin+ Project highlighted a permanent concern regarding their inclusion in the professional team working on the QoL of persons with CISN. They came from these specific domains:

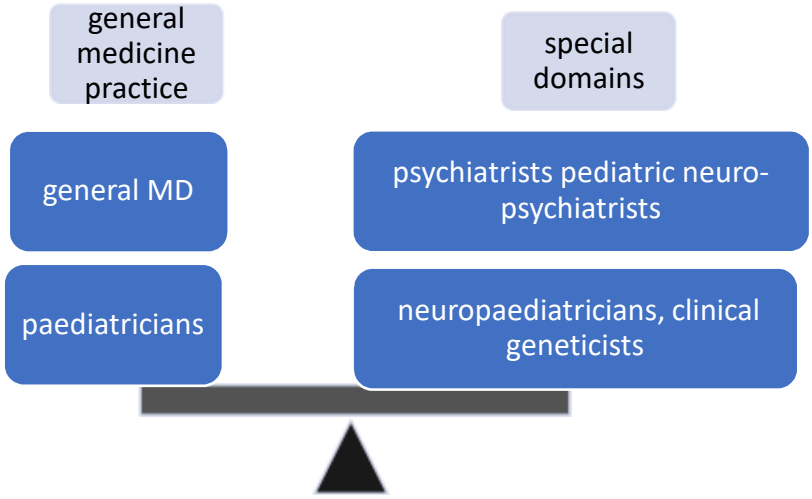

Figure 8 Medical professionals group members

People dealing with everyday-, basic and social welfare issues were grouped into the category of “caregivers” (Figure No. 8). This group consists in every partner’s case of:

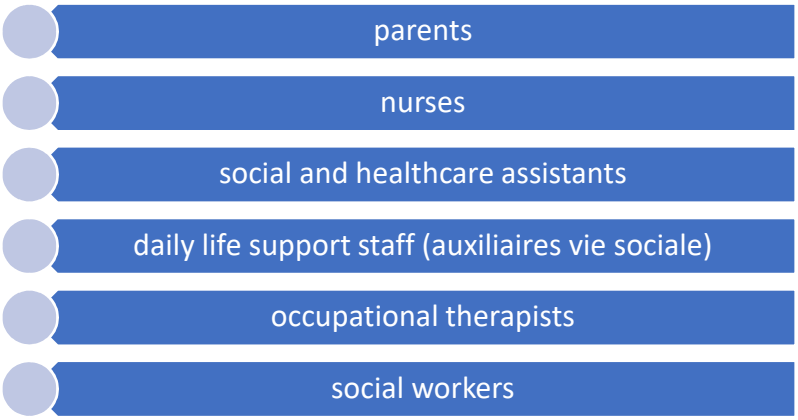

Figure 9 Caregivers category members

Every partner emphasized, invited and trained, besides the "professional actors" in the CISN person's life, the decision and policymaking personnel, at least at local/institutional level: policy makers, institution managers, school directors in special and regular education, and even administrative staff. Their knowledge on PIMD and CISN and the QoL of the impaired and in need persons was often reported as being superficial, segmented on their narrow field, as stated in the job description, often with no connection and communication or even knowledge on the where about of the professional teams work. In some partner countries there is much more interconnection of medical and non-medical staff.
Some partner countries managed to raise interest in high-level decision makers, e.g. in Belgium, the Minister of Welfare opened the pilot training week and some high-ranking decision makers of the Ministry of Education were present. Portugal managed to obtain the presence of the person-in-charge of Welfare in the Region.

Also present were researchers and students in special education, psychology, medical studies, social studies, inclusive- and occupational studies, who were called to benefit the other partner professionals work and to share their expertise and theoretical know-how or to elaborate new educational and QoL paradigms.

Types of courses

Regarding the type of the adapted and target-designed pilot courses, we identified several forms of delivering and sharing the knowledge and information: there were organized **seminars** and **presentations** in all the partner countries, on topics designed in the core training program, but tailored to the specific audience and the specific target population (e.g. specialists groups or family members, general auditors or mixt audience).

Other course forms, organized in almost every partner region, were **thematic workshops** on given topics related to the core training, completed with individual case presentation or

reflection questions on theoretical and/or specific presented case studies and good practice examples.

In several cases (BE+NL, BG, RO, FR) besides the indoor training **topic related institutional visits and small group sessions** were integrated into the course frame. In Romania's case a practical stage in a special Educational Settlement ("Kozmutza Flora" School for Special Education); in Bulgaria's case at the member-partner, Karin Dom Centre practical stages were also included in the program.

Most partner countries organized **one- or two-day training seminars** for small groups, which covered the basic common core-training format. In Belgium, the organization was different: because there is already an expert centre (Multiplus) which has been organizing in-service training workshops for the target group in the past years, a special consortium was made between the Universities of Antwerp, Ghent and Leuven, two University Colleges and two service centres for people with CISN, who chose the option to organize a **thematic week** on the theme of integration of education and care, because this is a relatively innovative idea. The main purpose of organizing the pilot training in this format was to create awareness in the general subject of the possibility and necessity of education, next to offering a variety of workshops and visits, so that everyone, high or low in the institutional hierarchy, could participate in one or more of the events during the week, according to his/her interests or possibilities. The week started with a **conference day**, targeted at policy makers, directors and people in a consultancy position, in the presence of the Minister of Welfare, meant to raise awareness on the issue of integration of care and education. Two scientific reports were presented there and a debate led by a TV-journalist who is also a parent. The conference day was followed by an **intensive training week** with half-day workshops in different places in the country, in combination with on-site visits at different schools, in order to allow a maximum number of staff members to participate and limit traveling. One of the events was a **theatre evening** "Put a comma in your ear", in the auditorium of the University College of Ghent, led by a performing comic artist, a retired educator with children with CISN. He managed to keep the focused attention of an audience of 350 participants, mainly students of special needs, without any flashy modern technology, just by telling stories from practice. All the themes of the common core training were conveyed in a humoristic way.
Next to this concentrated intensive week, also other formats were experimented in Belgium: a series of seven half-days on the topic of behaviour management; and an 11-day-long training on the subject of Down syndrome, according to life phases (early intervention, school life, transition to adulthood). These are not incorporated in figure 3.

Similarly, in the Netherlands, next to a 2-day interprofessional pilot, also a long-term (one-year) training was organized. There it was specifically targeted to low-schooled educators. CESAP (France) , who has the most longstanding tradition in organizing in-service training courses in the area of CISN, organized an association day whereby members of the foreign partnership were invited, and also two-day interprofessional introductory days for beginning staff members.

3. Pedagogical methods

A variety of **pedagogical methods** was used in the delivery and sharing of information. Besides the (rare) classical plenary presentations, all pilot trainings amply used smaller group sessions, dialoguing with reflective questions, discussing videos of good practices, case study presentations, and discussions.

Some of the partners also experimented with new information sharing methods: in the Netherlands, an "e-learning environment" was introduced and used. This is a computer-based learning platform, which requires good proficiency in information technology usage.

In many cases (CESAP France, Isle de Reunion, Karin Dom Centre, Don Gnocchi Foundation, Expert Centre on Education Wijhe, l'Association François d'Assise Reunion) **practical work** and **technical demonstrations** were commonly used as pedagogical method in **learning to handle instruments** and ordinary objects indispensable to every day comfort and for the security of the CISN persons. **Handling and grasping, moving and resting, non-verbal communication, mimics, gesture, imitation, repetition and demonstration** were elevated up to teaching methods.

P**ractical debate** and **critical case analysis** of concrete cases were introduced to face real life situations and elevate problem-solving skills in the participants. The participants' own cases were debated, **individual experience sharing** was promoted, and a **critical thinking elicited**. The practical analysis elicited case-related response searching skills in the participants.

The **elaboration of adapted responses** was commonly used as an **active, reflexive and eliciting method,** together with the pathways for eliciting **feasible responses to particular case-related questions.**
The **testimonies** of parents and professional were reported in every partner's case to be present as a pedagogical method.

4. General themes of the pilot trainings

Considering the wideness of the topics related to the QoL of children with CISN, besides the general objectives traced within the Enablin+ Core Training Program, we enlist an inventory of the general themes approached in every partner's own re-designed training programme. These themes approached distinct person-related domains as:

- Physical well-being: feeding, personal hygiene, sleeping, toileting
- Healthcare: nursing, pain management and control
- Sensory stimulation, basal stimulation, psychomotor development
- Behavioural management, control and modifiability
- Development of basic and specific abilities, skills and "capacities"
- Movement related topics: motor (fine- and gross motor) development, psycho-motor development, speech motor development, kineto-therapy and animal supported therapy, aqua-therapy
- Cognitive learning, cognitive development (e.g. memory, language, attention
- Social skills, speech, auditory, visual, tactile, taste and olfactory perception

- How to relate, how to facilitate interaction and relationship
- Communication styles development: verbal, non-verbal (mimics, gesture), sign-language, augmentative and alternative communication
- Early intervention in PIMD, CISN and other severe developmental disorders
- Special education in PIMD, CISN and other severe developmental disorders
- Integration and inclusion in PIMD, CISN and other severe developmental disorders.

Besides these topics approached in every partner's training course design, **specific course topics** were introduced, such as:

- Legislation and policy making on inclusion of persons with CISN.
- Articulation with specific devices
- Psycho-, alternative-, educational-, professional-, environmental-, developmental diagnosis
- Specific therapies: arts, crafts, music, dance and movement
- Special therapies: speech-, physio-, social-, self-help, cognitive-, behavioural, life-coaching, coping, animal assisted therapies
- Special training on assistive devices and environmental facilitators
- Parent and relative support and family therapy, parents support groups
- Specific methods were talked about: neurodevelopmental therapy according to Bobath, Feuerstein-LPAD and mediation, Sindelar, kinesiology, Picture Exchange Communication System; of course none of these subjects could be dealt with in-depth.

Evaluation & discussion

As formal, standardized quantitative evaluation was not possible because of the heterogeneity of applications, a qualitative evaluation was done.
An analysis has been done using the SWOT model (strengths, weaknesses, opportunities and threats).

Strengths of the common core course

Did the pilot course reach what it aimed for?

As a general finding, the following aims of the designed core training course can be considered to be fulfilled: (1) more awareness and knowledge about how to assess the needs of children with CISN in a broad, ecological way and in a variety of ways; (2) more awareness and knowledge as to how to enhance the children's and the staff's interactive, cognitive and communication skills; (3) more awareness and knowledge as to how to improve daily life activities; (4) more awareness and knowledge as to how to control and regular problematic behaviour; (5) induction of a change of attitudes and a shift in the belief system and (6) to promote inclusion in school, in lifestyle and integration in society.

Although not explicitly stated as such, all these are aspects of Schalock's quality of life model.

Have the intended target groups been reached?

Additionally we can notice that the pilot courses succeeded in reaching out to all types of support staff, whether specialists or not, in enhancing their general and specific knowledge regarding topics of PIMD and other developmental disorders. The courses succeeded in calling the different types of actors who support children with CISN in their daily life into reflection, action and reaction.

Involving and training the parents as equal partners in the teamwork for the enhancement of the QoL of their children opened a fruitful dialogue between the different professionals and the family, leading to mutual recognition, respect and reciprocal aid. This integrated teamwork between professionals and parents –underlined the importance of open dialogue in establishing a common language (not every field with its own professional jargon, mutual for the "accomplices",) unintelligible for the outsider). This created a feeling of equality for parents, not being an outcast from certain (professional or medical) decisions and makes parents totally involved, responsible, sharing and eager for knowledge and information.

It must be said that the parents who participated in the pilot training events were "biased" by being already advocates of co-constructive decision-making. Their presence was in this sense very important because it create more awareness in the participating professionals.

Did the content of the pilots match the needs of participants?

The topics, good practices, cases and examples presented and discussed acknowledged the need for up-to-date information and knowledge regarding the state of art of children with CISN and the development and enhancement of QoL, and more specifically the involvement of the environment, action, inclusion and participation.

Everyone also agreed to the usefulness to have attention for aspects of physical wellbeing, such as pain control and management, breathing difficulties, epilepsy treatment, etc. which create a need to offer specific courses on these topics.

Another major accomplishment reported from the Italian pilot trainings was the demonstration of the possibility of enhancing a child's qualifications, skills and development, taking into account his active skills, his participation and the context of the environment, inspired by the ICF –CY (Saragoça et al., 2015).

How well was the interprofessional heterogeneity accepted?

One of the greatest assets of the common core pilot trainings is that they realized a multidisciplinary, interprofessional form of learning, which reflects the situation on the work floor. Participants highly valued learning together in heterogeneous groups, learning from each other, having the opportunity to dialogue between the different medical, educational, social, therapeutic, supportive, administrative, decision and policymaking professionals in a concrete way. Thus learnt how to work better as a supportive team.

Learning in a co-constructive way, with each other, and with the trainers, about concrete problematic situations, has been highly appreciated everywhere: e.g. to obtain a new look and approach on challenging behaviour, on alternative communication ways, on improving communication skills and on the importance and benefits of positive reinforcement. An

especially positive evaluation was given to the modules on augmentative communication with a child with CISN, which highlighted the necessity of working in context, in relation with the environment and grounded in the real life of the children with CISN.

However, next to heterogeneous, interprofessional learning groups, also a need emerged to organize intraprofessional in-depth learning, e.g. in medical issues, pharmaceutical approaches, assistive technology in communication.

How were the course formats evaluated?

The variability of course formats proved to be a good choice, because they were appreciated much by participants. In this way, everyone was able to find the content according to perceived needs. People also highly valued exchange between peers, or between professionals of different backgrounds. Seminars of 1 or 2 days were positively valued because of their practical feasibility, but they regretted the lack of time to have more of such experiences.

All courses were face-to-face meetings. This aspect proved very beneficial, because people valued dialogue and meeting. Only one of the partners tried out an e-learning environment, as an extension of the real meeting time. Because the content was not yet sufficiently prepared it is too early to evaluate its effect. Potentially an e-learning platform could present a good modality to learn techniques and approaches, and thus be a facilitator for enhancing the QoL of children with CISN. It could be a means and a communication channel between families and different specialist and/or community, support or leisure groups. It can be a “gate to knowledge” a “pathway to learning” and a “window to the word”. In France, such as network already exists (Réseau Lucioles). It is however doubtful whether e-learning could replace face-to-face meetings. It is more likely to become an adjuvant modality to real meeting. In some partner countries, e-learning however is unlikely to be a main means of information exchange, if we consider the financial restraints and the education level of most parents and families caring for a child with CISN.

The following quote of one of the Belgian participants reflects the opinion of multiple participants of the pilot training 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 you the chance to learn about small – but important! - things to integrate in your own practice.”

Weaknesses

We were also able to identify some weaknesses of the pilot courses:

1. Despite the UN Convention on the Rights of People with Disability, there are discrepancies between the member states of the EU regarding the application of the directives or there are differences in the speed of their implementation. This implies also a difference in time and accent put on the aspect of rights, leaving much less time for other points. A two-day event is in this case certainly not enough. It can be circumvented by offering this course in a longer format, spread over a longer time.

2. Even though certain basic modern concepts in the domain of disability rights (e.g. quality of life, capability, inclusion, support paradigm, biopsychosocial model) may be widespread, they are certainly not a well-rooted part of the conceptual system of all people concerned in the world of disability. Even the smallest interpretation or difference in the definition of “continuity of support” and “complex and intensive support needs” – even on the territory of the same country – induces theoretical and, thus, practical differences which affect the core training and induces changes which are emerging from the legal, cultural or belief system of the organizing partner.
3. The different speed in the implementation of the legislation leads to a different legal approach and different financial resources. This inevitably influences the dialogues in the common course: a discussion e.g. on “quality of life” could be stuck at the first point of “lack of material resources”.
4. Different legal and financial support systems between the partners’ institutions piloting the common core training affect: (1) the number, length and periodicity of courses/trainings that can be offered on CISN; (2) the quality and quantity of the teaching staff on CISN topics; (3) the mobility of the trainings and of the training staff (only in-door training, in- and out-door training, visiting trainings, fields trips included).
5. Because the group of children with CISN is relatively small (as compared to the overall percentage of children with disability) and because of the complexity and sometimes specificity of their needs, the training is dependent on specific experts on specific topics (e.g. communication, technology, behaviour management, medical aspects), who are scarce now, within and certainly across countries. This makes training more specific and more costly. It means that the real experts, certainly in a beginning phase, should be able and ready to teach on an international level. We tried to circumvent this drawback by organizing a Train-the-Trainer course in one place, inviting foreign “true” experts in certain fields. In this way, new knowledge was disseminated more rapidly and more widely.
6. Not all important topics have been covered. The subject of “working with families” and “ethics of care” have received too little attention; we circumvented this by inserting these subjects in the train-the-trainer course.
7. The short length of the project makes impossible a follow-up of the changes that the training induces, neither in the direct targeted groups (parents, specialists) nor in the ultimate target group, the children themselves. This would require a much longer and higher budget and time course.
8. Time constraints: the short length of the course itself made in-depth learning difficult. Nobody succeeded in organizing a full 6 days, this was only for pragmatic reasons. In this field ,the school principals and directors are very reluctant to let their staff go on training during working hours, because that puts a stress on those who stay with the children. A way to overcome this is to organize several 1-day events, with breaks in-between, or a thematic week such as was done in Belgium.

Opportunities

The pilot courses on the subject “Supporting children with intense and complex support needs: enabling quality of life through meaningful learning” offered some important opportunities:

1. The opportunity to reflect on certain core topics, which are part of new conceptual paradigms (quality of life, human rights, inclusion, human capabilities), which might look philosophical, but which have very concrete implications in daily life
2. The opportunity for dialogues between professionals of different background and parents, for which, in "normal" daily life, there is often little time
3. The opportunity to involve policy makers, even if only briefly present in some cases, was important and could be a lever towards political (and financial) changes
4. The opportunity to merge academically oriented (research based) and practically oriented (experience-based) knowledge
5. The organisation of the courses helped the creation of common video-based training materials with examples of good practices. It helped research for such examples
6. The courses helped to enhance awareness, to put the often forgotten group of children with the most severe disabilities in the spotlights
7. The opportunity of this course to generate sustainable long-term developments:
   - In Belgium, after having attended the thematic week conference and workshops, the participants to one of the workshops (class on wheels) organized a site visit to the Netherlands, which took place one year later, and has led to the start of a similar project in Belgium. So there has been inter-country transfer of knowledge, leading to concrete changes
   - Sustainable networking has been the result in many partner countries. E.g. in Belgium, at the occasion of the organization of the thematic week, the 4 higher education institutions and 2 service providers created a firm network, which was amplified by involving trainers from different centres and service providers – people working in daily practice. The fact of organizing site visits, and doing the workshops on site instead of in a central location such as the university, created more firm networking
   - The e-learning environment applied in the Netherlands has led to a sustainable e-platform. An e-learning environment presents a good alternative and a great facilitator for enhancing the QOL of children with CISN. But this proficiency could not be very prolific for every user, if we consider the financial restraints and the education level of most parents and families caring for a CISN child. But this And also a mean and a communication channel between the families and different specialist and/or community, support or leisure groups. It can be a "gate to knowledge" a "pathway to learning" and a "window to the word".
   - Also in the Netherlands, a Quality of Life expertise centre has been set up which will provide consultancy to families and service centres
   - In France, the common core will be repeated every year and will be part of an obligatory training trajectory
   - In Belgium, the students of the Medicine from now one do a short awareness-apprenticeship in a service centre for children or adults with CISN
   - In Italy the model applied had the advantage of being attended by the whole inter-professional teams working in the same unit and on the same children with the participation of some of the parents and some of the teachers of the normal school in which the children were included. This contributed in developing a same language and to improve communication. This pilot training is a model to spread to other different teams working with children CISN either in Don Gnocchi Foundation (other centres in Italy), than outside (other teams, parents associations and schools).

Threats

Some of the "threats" have already been discussed in the section on "weaknesses". When looking at the future of this "new" kind of training, there are elements, which put the development of a sustainable effect under threat:

1. The constraints in time and financing. Except for France and the Netherlands, the continuity of training services is not guaranteed because of lack of financing. France has the advantage of its size and system of training, which allows the operation of a service such as CESAP, and that can be an example for other partners. The Netherlands have installed government-financed expert centres for people with CISN.
2. A second threat is the "we know all this" phenomenon, the tendency to fall back in the "old paradigms" and "old habits".
3. To learn to work really interprofessionally – which is a step further than and in fact very different from working multidisciplinary - is not self-evident. Training teams to really work interprofessionally requires time and a special way of working (Tsakitzidis et al., 2015)
4. Longer trainings or at least longer-term trainings would be preferable in order to deal with all relevant topics.

Conclusions

At the beginning of the Enabling+ Project several questions were raised: what is CISN? Who are they (the children with CISN)? Where are they? What are they doing? How? Who are the caregivers? What they do? Where? When? Designing the common core-training program targeted these questions and tried out the proper answers to them.

Considering the qualitative analysis of the results of the adapted pilot trainings, we can conclude:

1. The pilot trainings succeeded in **elaborating a mainframe** regarding the theoretical description of the background of the children and youth with intense and complex support needs. This theoretical module is inserted in every partner's activity, as a compulsory – and introductory module – at the beginning of the training.
2. There is a successful inventory on the legislation - rights and obligations – of the children and youth with CISN, from the emergence of the UN up to day, in every partner country. The main success lays in the fact that every training activity in every partner's case begins with the presentation of the legal issues regarding the EU, UN and local (country level) legal framework that supports this specific type of population.
3. The target in every case is the **enhancement** of the QoL of children and youth with CISN, not only the support of the present stage. Every course topic within the core and/or adapted training **aims higher: to enable, to enhance, to learn, to acknowledge, arising awareness, to be active actor not passive supporter.**
4. The pilot trainings proved that above all **sharing good practices, expertise and practical advice is** more effective than only classical learning from books. Enhancing sharing and inter-activity between the trainer and participants or even between the participants themselves to international level is even more effective and valuable. Sharing not only knowledge, but common values, beliefs, thoughts, fears, nightmares, worries, but also possibilities, options, expertise and attitudes is more effective.
5. A great added value of the pilot trainings is the fact that a group of specialists and parents – those involved in the design of the training activities – raise **awareness about the necessity of thinking, working, acting and practicing together for a higher purpose and good: the QoL of the children with CISN.** This group succeeded in enlisting and signalling the delays, lacunas or even total missing legislation regarding the CISN in the countries represented in this project

6. It has been proven that the targeted population of the trainings – those involved in the education, health, caregiving and leisure activities of the children with CISN, identified above – needs to be trained in different ways, at different times, targeting different outcomes. **This differences are concerning**:
   - The **multi-disciplinarity**: every type of specialist needs to know at least the theoretical and practical basics of the *multiple disability types* and *the descriptors of the complex and intensive support needs*
   - The **inter-disciplinarity**: every specialist needs to be trained in an interdisciplinary approach, dealing and treating at basic level with the person with disability as a whole of (not only the body as the exclusive domain of the doctor, the behaviour as the exclusive domain of the psychologist, not the learning as "belonging" to teacher). Learning e.g. has biological aspects (e.g. attention, muscle tension, etc.), psychological and teaching aspects. Hence, everyone is concerned. This supposes that every specialist must be able to adopt the holistic view described in the literature
   - The **sharing**: participating at the Enablin+ core training gives an opportunity to share: information, empathy, knowledge, know-how, practical advices, expertise.
   - The **timing and scheduling**: the targeted student of trainings – no matter if specialist or parents – have difficulties to find time for enhancing their information and knowledge on the physical and mental status and wellbeing of their child or of themselves. The common core training sessions were considered relevant, giving a boost in motivation and energy and thus could become a ways of preventing burn-out and depression, which are so common in the caregivers of this highly demanding target group.
   - The **informal learning spaces**: the e-learning platforms, the different supportive devices (i-phones, apps) have a potential to be helpful for in-house training (at the domicile of the trainee), saving time and finances, enhancing confidence and avoiding remorse (of cutting precious time and money from the beloved child with CISN for leaving for courses).

In this respect, we would like to formulate the following recommendations.

1. A European-wide network should be maintained for the years to come in order to make an informal (or even formal) follow-up
2. Further elaboration of specific trainings, based on this common core training, taking into consideration and refining them, based on specific needs (customer-tailored trainings)
3. follow-up research should be set up regarding:
   - The enhancement of the QoL of the children and youth with QoL, whose parents, specialists and caregivers were trained within the project
   - The enhancement of the QoL of the trained parents, specialists, caregivers, due to the learning, knowledge, information, good practice examples given
   - The enhancement of awareness of policy and decision makers
   - The paradigm- and mind shifting of everyone involved in the pilot trainings, including the trainers themselves, who faced new information, new „cases", new experiences
4. Introduce the experience of the common core training into the formal, non-formal and informal education of:
   - children in mainstream education schools, in order to realize inclusive education at every level (from kindergarten to post-secondary education)
   - college and university students – no matter what major or minor specialty – in order to learn the basics of theory, practice and living and being inclusive with persons with CISN.

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