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Enabling & Including Young People with Complex & Intense Support Needs

Enablin Newsletter N°1 - January 2015

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Editorial



1 children's drawings from Karin Dom Centre, one of the Enablin+ partners in Bulgaria

Jo Lebeer, project coordinator, University of Antwerp, BE

We are pleased to present you the ENABLIN+ project, which was launched at the beginning of 2014. 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. Based on an analysis of needs and of models of good practice, we want to develop a system of interprofessional in-service training, where professionals and parents of various professional backgrounds learn together, with the aim of enhancing quality of life of the children at various age levels. More specifically, Enablin+ will develop a series of on-the-job training modules to improve inclusion, communication, behaviour management, activation and learning, support for daily life care. The project is going on in 8 countries in from the North, South, East and West. It brings together experienced partners from Universities, colleges, vocational training institutions and support centres for children with severe disability. With this exchange of information across languages and countries, we hope to improve the lives of all children around Europe (and beyond) who are largely dependent on good quality of support from the people in their environment.



Start-up meeting and symposium Antwerp January 2014

From 31 January -1st February 2014, the partners met for a kick-off meeting in Antwerp, in one of the University's historic buildings, the "Grey Sisters". At this occasion, a mini-symposium has been organised with the theme "Who are they? Children with complexes and intense support needs: Towards a more inclusive and more active high quality life". The idea was to invite key people working in the domain of severe disability, in order to involve them right from the start. Next to 18 international participants, 55 participants attended from Belgium and the Netherlands. We succeeded rather well in getting the "right" people present, e.g. the involvement of the main professional networks (Multiplus, SEN), Parent-Professional networks in Dutch-speaking (Rett-syndrome Foundation) and French-speaking Belgium (AP3), the official governmental funds (VAPH and AWIPH), and delegates of many centres caring for children with complex disabilities, and the president of the European Association of Service Providers. The objective of this symposium was to create a better understanding of the living conditions and needs of care and support concerning activation and participation in the various domains of life, of children and youngsters in a situation of complex disability, who often remain nearly totally dependent on others, often labelled as having "profound and multiple disability", to introduce partners to the public and to each other, and to present new models of assessment of quality of life.

In the morning there were three highly inspiring lectures. The symposium had the honour to have Dr. Elisabeth Zucman from Paris as a keynote speaker. She is the "eminence grise" in this field, founder of numerous initiatives to improve the lives of children with very severe disability. She talked about the history and present challenges of supporting children with "polyhandicap" as they are called in France. We have come a long way from the time where these children were just lying behind curtains and doing nothing. Claudia Claes of the E-QUAL Centre of Ghent University spoke about Shalock's model of quality of life. Based on a social model of disability, she presented different new qualitative as well as quantitative approaches to assess it. Bea Maes of the Catholic University of Leuven (BE), president of the Special Interest Group on Children with Profound Intellectual and Multiple Disabilities (PIMD) of the International Association of the Scientific Study of Intellectual Disability (IASSID) presented the "new" thinking Multiplus, an expert centre on PIMD. In the afternoon, the Enabling+ partners presented their work. Very important as well were the parents (Jacques Lodomez of AP3 and of the Rett Syndrome Association), who represented the voice of the children. An abstract book is available [here](#).



Enablin+ Research on Needs Assessment

The first Work Package consists of getting the needs of children with complex and intense support needs (CISN) clear. To that purpose, we organised a research in the 8 partner's countries. A questionnaire was made, translated in 8 languages, enquiring about the living situation of children with CISN, their needs; the way professionals assess their functioning and needs, and the needs regarding the kind and content of further training, also requesting nominations of examples of good practice and essential literature. The call for participation is still open. Here is a link to the Portuguese questionnaires: <https://inqueritos.uevora.pt/index.php/777536/lang-pt>



Enablin+ reaches out into India

The project, which has as a scientific coordinator dr. Marina Rodocanachi is held in the South of India (**Warangal** district, **Andra Pradesh**) and addressed to **Mallikamba Institute for disabled children**. Mallikamba is an institution addressed to more than 200 children and young adults, mostly with very severe forms of disabilities, and coming from a very poor context. Services provided by the Institute are schools, residential recovery if needed (many orphans), food and basic physical care. The first project has provided the Institute with facilities and basic sanitation measures and set up a system of children evaluation in order to identify basic rehabilitation needs. Among the children seen at Mallikamba, some of them, young and with multiple disabilities, were found lying on the floor, not having the possibility to sit on a normal chair nor any opportunity to be provided with postural seats. For this reason, they were excluded from school education and had severe problems in eating and relating to caregivers and peers. In 2014 the **Italian Association, Barzakh - Culture and cooperation (www.barzakh.org)**, together with **Filo Diretto Onlus (www.filodirettoonlus.org)** an International Assistance Group as a financing subject, started with a new project: **“Sitting at their place: study of a therapeutic and rehabilitative model based on the construction of postural seats for children with severe multiple disabilities in an extreme poor context: Southern India”**. The project intend to teach the principles and spread the use of individualized postural seats built in cast at a very low cost for preschool and primary school children with severe disabilities at Mallikamba to local staff, to physiotherapy who teach in local schools, to teachers and parents. [More information.](#)

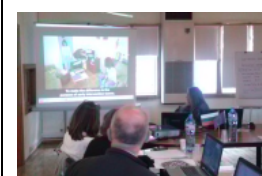


Second partner meeting in Varna, Bulgaria, September 2014

From 25-28th September 2014, we had our second Enablin+ partner meeting in Varna at the border of the black sea in Bulgaria, at the [Karin Dom Centre](#). KDC's staff Apostol Apostolov and Magdalena Tsoneva took good care of the 15 foreign guests. First, they showed them around the work of KDC, which has a pioneering role in supporting children with disability in Bulgaria. The KDC is situated in a beautiful old manor house in the park at the seaside, donated by the famous Bulgarian philanthropist Ivan Stancioff. After visiting the centre, the partners discussed mainly two subjects: the results of the needs' analysis research and "good practices" of continuing support systems and inclusion. The partners presented a selection of projects, as widely diverse as early intervention, to taking care of a daily bath. That meeting was attended by local invited professionals. We discussed a list of 14 criteria of what are to be considered good practices based on a quality of life approach, activation, participation in society, universal design, modifiability and teamwork. We also discussed competences required by the various professionals working with children with complex and intensive support needs. In this way, we gathered already quite interesting training material. We also visited the school for visually impaired "Prof. Dr. Ivan Shishmanov". The school has classes for students with intensive and complex support needs. It has all modern technical equipment, such as electric wheelchairs and computer-assisted communication. But above all, it has very enthusiastic and competent teachers. The music teacher gave us a demonstration. Indeed, music is a language, which is accessible to everyone, including the most severely impaired children. Music conveys affective communication, but can also be used to mediate cognitive concepts and skills, such as rhythm, counting, and reading. The children also learn in kitchen workshops, art workshops, and an indoor garden (photo). Most of the children have visual impairment, in various degrees. The walls of the school contain symbols, which guide the children's orientation.

In the afternoon, we continued our discussions on training materials/ information sources we already have and we still need. We decided that we mainly need video material of just daily situations, around certain topics (which can be the chapters of "activities and participation" and "external factors" as indicated in the ICF. Case-based learning, based on confrontation with daily problems, is the best way of learning, not only in undergraduate training, but also in post-graduate continuing education.

Of course, we also took some time for team building and social gathering, but not much, only after long working days, combining dinner with music. Bulgaria has very nice folk music and dancing. A report can be found [here](#).



In search for good practices

Enablin+ launches a call with all partners, to look for innovative projects oriented at improving quality of life of children with complex and intensive support needs, in particular aiming at improving activities and participation in inclusive settings (education, leisure time, working with families), improving daily care (nutrition, toileting, behaviour regulation), improving social competences and relations, communication, ethics of care. We developed a list of criteria and a short questionnaire to fill out. Anyone can nominate a project. Please send your candidatures to Work package leader BNK rienne@nijlandenkroes.nl. The form can be downloaded [here](#). The Portuguese partner will organise at the University of Évora on March the 14th 2015 a meeting "Good Practices with people with complex and intensive support needs" — Colégio Pedro da Fonseca. <https://www.facebook.com/events/386987454788977/>



Going places: Bilateral partner meetings

◆ **March & May 2014: Belgian and Romanian partner: teaching master students in dynamic assessment**

During one week in March and one week in May, the students of the master degree in psychological counselling and intervention of the Babes-Bolyai University of Cluj-Napoca, were introduced by Jo Lebeer of Antwerp University and Eniko Batiz of the BBU, in the methodology of dynamic assessment in the course "Assessment Methods of Learning Propensity and Cognitive Modifiability". The much-appreciated highlight during the May seminar was the practice session with hearing impaired pupils of the Kozmutza Flóra Iskola, where applause is demonstrated by waving hands, as shown in the picture. This part created a lot of enthusiasm with the students (and the pupils); because they realized that, they could best learn dynamic assessment by doing it with real children and seeing their reactions to mediation and believing in them.



◆ **October 2014: BE +NL: symposium at Groningen University**

On October the 14th 2014, Mia Nijland (of BNK Wijhe- NL) and Jo Lebeer went to Groningen University (NL) to attend a symposium in the honour of Prof. dr. Carla Vlaskamp's official retirement. Carla Vlaskamp dedicated an entire lifetime to research and intervention reaching out to children with profound intellectual and multiple disabilities. She is the author of numerous articles and co-authored a book with Prof. Bea Maes and Anneleen Penne on innovative care and support of children with PIMD, which would be suitable to be translated into English, because it contains the basics of what our project stands for. There were other foreign and Dutch speakers, including parents.



◆ **November 2014: Italy and France: conference on quality of life**

On 20 -21st November, Marina Rodocanachi & Ana Del Brun went to Paris to attend the conference on Quality of Life and polyhandicap, organized by the "Assistance Publique des Hôpitaux de Paris". Enablin+ partner CESAP was part of the scientific committee. The themes were those of the European Enablin+ project: how to assess quality of life; how to improve daily care, nutrition, activity, epilepsy, reanimation procedures, pain management. More information (in French) can be found in this [document](#)



➤ **Italy and Belgium meet at Don Gnocchi in Milan**

◆ On January 15th, project coordinator Jo Lebeer visited the Vismara Rehabilitation Centre, part of the Don Gnocchi Foundation. Chief rehabilitation doctor Marina Rodocanacchi showed how they work with children (until 18) with a variety of developmental disabilities, some of them very serious and complex. They are also one of the National Rett Syndrome Reference centres. The large part of their work is to do functional diagnosis and multidisciplinary therapy. One of these therapies is hydrotherapy in a hot (32°) swimming pool, where we met Canadian-Italian David and his swimming mediator. Children with Rett syndrome (who usually lose their ability to walk), are often able to walk in a hydrotherapy bath (because they don't feel their weight), thus keeping them more mobile, less spastic, and allowing many of them to preserve their walking ability



Drawings made by children of Enablin+ partner Karin Dom Centre, Varna, Bulgaria

News from the partners

Karin Dom Centre - Bulgaria

- ◆ Karin Dom Centre organised a very successful International autism Conference that took place in the period 30 May - 1 June 2014. <https://karindom.org/en/moments-from-the-international-autism-conference-2014/>
- ◆ We are developing a wide training programme. for a UNICEF-run project: <https://karindom.org/en/training-patronage-nurses-unicef-2014/>
- ◆ Recently a contract was made with the Government to undertake a nation-wide training on early intervention: <https://karindom.org/en/social-inclusion-project-ministry-of-labour/>



Coming events

- ◆ 19th March 2015 Zwolle (NL) EMB yearly congress www.embcongres.nl (in Dutch)
- ◆ 26-28th March 2015, Zwolle (NL) Enablin+ Partner Meeting. Theme: interprofessional training in supporting children with EMB; how and what?
- ◆ 27-29th May 2015, annual meeting of the European Academy of Childhood Disability, Copenhagen. Marina Rodocanachi of Don Gnocchi foundation will present music therapy with children with Rett syndrome. More information: <http://www.eacd2015.org>
- ◆ 5-17th July 2015, Florence, Italy. International Summer Workshops by the Feuerstein Institute, on Feuerstein's theory of Structural Cognitive Modifiability and Mediated Learning Experience and its applied systems: Instrumental Enrichment Programme and Learning Propensity assessment. More information www.feuerstein-institute.org
- ◆ 17-19 September 2015, Cluj-Napoca, Romania. Goal: how pilots of training initiatives are organized in each country; research protocol
- ◆ 5-6-7 Mai 2016, Rome, Italy. 2 days train-the trainer conference



Recent publications

- ◆ "Clinical and educational applications of Reuven Feuerstein's Mediated Learning Experience Theory: current scientific evidence". Published as a Special Issue of the Transylvanian Journal of Psychology, 2014, by the Cluj University Press. Reuven Feuerstein, whom past-APA president Robert Sternberg called "one of the greatest 20th-century psychologists next to Piaget and Vygotsky", left an important intellectual heritage, which is a challenge for the world of today's problems. In this volume, a number of invited scholars who have known him and worked with him (such as David Tzuriel, Robert Sternberg, Carl Haywood, Carol Lidz, Noami Hadas-Lidor, Hefziba Lifshitz, Jo Lebeer and David Martin), present reviews on the scientific evidence of Feuerstein's MLE and SCM theory, as well as on educational and clinical applications. There are also two original contributions by young PhD researchers, Reka Janos and Cristina Vedovelli. Although more applied with children with mild or medium learning disability, the question is whether MLE and SCM theory also holds for children with PIMD. Surely it does, there are numerous examples showing that activation and mediation are also relevant for children with complex problems. See the abstracts at <http://epsz.psihologia.psiedu.ubbcluj.ro/en/index.php>. Order a copy by writing to: demeter.karmen@yahoo.com



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University of Antwerp INCENA-Inclusion & Enablement	Expert Centre for Education & Care - Wijhe	Comité d'Etudes, d'Education et de Soins a.d. Personnes Polyhandicapées - Paris	Babes-Bolyai University Dpt. Applied Psychology Cluj-Napoca	Association St-François d'Assise – Pôle Handicap	Karin Dom Foundation – Varna	Child Rehabilitation service, Vismara Institute, Fondaz. Don Carlo Gnocchi - Milan	Centre for the study of Psychology & Education - Evora
Belgium	The Netherlands	France	Romania	Isle de la Réunion-FR	Bulgaria	Italie	Portugal