

2014 ●

enablin+

● 2017

Enabling & Including Young People
with Complex & Intense Support Needs

Project Enablin+

Project Enablin+ Enablin+ is a European multi-lateral cooperation project in the area of vocational training – within the LEONARDO programme of the Life Long Learning Programme of the European Commission. Its objective is to contribute to enabling children and youth with complex and intense support needs, and the people who support them, to participate more actively in ordinary life, in families, at school, and other community life. In order to reach this objective, Enablin+ will develop an interprofessional inservice training programme.

News from Italy

Successful train the trainer and conference in Milano (september 2016)

Our 5th Work Package consisted in the organisation of an international Train the Trainer course and a conference in Milano (22-24 september 2016) about **“Enabling Quality of Life in Young People with Multiple Disabilities and Complex and Intense Support Needs: from Theory to Practice”**. About 70 Italian and 30 foreign participants from all professions attended the two-day Train the Trainer Course at S.M. Nascente rehabilitation hospital of the Don Gnocchi Foundation, to learn How to Train Multidisciplinary Teams and Families for a Better Quality of Life”. The course has been developed during the past 30 project months. Thanks to a very dedicated team headed by Dr Marina Rodocanachi and Dr Anna Dal Brun, with a fantastic logistics support by Jessica Matera and translation support by Nagley Bertoldi, these days were very nice and extremely rich in content. On Saturday a conference day was added at the Bicocca University. This aimed at a wider audience, with more speakers from Italy and abroad. Quantitatively and qualitatively it was a big success: 200 people attended this conference, this first of its kind in Italy, about the subject of complex and intensive support needs. In his final speech of thanks, our coordinator said ‘The only thing I regret is that I couldn’t be in all workshops.’ An evaluation, pictures and the presentations are available on [our website](#).



International Congress on Rett Syndrome in Rome

From October 30 to November 1st 2015, Enablin+ partner Marina Rodocanachi and her team (Valentina Gesta, Alessandra Gandini & Kumiko Toshimori) from Vismara Centre (Don Gnocchi Foundation) made important key-note contributions to the International Congress on Rett Syndrome, which took place in Rome with 400 participants from Europe and non European countries. Besides introducing the Enablin+ project, they also presented their research: first, a Proposal for a new grid to observe gross motor modifiability; another research report about Rehabilitation of gait initiation: from gait analysis to clinical practice; and finally, Psychological care and quality of life. [Read more](#)

INDIA: Sitting at their place project

In our 2nd newsletter we wrote about the [Sitting at their place project](#). During the last week of March Marina Rodocanachi, Nuccia Viganò, Valentina Gesta and Francesca Grange from Don Gnocchi Foundation and Francesca Bellecci from Barzack Association went to develop the last module of the training course for physiotherapists on severe cerebral palsy at Mallikamba Institute for disabled children, southern India. The last module is also directed also to teachers and families. A booklet for therapists, teachers and families will be edited in English and translated in telegu, local language.

Roundtable meeting of the Special Interestgroup of IAS-SIDD in Sweden

From 23 – 25 September 2015, Marina Rodocanachi participated at the 7th roundtable meeting of the Special Interest Research Group (SIRG) of the IASSIDD (International Association of the Scientific Study on Intellectual and Developmental Disability) on Profound Intellectual and Multiple Disability (PIMD) in Vasteras, Sweden. She presented the Enablin+ Needs Assessment Research: “ Who are they? Assessing the need of children with intensive and complex support needs in eight European regions” to the 35 participants - researchers from Europe (Switzerland, Sweden, Belgium, UK, Netherlands, Germany, Japan, Canada. Many researchers asked to be involved in the Enablin final Conference in Milan 2016!



Multiple and severe disability becomes part of the curriculum at University of Milan, School of Medicine

A real multiplier effect: the Enablin+ project was introduced to doctors specializing in child neurology and psychiatry at the State University of Milan, School of Medicine, during a lesson by Dr. Marina Rodocanachi. This is the first time the subject of children with multiple and severe disabilities is being studied at an Italian University. 25 specializing doctors listened and discussed, considering children from a quality of life and support needs system model. Head of the Child Neuropsychiatry Specialization school, Prof. Maria-Paola Canevini asked for the introduction of this subject in the regular curriculum of specialization school, starting from next academic year.

News from France

CESAP Associative Day

On 7 and 8 December 2015 The CESAP organized in Paris its “Associative Days”. This is a symposium to which the families of children or adults accompanied by CESAP services, professionals and many friends are invited. These days had a “special flavor” as they marked the 50th anniversary of the association. The theme this year was “Polyhandicap & Complex Disability : looking forward to the future”. Two foreign Enablin+ partners attended this meeting, to present preliminary results of the research project. [Read more](#)

New Training Catalog

CESAP is a pioneer as it comes to offering a wide variety of in-service trainings to all sorts of professionals working with – as they call it in France – “children with polyhandicap”. As every year, the month of September saw the release of the new catalog of CESAP Training Resources. It is [available online](#).

Pilot training in France

For several years now, CESAP has been organizing introduction & welcoming days for the new managerial staff. It takes place every two years. During these induction days, one of the goals is to see what kind of training courses participants are likely to ask from their management, in order to enhance their job-related skills and develop new ones. Christine Plivard told us everything about the training results at the Train the Trainer meeting in Milano. You can find the presentation [here](#)

‘Accompanying children with multiple disabilities and their families in the special services for education and care at home’.

A trainings day organized by CESAP.

News from Belgium



PhD defense of Heleen Neer-inckx (member of the Belgium Enablin+ team).

Need time: Joint

attention in interactions with people with profound intellectual and multiple disabilities.

Because of a combination of a cognitive impairment with motor and/or sensory impairments, people with profound intellectual and multiple disabilities (PIMD) need others to explore the world and to show their abilities. Therefore, high quality interactions are critical for a good quality of life of people with PIMD. Joint attention is described as a constituting factor of high quality interactions, indicating the sharing of a focus of attention between two partners, while both partners are aware of each other's attention towards the element of mutual attention. The development of the ability to share attention requires specific skills: reactions and initiatives, respectively. [Read more](#)



Thematic week in Belgium (May 17-21, 2016)

In Belgium 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. 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. An awareness raising conference day, in the presence of the Minister of Welfare and government policy makers, families, field workers and directors, was followed by an intensive week full of workshops and visits, focussing on the innovations in the integration of care and education. About 500 people participated in at least one of the events. You can find the presentation here. About 500 people participated in at least one of the events. [You can find the presentation here.](#)

News from Bulgaria

A New Group for Children with CISN at Karin Dom
In September 2015 after a successful charity festival "Smile, Karin Dom" we started a new group "Smile" for children with complex and intensive support needs

[Read more](#)

News from Romania

Fourth partnermeeting in Romania In September 2015, Enablin+ partner Babes-Bolyai University of Cluj-Napoca (RO) hosted the 4th partner meeting, falling in Work package

4. Objectives of WP4 are to evaluate the efficacy, feasibility, content and modalities of in-service training modules. However, the partner meeting also had also other objectives: the project being half-way, it also served as a self- evaluation, and further planning. The partners also took the opportunity to visit three centres, the Department's cognitive assessment & training "Feuerstein Centre", the Hungarian Kozmutca Flora Special school for language & hearing impaired children, and a Romanian-speaking Special School. On Saturday morning we invited "stakeholders" (school directors, parents, teachers, therapists, policy makers) to a meeting. [Read more](#)

News from the Netherlands

Quality of Life Centre; for a good and Quality of life for people with CISN.

The centre is a centre of expertise founded by the Dutch partners of Enablin+. It's existing knowledge developed for the target group and structured into a coherent range for everyday use. The results are presented in an exhibition and made in this way available to the public. Methods, technology applications and the combination of both, are an important part of the offer. [Read more](#)

To flourish; In search for a good life for people with a severe intellectual disability and serious behavioural problems.

Janny Beernink-Wissink [brings us a new paradigm in the care of people with severe intellectual disabilities and serious behavioral problems.](#) It describes a quest for enrichment, to speak of citizenship for them. On the basis of the 'capability approach' (Nussbaum), she describes a set of basic human needs and conditions. The method will probably be used in the Enablin+ training.

News from the Netherlands

Scientific research - Together to School Classes

For parents and carers of children attending the Together to School classes, there is no doubt about it: they perceive that their children are more alert during the day and sleep better at night thanks to the Together to school class. In practice, they see their children make great leaps in their development, because they learn from peers without disabilities and because there is a lot of personal attention for their child. This practical experience is not yet supported by scientific research. This will change soon. [Read more](#)

VNG conference: "Create proximity"

The Dutch Association of People with Disability (VGN) is the association for care and services providers to people with disabilities. On December 10, 2015 they organized a conference. The disability sector is well advised to make themselves more visible in society. The sector must be careful not to "loose" in the current changes that are going on. The new VGN president (Femke Halsema) argued that the disability sector appears to be a closed system. She also referred to the discussion of the UN Convention, which the Netherlands ratified just recently and reluctantly as one of the last countries in the world, the day prior to the conference. Halsema supported the words of Otwin van Dijk, who made a plea for "a society in which everyone counts. We do not settle separate issues for people with disabilities, they are not the exception. We must organize our general facilities in such a way that everyone can use them, disabled or not. Some ideological debates within the sector, for example, inclusion are a hot topic. The pragmatism which now prevails, will be a relief to many, they argued, but there are also disadvantages, such as the danger of technocracy. "This sector has a lot of jargon, policy is quite rich," she said. "The language is sometimes so inaccessible as a closed setting in the woods. The risk is that bureaucratic goals will lead their own lives.

[Look here for an impression of the day](#)

Rhythm of your life

On March 24th 2016, the annual gathering of the Platform EMG (which means "serious and multiple disabilities") took place, where professionals and parents meet and actively share knowledge. This year the theme of the day was: "Rhythm of your life". The rhythm of your life affects your quality of life. Live in a natural rhythm is a vital condition for life. When we organize our life rhythm, we create routines that we do not have to think about having to say Marli Huijter, professor, in her book Rhythm.

Rhythm in our lives creates recurrence but also for variety. Precisely because of that recurring aspect we have opportunities for change and renewal. This allows us to organize your life easier as we can and want to do more things that myself we really want, which we might otherwise have the "time" had not had before. But how is that for people with CISON? Today we look at the rhythm of their lives.

[Read more \(in Dutch\)](#)

The Platform EMG is the Knowledge Network for Parents and Professionals in the Netherlands. [View their agenda here.](#)

Pilot training in the Netherlands

In the Netherlands we organized three pilots last year. One of them was the proposed Enablin+ training. Mia Nijland told about the experiences with the pilots at the Train the Trainer meeting in Milano. You can find the presentation [here.](#)

News from the Portugal

Final partner meeting in Evora

From 16-18 th of February 2017, the Enablin+ partners planned their final partner meeting in Evora, to discuss evaluation and quality assurance. The meeting will be conjointly organized with a national dissemination conference. More news about this event in the next newsletter.

Signs of risk for autism in babies

Replying to an invitation made by the Organizing Committee of the Cycle of conferences in Psychology, Enabling+ organized and supported the interesting conference held on February 10, 2016: «Signs of risk for autism in babies». The conference room was completely full (100 students and other professionals) to listen Erika Parlato, Associate Professor at the Federal University of Minas Gerais, Department of Speech Pathology, Faculty of Medicine. She is currently studying the mother-baby interaction, oral language acquisition and, especially, autism.

World Café

Thinking on the design of the Enablin+ course, the portuguese partners participated in the World Café "Who decides what? (in inclusion)", for people with disabilities, families, professionals and community. The goal was to gain experience in this type of methodology and and deepen knowledge in the inclusion area.

International Congress on Interdisciplinarity in Social and Human Sciences.

This congress held at the University of Algarve, in Faro, Portugal, organized by the Research Centre for Spatial and Organizational Dynamics (www.cieo.pt). It was an opportunity for an interdisciplinary systematic approach, as well as to show innovative research in social sciences, but also to improve the networks between researchers from different scientific disciplines.

The main themes of this congress included research topics from different scientific fields, like Sociology, Psychology, Education, Economics, Management, etc. Adelinda Candeias and Hugo Rebelo presented the poster «The International Project Enablin+», to about 200 participants.

First scientific meeting in psychology

The Department of Psychology of the University of Évora and the Psychology Institute of the University of Leipzig in order to deepen the academic, educational and scientific cooperation, organized the First Scientific Meeting in Psychology, on May 13, 2016. The organization intended that teachers, researchers and students reinforce mutual knowledge and strengthen the scientific production and inter-institutional cooperation. This event ended with a session open to the academic community and the general



public, reflection and debate on current challenges of psychology as a science of mobilizing human and social development. Enablin+ team took this opportunity to present the pilot course that has developed with national and international partners, and Hugo Rebelo received excellent feedback and contributions from the audience.

Enablin+ was present at the 3rd International Congress about Fragile X syndrome

Doing the Presentation of the EQOLMI: course of mediators for inclusion, that will be tested in December. With this presentaion the Portuguese team pretended to colect contributions, make dissemination of the course and attract interest to participation, since the audience was composed of many target members.

The congress was also a great learning expirience, with inational and nternational speakers looking at the difficulties and challenges faced by the family, school, teachers, other professionals and the entire community in the inclusion of children, youth and adults with Fragile X.