enablin+
Enabling & Including Young People
with Complex & Intense Support Needs

Education and Culture DG
Lifelong Learning Programme

Workpackage 1 – Delivery 1a

Report

Who are they?
Assessing the needs of children with intensive and complex support needs in eight European regions

Jo Lebeer (Editor)

Antwerp, 2015

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Colophon

Who are they? Assessing the needs of children with intensive and complex support needs

Report of Enablin+ Project Workpackage 1 – Deliverable 1

Jo Lebeer (Editor)

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Introduction: principles and goals of the ENABLIN+ project

Jo Lebeer, project coordinator, University of Antwerp, Belgium

Project Summary

The project ENABLIN+ is addressed at the needs of children and youth with complex and intense support needs (CISN), their caregivers and supporters. It wants to develop a system of interdisciplinary in-service training, where professionals and parents of various professional backgrounds learn together, with the aim of improving inclusion, promoting de-institutionalisation and enhancing quality of life of the children with CISN, at various age levels. It responds to urgent needs for training, signalled in richer as well poorer EU member states, to meet the increasing demands for supporting children with CISN and comply to 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. Actual vocational training insufficiently prepares professionals to deal with these issues. There is a need of transdisciplinary collaboration of all concerned: parents, teachers, daily-life supporting staff, medical & rehabilitation staff and vocational training staff.

To that purpose, the project wants to do (1) a needs study, (2) search and describe examples of good practice, (3) develop a set of training modules in EN, NL, FR, IT, RO, HU and BG languages, oriented at support needs assessment, staff attitudes, beliefs and conceptual systems, enhancing children's communication capacities, daily life activities, behaviour regulation, activation and participation in learning and inclusive schooling. (4) Modules can be on-line as well as in real meetings. (5) An international summer school will be organised. (6) Results will be disseminated in newsletters, professional articles, a white-book and DVD.

Why do we want to this Enablin+ Project?

Children and young adults with complex and intense support needs (CISN), sometimes called "profound intellectual disability" or "polyhandicapés", or "multiple disabilities", are difficult to put into one project category. They have indeed multiple needs: they are difficult to include in regular schools, they need a lot of care and attention, staff is usually ill prepared and parents have many needs too. According to the 2006 Convention of the United Nations on the rights of persons with disabilities, countries that ratified this convention now have a duty of deinstitutionalising children and to organize the possibility of including children with a disability in normal schools, to promote social inclusion. This is not obvious, especially for youngsters who have severe and multiple difficulties in daily activities of self-care, learning, communication, mobility, as well as in participating in education or other activities.

First, these children often do not get adequate early intervention and parent support; later, they are often taken care of in separate environments. In some countries, education is very rudimentary. An often-heard complaint is that there is never enough staff. Inclusion policy is still lacking. In most countries, except Italy, Portugal and Scandinavian countries, they are not usually integrated in regular environments. Dedicated professionals, who support or teach these children, do not necessarily know the means or ideas how to assist these children in mainstream schools or other inclusive settings. Parents are in need of help. Another problem reported is the lack of activation of many children with serious intellectual disability. Staff and children of mainstream schools are not accustomed nor prepared to accommodate these children.

The reason why these situations continue to exist can be found in a lack of belief that it is possible and worthwhile to activate children with severe intellectual impairment; that it is possible and worthwhile to take inclusive initiatives and that in the long run quality of life of everyone (including those who support) can be enhanced. Other reasons that the target group is usually neglected in training initiatives might be that they do not represent an economic power and it is easier to do passive caring than active involvement.

Deinstitutionalisation needs to be accompanied with training of all people involved, and on all levels. People, who work with children and youth with intensive caring needs, are insufficiently trained during their basic training. This happens at all levels: in vocational training, at university and colleges. Moreover, once at work, other needs of training arise while working. There is a need to develop ongoing training systems on the work floor.

People do learn various techniques in their basic training, but what is lacking is a basic attitude and belief system, that it is important to activate the children from early on to give them experiences, that one believes they can learn; that people have an inquisitive, explorative attitude to look for solutions which work, that it is important to participate in life's opportunities as much as possible, including going to school, that the way you address these children matters, etc. Therefore, training needs to address attitudinal and ethical issues, as well as practical aspects. It needs to work at a shift in belief systems and conceptual systems, as well as provide hands-on practical advice.

To realize this goal of inclusion and activation, there is a need of transdisciplinary collaboration of all parties concerned: parents, teachers, daily-life supporting staff, medical & rehabilitation staff and vocational training staff.

Solutions, which have proven their efficacy - inventions made by professionals or parents -, remain often local, because of language and organizational barriers. Local organizations could therefore benefit from an exchange at a European level. To achieve this goal, parents-professionals cooperation must be strengthened, and in-service training models should be developed which are of benefit to institutional supporting staff, regular school staff and parents, in approaches of intellectual activation and inclusion.

Hence the name "ENABLIN +", which has three aspects:

(1) enabling = the opposite of disability; it means: to allow the person to function;
(2) the IN standing for "inclusion";
(3) the "+" standing for "multiple disabilities" or "extra and multiple needs"

For whom is the Enablin Project intended?

We want to reach out to children and young adults (0-21) with *complex and intensive support needs*. This new term is somewhat different, but overlapping, to the existing concept of "PIMD" in English (Profound Intellectual and Multiple Disabilities) as accepted by the IASSID (International Association for the Scientific Study of Intellectual Disability) or the French "polyhandicapés". In many non-Anglophonic countries, or in countries who do not (yet) participate in the IASSID, the term is used in a less restrictive way. We wanted our definition not to be formulated only in terms of what goes wrong – their impairments - but to comply with the international developments towards a social model of disability. This sees disability not as a characteristic of the person, but - to use the definition of the International Classification of Functioning by the WHO - as a situation which is the result of several interacting domains: physical or mental impairments, restrictions in activity and participation, external factors which can be inhibiting or facilitating activities and participation, and personal factors. This also leaves room for positive characteristics and contributions.

Our target group "children and young adults with CISN usually has multiple impairments and severe restrictions in activities and participation in the field of daily life self-care, education, communication, mobility and leisure activities. A child may be defined as having complex needs if he or she has:

- Severe or profound disabilities in at least three of the following disability categories:
    - Motor impairment
    - Hearing impairment
    - Cognitive impairment
    - Speech and language impairment
    - Behaviour problems
    - Feeding problems
    - Additional chronic health needs

- Or severe or profound disabilities in at least two of the disability categories plus the need of at least two types of the following resources:
    - Therapy services
    - Additional educational resources
    - Nursing care needs
    - Social care resources
    - Mental Health services

This definition does not use IQ categories, nor syndrome-based admission. One can e.g. have Down syndrome, yet have multiple disabilities; but not all children with Down syndrome have complex and intensive support needs. One can have the ability to walk, yet have multiple and intense support needs, as e.g. is the case of most children with Lesch-Nyhan syndrome.

There is always something wrong with a definition of a category, because it excludes some elements, whereas the basis of our project is inclusion, not exclusion.
However, we wanted to focus more on those who tend to be neglected when it comes to initiatives towards inclusion in society.

The direct target group of the ENABLIN+ project is composed by the staff of specialized centres, mainstream and special education staff (teachers and other professions), educators or personal assistants for daily living, parents, medical & rehabilitation staff (doctors, speech therapists, physiotherapists, occupational therapists, psychologists, nurses), representative organizations for the disabled, vocational training staff at secondary and continuous professional development level.

What do we want to achieve?

1. Promote the quality of life of children and young adults with complex and intense support needs (CISN)
2. Increase social and educational participation, facilitating activities, learning and development of children with CISN
3. Raise awareness, and create a shift of mind in people supporting children with CISN
4. Enhance the quality of support in enabling children with CISN towards a more inclusive and active life.
5. Develop interdisciplinary in-service training modules for professionals and parents working with this target group, in areas such as increasing learning, autonomy, activities in daily life, communication, behaviour regulation and in inclusive education.

6. Professionalizing staff of mainstream schools in welcoming children with complex dependency needs.
7. Strengthen parents-professionals cooperation.
8. Empower parents and professionals.

What is innovative about the Enablin+ project?

The transdisciplinary character and multi-level learning: it is clear nowadays that in complex care situations, one profession cannot have all the knowledge to handle a difficult situation. Take e.g. the situation of a child with many epileptic fits, which are difficult to control via pharmaceutical drugs. That requires fine-tuning between parents, doctors (specialist as well as general practitioner), nurse, educator, school staff, etc. This is called multidisciplinary collaboration, which has become good standard of care. In multidisciplinary collaboration, professionals collaborate in a patient-centred way, discussing common goals and ways to achieve them, each inputting their specific professional expertise. Transdisciplinary collaboration, however, goes beyond multidisciplinarity, in the sense that professions are also aware of the specific expertise of other professions and are capable to meaningfully make use and reinforce each other's skills, with a common purpose to facilitate the quality of life, based on a common ethics. In our example of epilepsy: the knowledge of the daily support assistant about what triggers epileptic fits is as much important as the doctor's knowledge about the drug effects. Both professions need each other and are highly dependent on each other.

The valorisation of expert knowledge by different sources: parents, daily care professionals, researchers, teachers, medical/rehabilitation staff etc., all have valuable contributions to make to the quality of life, with their knowledge, their skills and personal commitment and attitudes. A parent may be able to understand small signs of their child as expressions of will. The speech therapist is not the exclusive guardian of knowledge about communication.

Learning together: training parents and professionals of different hierarchical levels together: carers, teachers, parents, doctors, educators, etc. Usually, specific professions have their specific moments of continuous training, e.g. physiotherapists come together in their own sessions. Enablin+ project wants to organise training activities where various professions learn together, also involving parents. This is certainly needed in the case of children with CISN, where communication is a real difficulty, and inter-professional communication is necessary. This is always a necessity, but more so in children with CISN. In the past 10 years, the Faculty of Medicine & Health Sciences of the University of Antwerp - in cooperation with all the health-related higher education institutions of the City of Antwerp (school of physiotherapy, speech therapy, psychologists, nutritionists, school of nursing, of occupational therapy, of social work and socio-educational work) organised a 1-week training course in interprofessional collaboration where all the students in these various professions (now amounting to 700 each year) learn to work together on case work. The course is abbreviated as IPSIG (in Dutch meaning: interprofessional collaboration in health care) (Tsakitsidis & Van Royen, …) Very little theory, but a lot of practice. Most of the week is spent in study groups of 7 students, in the presence of a tutor. The cases they bring in are always complex. Practical as well as ethical aspects are discussed. Project ENABLIN would like to take similar initiatives for the target group of children with CISN, and also in post-graduate in-service training.

Complementarity to basic vocational training which is taking place separately, and in-field training which is really interdisciplinary. An important innovation in Enablin+ is learning together while already working. Usually, graduates from the various professions (doctors, educators, teachers, speech therapists, even special needs psychologists, etc.) know next to nothing when they start working with our target group of children with CISN. They might have heard of it at college; if they are lucky, they might have worked with them during their apprenticeships. Rarely do they have had the opportunity to get to know the field and the possibilities. In addition, even rarer are those who have had the opportunity work in centres spearheading innovative practices. Therefore, it is of utmost importance to create a possibility of post-graduate learning opportunities, when questions arise from the daily practice.

The needs- based and not impairment-based approach: we refer to the discussion in the section above, on the needs-based definition of the Enablin+ target group, rather than an impairment-based definition, in order to comply with a more social model of disability. If disability is not a characteristic of the person, but of the situation resulting from complex interactions between body, activity, participation, environment and person, then the needs are neither defined by the medical syndrome, but by this complex interaction of factors, and interventions, as well as training initiatives, must be oriented to fulfilling the needs on these various domains. In many instances, the impairment in itself cannot be improved, but activity and participation can, as well as the organisation of support by human resources as well as technical means. A needs-based approach is therefore oriented at the individual. Two children with the same diagnosis can have different needs. Equally, the innovation of Enablin+ is that we do want to suggest a new definition of the target groups in terms of needs, rather than in terms of impairments, i.e. as having “complex and intensive needs”, allowing also for positive characteristics. For example, a child who cannot speak nor walk might represent a positive contribution in a regular school, but e.g. inviting the teacher to use more singing and playing modalities and inviting the children to make contact in different ways than usual.

The stress on inclusion, not only in social life but also in education: similarly, ENABLIN+ wants to make efforts to facilitate inclusion not only in social life, but also in regular schools. Although inclusive education has been on the agenda for the past 40 years, it is only gradually being introduced in practice in most European countries. Some countries are spearheading these inclusive developments (e.g. Scandinavian countries, Italy and Portugal), others are years behind (e.g. Belgium), meeting resistance from special as well as regular teachers. Since the UN Convention of 2006, all countries must take measures to take away barriers against inclusive education. This requires a huge social transformation process. This is still innovative for most European countries. It took Italy, the pioneer of inclusive education in the world, two generations to develop it. Enablin+ is proud to have in its partnerships some of those pioneering countries. Moreover, inclusive education for children with CISN is still very rare, and needs a boost of support to overcome resistance, and to show that it is possible.

The construction of training modules is based on real needs: the project wants to design training modules and contents, based on surveys held among professionals and parents working with the target group.

A common framework, based on the ICF (International Classification of Functioning, Disability and Health), modifiability and inclusion paradigms: the ICF has been adopted by the World Health Organisation in 2000 as a common framework to describe the functioning of individuals. It is based on a social model of disability, where disability is no longer seen as the characteristic of the individual determined by his bodily condition, but as the result of an interplay, as described above. The ICF-CY (children and youth version) has been launched in 2007. Gradually, it is being implemented in different sectors in different countries. This framework is above all a conceptual shift of vision about disability with a focus on activity and participation. “Modifiability” is a concept described by Reuven Feuerstein to designate the capability of people to become durably modified by contact with the environment, in order to shape and develop the mind. The neurobiological basis of modifiability is neuroplasticity. To look at children with complex and intense support needs from these conceptual frameworks, is both innovative and has strong practical implications: all too often these children have been "treated" in a rather passive way, based on the idea that little development could be expected. When activity, participation, activity and inclusion are the basis of our common daily way of interacting, then the perspective changes. It remains to be seen and subject of research, whether indeed a change of perspective also leads to real changes in daily life. Project ENABLIN+ wants to create awareness, and create opportunities of training in these innovative conceptual frameworks, in order to facilitate these changes.

What activities does this project want to do?

WORKPACKAGE 1: WHO ARE THEY? NEEDS OF PEOPLE WITH COMPLEX DEPENDENCY NEEDS

Objectives:

- To clarify the problematic issues regarding living conditions, care and education of children and youth with complex dependency needs
- Using the ICF (International Classification of Functioning) as a basis to describe difficulties and needs of people with complex dependency needs with regard to activities and participation in different domains of life
- Exchange with respect to description and quantification of quality of life and support needs
- Revise the work plan and make concrete work assignments revision

Activities:

- Operationalize a project management system: Revise the work plan; assign concrete tasks
- Literature research
- collecting information from partners; do a survey/ questionnaire/interviews with parents/caregivers/doctors/rehabilitation staff; collect existing research; videotapes of situations
- Information has been shared in a 1st partners' meeting in Antwerp, Belgium on 30-31/1 & 1/2/2014

Result:

- revised work plan
- a report about needs assessment systems
- an article summarizing the report
- management committees
- task assignments
- Research design: networks survey

Lead partner: University of Antwerp (BE) & ASFA (Réunion)

WORKPACKAGE 2: CONTINUOUS SUPPORT SYSTEMS AND INCLUSION

Objectives:

- Define what are good systems of continuous support for people with complex and intensive support needs, at different age levels (early intervention – pre-school age – school age)
- Clarify underlying resistances against deinstitutionalisation and inclusion, as well as belief systems regarding activation and inclusion
- Find, describe and exchange examples of good practice combining adequate support as well as initiatives in activation and participation in education and other domains of society
- To promote a more efficient organisation of support systems at various age levels, starting with early intervention
- To find out what are the training needs of supporting staff; what are the required competencies to work with children with intensive support needs, in view of the daily life support skills, enhancing activities and participation, in view of the goals of inclusion and de-institutionalisation

Activities:

- Needs assessment of in-service training of professionals working with children and youth with complex dependency needs

- Define what is good practice in supporting CINS, in view of criteria
- Research into examples of good practice regarding continuous support systems
- research for approaches which have proven their success with the target group in the areas of daily activities and participation such as: mobility, toilet, sleep, hygiene, play, communication; difficultly understandable behaviour , cognitive activation and inclusion
- make video samples of good practice,
- construct an interactive website to the demands of the people working in the field & parents
- Define a list of required vocational competencies for different professional qualifications in the area of disability support workers. The list will have transversal competencies (for all professions) as well as profession-specific competencies. This list will be jointly developed by social partners (in this case: families of people with disability), service providers, associations of service providers, professionals from medical/rehabilitation/nursing field, from education and from caregivers' professionals. The competencies' list will be based on the inventory of real needs as identified in WP1+ the need to comply with the UN Convention on the Rights of People with disability.
- organize a national seminar/working group with policy and other decision makers, who have influence on financing and employment in the disability sector, to take measures how to make the profession of caregiver or supporter more attractive,
- Exchange in a partner meeting N°2 in Varna , Bulgaria, 25-27/9/2014

Products:

- a "white book" of good practice examples of activation and inclusion of children and youth with complex dependency needs, in paper, online and with DVD video samples
- a research report on needs assessment for in-service training
- list of required transversal as well as profession-specific competencies for various professionals working with the target group;
- an interactive website
- articles in scientific press and via web

Lead partner: University of Antwerp (BE) & Bulgaria

WORKPACKAGE 3: INTERDISCIPLINARY IN-SERVICE TRAINING DEVELOPMENT

Objectives

- based on the list of competencies developed in WP2, develop a transdisciplinary multi-level in-service modular training in the following topics: (1) quality of life and support needs assessment of children (2) communication; (3) basic attitudes and concepts regarding learning, development and inclusion (mediation and instruction) (4) education (special and inclusive); (5) difficultly understandable behaviour, prevention and regulation; (6) learning basic self-care skills (nutrition, toileting, other); (7) how to organize a continuous support system, prevention of burn-out, ethical issues
- develop training initiatives which are based on principles of UDL (universal design for learning) and which are accessible to students with special needs
- organize a series of meetings with VET providers at secondary and continuous-training level, to discuss practical implementation possibilities, training formats, budgetary consequences

Activities:

- based on the data generated by research, develop a set of modules of post-graduate training for staff of mainstream and special education, support (caring) staff and parents
- make a set of teaching videos on each of the topics
- define the kind of certification
- talk to authorities to recognize the certification
- partner meeting 3 in Wijhe, The Netherlands 27-29th March 2015

Products:

- Modular in-service training program
- Set of teaching videos
- A guide on the different topics

Lead partner: Buro Nijland-Kroes (NL)

WORKPACKAGE 4: TEST IST: PILOT TRAINING "SUPPORTING CHILDREN WITH INTENSE AND COMPLEX SUPPORT NEEDS TOWARDS ACTIVITY AND INCLUSION"

Objectives:
- To evaluate the efficacy, feasibility, content and modalities of IST modules

Activities:
- Develop a pre- and post-test according to agreed outcome variables, to look at the effect of training modules
- Each country will organize a training with a 1 to 2 groups of professionals and parents
- Before and after the start of the modules, a questionnaire will be given
- adjust the modules
- pilots with children who have difficulties on this domain
- research: do a search before and after to test the effectiveness of this module
- partner meeting 4 in Cluj-Napoca, October 2015

Products:
- revised module program
- Report on the implementation

Lead partner: Romania (UBB)

WORKPACKAGE 5: INTEGRATED TRAIN-THE-TRAINER COURSE « ENABLING+ »

Objectives
- To train trainers-of-professionals and trainers-of-parents in the different modules, to increase dissemination

Activities:
- organizing a 1 week international course, integrating all the modules
- partner meeting N° 5 in Rome, Italy, 5-8th May 2016

Products:
- training programme
- training manual

Lead partner: Italy (Don Gnocchi Milano)

WORKPACKAGE 6: DISSEMINATION & VALORISATION

Objectives:
- to make the contents known to a larger public
- to promote the starting of local initiatives
- to create awareness in politicians and other decision makers

Activities:

- edit a twice yearly newsletter, electronically and in paper version
- make leaflets in all the partners' languages

- produce a training handbook and DVD
- translations
- present the results on international conferences, a.o. the IASSID (International Association of Scientific Study of Intellectual Disability, Inclusion International
- to edit an interim and final report (public part)

Products:

- leaflets in the partner's languages
- to ensure proper publication (online and elsewhere) of the project's products interim reports and work
- newsletter (6 in total)
- book & DVD
- articles in international professional press and parents' organisation press
- participation in international conferences
- public part of interim and final report
- partner meeting N° 6 in Evora (Portugal), October 2016

Lead partner: Portugal

WORKPACKAGE 7: QUALITY ASSURANCE, EVALUATION & REPORTING

Objectives:

- to ensure that the activities and products are congruent with the objectives
- to provide for a self-providing project continuation after the project finishes

Activities:

- organise focus groups of end-users
- set up an evaluation plan

Products:

- Quality assurance plan
- Durability plan after the project finishes
- External evaluation report
- Final report
- 6th partner meeting report

Lead partner: Belgium

Part I Concepts and developments. A new look at children with complex and intensive support needs

Supporting young people with multiple disabilities: 60 years of developments and adaptations[1]

Multiple disabilities ... The challenge of learning

Élisabeth ZUCMAN MD PHD, Groupe Polyhandicap, Paris France (GPF)

Summary: In this article, the author looks back on 60 years of experience as a rehabilitation doctor dealing with children with profound and multiple disabilities. She witnessed an impressive evolution, from almost total passivity and mothering care, to a new social paradigm of inclusion. Nowadays, we look beyond appearances when dealing with multiple disabilities, and as a result, there are many developments in educational support. There remain, however, many goals for improvements in order to:

- better develop their "sensitive & intuitive intelligence" and nonverbal expression;
- respect the continuity of their attachment to people very close to them
- guarantee human resources indispensable for daily quality care;
- find a balance between care, therapy and education, but also ensure sufficient freedom for growing up.

In return, young persons with multiple disabilities teach us to accept, with their parents, their practical limits imposed by their impairments. However, they also teach us to recognize in them their adaptive genius of human beings and to become aware of the *«necessary interactions» linking* them indissolubly to their familial and institutional environments.

Key words: Attachment - Assessment (of functioning) - Education (of young persons with multiple disabilities) - Ethics - Evolutions (in care provided to the person with multiple disabilities) - Multiple disabilities - Necessary interactions - Nonverbal communication – sensory intelligence - Learning.

If I want to succeed to support a human being toward a specific goal, I must seek him where he is and start there, right there. ... To help a human being, I must certainly understand more than he understands, but first understand what he understands. ... If I can't, I can't help him.

Soren Kierkegaard (translation from Danish by Britt Mari- Barth)

Educational support for children and teenagers in a situation of multiple disabilities has very quickly and deeply evolved, in fifty years only, quite simply because it started from nothing. Until 1964, children known as "encephalopathic" were dying in early age, being without any care, their desperate parents were alone helping them. They were considered in France as those for which "there is nothing to do". In conformance with the ASE (Social agency to children), a few major religious foundations and Welfare Services of Paris gave too few of them friendly nursing care, but without any educational ambition.

It is only in 1964 that the Cnam (national public agency for medical care), on the request of the Cesap (the first French non-profit association for children with multiple disabilities), accepted repaying medical care and special education that would fit their complex needs and the legitimate expectation of their parents. It is not useless to remember it today. In June 1975 an innovating law gave to any person with disability – whatever the seriousness of his state – a full right to live, to be cared, and educated...in a mainstreaming environment, as much as possible.

In 1989, laws stating the main duties of specialised institutions for the first time explicitly recognize the rights of children and teenagers with multiple disabilities to have the same requirements for quality as in others disabilities: Personalised Projects (PEI), respect of parent's will, parent's place, multidisciplinary team… Disability laws of 2002 and 2005 impose rules in same manner, without any discrimination between

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[1] Text of key-note address to the 1st Enablin+ European partnermeeting and Symposium "Who are they? Children with complexe and intense support needs: Towards a more inclusive and more active high quality life", Antwerp, Belgium, 31 january 2014

deficiencies so that, since February 2005, children and teenagers with multiple disabilities have had to be enrolled in their neighbourhood school, like other children, being or not disabled.

In 50 years, the evolution of regulations has therefore been spectacular; and the quality of concrete realizations too (but it is not at all the same in terms of quantity of convenient places…). We shall consider, first, the largely positive evolutions in understanding of needs and capacities of young people with multiple disabilities, then we will consider the educational resources for their optimal development, next the support by and for families, before looking at professional specialized teams and teachers. We will examine the different aspects of educational support by formulating the following hypothesis: are the evolutions, which have been engaged, and that we keep on extending in these extremely complex situations such as multiple disabilities, also particularly useful to *all* young people in our difficult world?

Multiple disabilities: a particular way to be in the world

Today the term of “educational support”, which has recently replaced the one of "care", clearly means, “walking together and sharing the same goals”. We don’t look at them anymore, neither from a far-away distance, neither in an isolated way, neither from top-down … It’s this new approach, to share the same way of life and devoid of a priori, which allows us to speak about “a particular manner to be in the world”.

Children, teenagers with multiple disabilities, who are they?

In 1989, a law (called Annexe XXIV *ter)* gave a very restrictive, very negative and partly incorrect definition of multiple disabilities: "Association of motor deficiency and profound mental retardation (IQ <35), resulting in a severe state of dependency with extreme restriction of expression capacities (1), relational capacity (2) and perceptual abilities "... Some specialized institutions only admitted children responding to this definition which is the one of we call in France "severe multiple disabilities - polyhandicapé". Silence and immobility of everyone erased their own personality traits and tended to presuppose an increasingly severe retardation, often estimated to be worse than real. This led parents and professionals often to a simply mothering care, without educational perspective and without hope of change. Its impact has been severely detrimental to all, children as well as their human environment. However, more and more people nowadays are becoming aware that human diversity is a right and a benefit for all. Children with more or less dependencies, resulting from various conditions such autism and intellectual disability, traumatic brain damage, progressive neurological diseases, who live and learn together in the same centre with children with PIMD[2] in the strict sense of the term... allows establishing favourable responses of proximity that respect the child's bonds with its parents. However, diversification has a cost - the need for a larger team, itself diversified, in order to offer a personalized welcome to children whose differences we want to respect: a way of achieving a form of "integration" inside the institution itself, where the common denominator is not a medical diagnosis, but a situational factor, the one of great dependence. Whether it is physical - neuromotor disorders - and / or psychological - pervasive developmental deficit disorders and mental retardation.

New perspectives on their abilities

This diversification has also promoted a change in the way we see the child with multiple disabilities. We have to eliminate the thick wall of appearances in order to perceive in every single individual, his own

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[2] PIMD is the official term “profound intellectual and multiple disability” most widely used in Anglo-Saxon publications.

thoughts and feelings. When the educational team is numerous enough and with help of parents, we can perceive in the so diversified children with multiple disabilities, by example, the angry character of a great-uncle or the smiling kindness of one of his grandmothers, which is very important for his own educational project.

Thanks to close observation, neuroscientific knowledge and methods of communication, based on a non-verbal "yes" and "no", and now on Augmentative and Alternative Communication (AAC), we may discover in these children an ability to think a thought, even in someone who is described as “deeply retarded” , often referred to as "untestable". There is never “a vegetative state” in a child with multiple disabilities. However, in severe cases, which are the most common, we all have great difficulties in describing this thought, which is a singular but real way of understanding. Georges Saulus recently described it with the image of "Proof of existence” of which he is actually studying the more or less archaic stages, depending on the severity of the situation. This new concept of "proof of existence” indicates the sensitive and emotional origin of this thought centred on the "self", similar to Winnicott’s "continuous sense of being" , and which is, in my view, the most important goal of educational support.

For several years, I have been looking in the same registry to clarify what I understand of the singular thinking of young people with multiple disabilities, even if they are severely affected. It seems to me, it also pertains to the sensitive or emotional understanding; the one that stems from the attachment to one’s loved ones. Antonio Damasio, an American neurobiologist, links it to Spinoza’s definition of "Conatus”: as the effort, conscious or not, of the human being to acquire and preserve strongly his feeling to be alive. Spinoza, four centuries ago, described a conative intelligence in very young children, made of feelings and emotions related to the mother and that would be the basis for further development of logical understanding. These concepts seem to me to clarify the thought of the young child with multiple disabilities, constantly focused on his close attachments and his own feelings: it’s what allows him to understand early and precisely the experience of the close relations of those he loves, towards himself; this sensitive intelligence grows and matures with time, supported by the interaction with his proximal human environment; and this ability is reinforced by his generally well-developed memory capacity.

If today young people with multiple disabilities apparently remain "untestable", we can however observe and measure their original cognitive development through a new evaluating method developed within the CESAP by Régine Scelles (2013).

Feelings and social life are very developed in young people with multiple disabilities; even if they cannot express it with words, they do it through their attitudes and facial mimics. This is certainly true also for young people with autism even if they avoid body contact. The attachment capabilities of these very dependent children to their loved ones seem one of the dominant features of their natural adaptation to their situation made of multiple severe deprivations. Very precociously, they show an intense and sustained attention to their family environment; their eyes “call” for the parents, the siblings... to attract their attention... they “call” by a similar way their auxiliary nurse in charge of helping them to carry out activities of daily living. They get deeply fond of those who, for the daily care of their body, bring them kindness and well-being and, through that, allow them to build, a continuous feeling - to be alive. The powerful attachment to these close relations is exclusive, discriminatory and leads to this *sensitive intelligence*, which has been discussed above.

This person who accompanies him and helps him every day, and whom he loves, he knows her, he distinguishes her among others and intuitively understands which feelings she has toward him: interest? Affection? Anxiety? Indifference? Disgust? Rejection? Young people with multiple disabilities are surprisingly able to distinguish all shades of feeling towards themselves. Perhaps it is not the same for young people with autism. I do not know...

This ability to strong attachments generates very early and throughout the person's lifetime a very strong attachment to life, making it – whatever some people say – always worthy to be lived. But if their attachment ability is a cornerstone to build their self, it is also their weakness: distance or loss of a parent, departure without any explanation of their usual educator or the excessive turn-over of daily caretakers (personal assistants) immerse the person with multiple disabilities in a strong emotional distress, full of sufferings and risks. Unable to express it in words, he says it by somatic or psychological disorders; distress is in his body and his behaviour: status epileptics, food refusal, restlessness, withdrawal in an autistic manner.

These real and poorly known risks, as well as their underestimated ability for attachment should lead us to be more cautious about continuity of their close relationships: for example we should carefully announce to each of these young people that their own caretaker will go away, and when he will come back to take care of him.

Educational resources in evolution

In the area of multiple disabilities, special education methods have been multiplied over the last twenty years, in France and elsewhere: for example the Snoezelen approach, Basal Stimulation, Conductive Education ... all these came from research and creativity of professionals of education and each of them brings sensible and useful items. However, it is important not to be professionally locked, nor to lock tightly any disable child into one of them. Indeed, in modern times of the diversification, education must remain plural - associating several approaches – always personalized - to meet the different needs of different children in their tastes, desires and abilities ... - Professionals also have to fit their educational planning with the children's real age and with their slow but step-by-step improvements.

Assistance in daily living

When it is of quality, assistance for daily living is the most important educational resource for young people with multiple disabilities; their great physical and/or psychological dependence makes assistance a matter of absolute necessity. To varying degrees, they need a familial or professional assistant to get up, wash and dress, and eat ... All these simple and repetitive activities are unfortunately often seen as not valuable, considered as infantile and infantilizing, boring because they are always meant to be done again many times a day. Our Minister of Education has recently dared to say that it is not necessary to be graduated for giving clean diapers in nursery. However, as far as children with multiple disabilities are concerned, this is wrong. About 15 years ago, we became aware of the fact that when the daily life gestures are devalued and botched, any young child or child with multiple disabilities is reduced to be a mechanic, while the assistant is become mechanical...

When assistants give full attention to daily life activities, children are secured and proud to be alive, but it requires a lot from the caregivers: real presence, good training, regular support and networks. In these circumstances, the activities of daily life are a powerful factor in psychic development for all young people with multiple disabilities, whatever the severity of their condition. They are the support of a close relationship, from person to person: if the presence of caregivers is of sufficient continuity, it helps them to build a continuous sense of existence, brings a natural sensory stimulation, and provides a simple frame for communication and the practice of mini-choice. Activities of daily living (ADL) also allow the first cognitive acquisitions: knowledge of one's own body , sense of time and duration, space, size, quantities, colours; all caregivers should exploit these cognitive resources as such, when dressing or giving meals for example. This is what the educators of daily life are doing for blind children with associated disorders; that is to say, the developmental importance we have to attach to activities of daily living (ADL).

Today, as it is finally recognized as a major educational resource, in order to ensure to young people with multiple disabilities an optimal development of physical and psychological autonomy, the density of directly available human assistance in proximity, is strongly claimed by families, associations and professional teams, who are fighting against a shortsighted political economy.

Communication of young people with multiple disabilities

Communication remained the domain of utopia as long as we reduced it to mere verbal communication. It was not until the nineties, when parents made me aware of this, when showing me the non-verbal communication abilities of their child. They were often telling us that their child was « telling » them his activities at the day-care centre; we were wondering how that was possible until parents explained us how the child responded "yes" or "no" to their patient questions. How? With a look, a gesture, a facial expression, any sign they identified, after a time, as reliable and significant. We seized this natural mode of expression for each child; thus psychologists of the centre used the same set of “questions and answers” communication, to allow children to "tell" their dreams, dreams which were similar to those of all children. It was an open window, for the first time, on the inner life of these children deprived of verbal language.

This educational team, like many others, had thereafter spontaneously developed a specific mode of expression with these children: staying closely, at their level, seeking eye contact, speaking slowly, with simple but accurate words - not using baby talk, using a modulated voice and not flat one. We put into words what care we will for them in order to allow them to anticipate; we also talk about feelings and emotions for sharing it with them. And we have to take time in daily life, to ask their agreement or reluctance and even their refusal ... All these expressions have allowed us to verify, most of the time, their perfect understanding of speech on these subjects which they had experienced in common.

The majority of children and teenagers we were looking after, could not have access to communication tools created for young people with cerebral-motor disability: Grach code, speech prosthetics, computer-assisted communication that we still try periodically with each of them. Today, however, more and more of them can benefit from the “augmentative alternative communication” (AAC) disseminated in our country by Elizabeth Cataix-Nègre (2011). This is a multi-modal approach of communication, combining simple words, symbols, images, photos, sounds ... to give, with the help of an adult, a voice to the child, in an illustrated and concrete way for example with a "book of life" of his own. The "language bath" is not exclusively verbal, since he also can see it on "speaking walls": illustrating timetables, recent events, pictures or photos of himself and of people with whom he lives... This multiform "show” of language brings on the beginning of a verbalization for some, or enhance attention to language for most of them.

Interconnections between care and education

Interconnection between care and education is a recent development for young people with multiple disabilities, which should be further researched. Their precarious health condition requires attention and complex daily care that take a long time: treatments of respiratory, eating and digestive disorders, epilepsy, and bedsore prevention, rehabilitation of neuro-motor disorders, verticalization and corrective facilitating devices to reduce aggravation of orthopaedic deformities.

Until recently, this care only depended on the medical, nursing and therapists' team, which was often secluded from the educational team. A short while ago, probably because of a decreasing number of health-caregivers, but mainly because a global, unified understanding of child development, care and education moved closer toward each other and penetrated everyday life activities. This interconnection has been facilitated since 1989 by the implementation of the "personalized educational and therapeutic project". The connection did not happen everywhere, nor was it implemented without reluctance on the part of caregivers as well as educators, who both feared to lose their professional identity. Educators wished to do no less than parents, who are often left alone in managing technical care (as the enteral nutrition following a gastrostomy) and cognitive education of their children. That pushed the professionals to adopt some mutual sharing of skills and knowledge. Today, caregivers – even medical ones - are more efficient, thanks to a better knowledge of the child transmitted by a referent educator. In addition, some care is more easily performed when the child is reassured by him being there. Screening and treatment of pain also depend on this cooperation. Conversely, the place given to body comfort in specialized education - or the least possible discomfort - makes educators and caregivers closer to each other. For example, a lack of interest of a child to an educational activity does not always mean that it does not match his tastes, but can be explained sometimes by a change in treatment; and this has to be known... so for that we have to work together.

Let us take another example of interconnection: how to position a child for an educational task or for a meal ... it is difficult, delicate, repeated many times a day; it takes time, requires technical skills and abilities that must be shared by the educational team and the occupational therapist or physiotherapist.

But also, now, in the absence of a caregiver twenty-four hours a day, it becomes necessary to organize more broadly what can be called a "shared care" among educators, night staff, doctors and nurses who are present - in the best case – only part of the day; it would be absurd and humanly damaging to continue to send to hospital a child who just had a status epileptics only because no one in the institution can administer an intra-rectal Valium.

Therefore, a recent amendment to the French Disability Act of February 2005 (Article 1111-6-1 of the Public Health Code) allows delegating the permission to execute some simple care by non-health staff. However, this should obviously be done under very specific conditions, allowing everyone to exercise professional liability safely. Prescription of care remains the responsibility of physicians who must always be reachable twenty-four hours a day. The delegable care actions must be written and formalized by a protocol, which is updated for each child, explained and taught to all members of the educational team who might have to assume them.

For each child with multiple disabilities, a fair balance has to be found between care, activities of daily life and education: free time is one of the fundamental rights for all children, but the balance is often difficult to find between freedom and security.

Respecting the real age of the child with multiple disabilities despite its apparent stagnation

Respecting the real age of the child with multiple disabilities, despite its apparent stagnation, is a common educational principle that was forgotten for a long time, hidden by the massive and unchanging look of dependency. Now that we learned to communicate with children with multiple disabilities and that we understand their non-verbal answers better , we know that their inner world is also evolving with the different ways of life they are able to reach: their anxiety at a first separation from mother is the same as for any young child who has been welcomed at the nursery, or sometimes in kindergarten, in a centre for early intervention, or when a child goes to a day-care or residential centre, that is for him his "school". We should be more aware of his anxiety when a first menstruation or a first erection occurs without her or him being even informed beforehand.

It is precisely the unprepared appearance of puberty, which - in the nineties – reminded me suddenly of the real age of young people with multiple disabilities. This real age that we all, parents and professionals, had often forgotten in the silence and immobility of people with multiple disabilities. Once past the discomfort that together we felt in front of the disharmony introduced by the contrast between their accurate biological clock and the persistence of a heavy dependence; then we felt better thinking: *"So everything is not disabled when you live with multiple disabilities."* In addition, we began to think, with many other teams working with teenagers, in terms of specific educational needs of these teenagers. At first, it seemed to all of us impossible that they should not have many worrying questions about their bodily metamorphosis: bulky breasts, blood and menstrual discomfort for young girls; growing beards, hoarse voices, ejaculations for the young boys ... they assure us, if we ask them, that they want to understand and to adapt themselves to these quick and strong changes.

It depends on us, parents, care workers and educators, to help them by giving sex education that is simple and precise, which they are quite able to understand, because they are very motivated by what affects them and in a close relationship with others. Then, like all teenagers, they need more intimate answers to questions like: shall I be able to love and be loved? Shall I have fun with this unusual body and with the one of the other? ... With them, more than with the other "teens", the answers are difficult, but parents and educators – after they have harmonized their responses - don’t have the right to elude their difficult duty of giving answers. That may last for months and years. A sincere dialogue, careful and respectful, in spite of our natural fears, cannot be harmful. Refusing it condemns them to loneliness, guilt, and more often than we can think, to depressive states, silent but harmful.

The educational dialogue with teenagers is never easy, but always necessary and exciting: with multiple disabilities, they ask us the same problems as other teenagers: at first, we have to recognize them as "teens" when they rebel to assert themselves and they are full of uncertainties and contradictory and utopian desires. It depends on us to change our view and adapt our presents: giving a football balloon rather than a teddy bear, playing jazz rather than a lullaby, allowing them calculated risks, going with them to a pool and to the horse riding in order to complete their physical therapy, that must nevertheless be carried on in this period of orthopaedic aggravation.

We must also give teenagers and children with multiple disabilities responsibilities, allow them to expand their friendships to flirts if they wish, and give them as much information about themselves (for example on a possible surgery) and relatives they are fond of (parents, siblings, friends, teachers, etc.) to whom they are able to give instead of always receiving.

Between 18 and 25 years, waiting often too long for an admission to a foster home or residential care centre, they have to be allowed to live among their peers, with their psychic and emotional capacities of young sexual adults: the loves and pleasures one gives to oneself, but also the social, friendly, and mostly cultural, artistic, creative and civic life. By varying the offer, we often discover them "differently able" (as Eric

Plaisance said) in a particular area of their predilections. What surprises they offer us in turn, especially in the cognitive and intersubjective fields.

EDUCATIONAL SUPPORT *BY* AND *FOR* PARENTS

The experience of parenthood and educational support to their child with multiple disabilities has evolved considerably over the past twenty years on various levels and for many cultural and social reasons. So young parents of young children are somewhat different from their elders. Anyway, generalities are inappropriate because they are, like everyone else, and as their children, single human beings; one would not dare today to talk about "disabled parents", always being attributed a prejudice to be either overprotective or rejecting, as we did in the past! Each of them, however, somehow is carrying an unquenchable pain and a strong will to exercise fully their parental responsibilities (in my experience one out of a thousand renounces it). However, since the medicalization of procreation and gestation appeared, it is also in the name of their parental responsibility that some parents, in our "zero risk" society, express their will to put an end to the life of their child, shortly after the announcement of diagnosis and prognosis of multiple disabilities, especially when this is said abruptly.

However, let us return to all those we have been supporting for years in what they call a "*constant fight"* for the well-being of their child with multiple disabilities. Indeed, despite the hopes raised by the laws of 1975, 1989, 2002 and 2005, and in spite of help given by Associations and professional teams, a significant lack of centres and services for care and education, still remains today, for young people – and even more for disabled adults; this lack is more severe in Paris and surroundings, where prices of land, and rarity more than anywhere else, hinder the creation of new centres. Personally, at the opening in 2002 of the first establishment (externship and internship) for teenagers with multiple disabilities aged 12 years old at least, we found that 20% of them were coming directly from their home, not having benefitted before from any support in another institution. Nationally, we do not yet have in France a statistical knowledge on disabled people. We should get it from the regular reports written by our administrative committees (CDES since 1975, MDPH since 2005).

Today, many parents are weakened by social uncertainties; this increased with the individual insecurities (divorce, unemployment, internal and external migration). These difficulties explain why many children with multiple disabilities stay totally or mainly in their parent's homes or with their single and often lonely mothers, exhausted by taking in the triple charge of care, daily assistance and re-education. The support that can bring, in the best cases, a specialized education service and home care (SESSAD), allows them to fight against a terrible isolation, but it is not enough to give them a feeling that all potential of their child can be fully developed. Early support by a CAMSP[3] (centre for early medical-social action) has, in the eyes of parents, the same interest and the same limits; disappointed hope of a long-waited-for admission to an ambulatory medico-pedagogical centre, reinforces among parents the overwhelming conviction that they are the single continuous support of their child. This does not prepare parents to develop flexible and trusting relationships with the residential or ambulatory teams; these often give them the feeling that they are unable to do more for a better development of their child. Parenthood in such conditions is bristled with

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[3] (Centre d'Action Médico-Sociale Précoce)

many difficulties, despite the will and collective efforts – those of medical and educational teams and Associations – where young parents are less active than in the past.

At the individual level, two problems remain unresolved, despite recently increased awareness: there is a real risk of burnout for parental caregivers, which they share with professionals, when requests for support and services to rely upon remain unanswered. This might lead to a risk of unintentional family or professional abuse.

The other difficulty with parenthood, which does not change very much despite the awareness provided recently by the work of Régine Scelles (2010), is an unconscious parental negligence toward the siblings of children with multiple disabilities. It is natural for parents - sometimes unintentionally encouraged by professionals having unreasonable demands of care – to focus all their attention, their efforts and their availability on the dependent child, in detriment of what is due to his brothers and sisters. Maybe this happens as if the parents did not allow themselves to be happy parents of happy healthy children. This deprivation can cause serious trouble in siblings, often revealed only during teenage years through a silent breakdown or depression. In others, if they are resilient, that can lead them to choose a profession in which they are going to help the others in the field of education or medical care.

As a whole, parenthood remains confronted with many serious difficulties in spite of "equality of opportunity" written into the 2005 law. I think that what has changed for the best, over the past two or three decades, is that parents started to speak out individually and via associations. Now parents themselves clearly and precisely express their needs and desires, but also their sometimes-critical analysis of the situation made to their child. In theory, the 2002 law offers them a recognized authority to do this: in the “Social Life Council” which is part of every Institution. However, it is not always easy for them to be heard there (and it is distressing for me to note that parents are still afraid - rightly or wrongly - for their child sake; if they express criticisms).

As I know through the Association “Group Polyhandicap France”, parents have the wisdom not to claim, in the first place, schooling for their children in an ordinary school in their neighbourhood. However, the law of 2005 gave to any child the right to attend an ordinary school. However, they know from experience with the brothers and sisters, that these schools do not have the essential human resources to welcome a child in a situation, which is so serious and so complex. On the other side, they want that the specialized centres and services should be able to assume the best cognitive development of each child they have in charge. We will return to this later. In addition, they devote much attention, time and effort - individually and in the organisations - often with help of the teams of Early Intervention Centre (CAMSP), of the Home Supporting Centre (Sessad) and of the medico-pedagogical day care centres (EMP), to improve the social integration of their children with multiple disabilities, to get access to public places such as: the children’s library, swimming pool, restaurant... This is a fight that young parents are assuming and often winning. The educational and ethical value of social integration of children with multiple disabilities, among other children and in our society, is now recognized everywhere, although the accessibility in the city and in minds has to improve further.

Otherwise, parents of children with multiple disabilities do not adhere to the deinstitutionalization advocated in 2010 by the Ministers of the European Council, who seem to know nothing whatsoever about the severe constraints of great dependency... However, parents have very specific ideas about desirable changes in the institutions and specialized services: they want them to be small-scale, nearby, open and flexible facilities with gradual admission, to get away from the "all or nothing" and to adapt their child slowly to outer world. They wish to be "welcome", as parents to receive full information on everything related to their child: problems, needs, educational and nursing responses that are proposed. They want to be involved in the child’s educational and therapeutic project (all parents want also to be informed immediately of any change of the medical treatment related to occurrence of an intercurrent disorder). By being informed and involved, they already feel strongly supported. In addition, they wish to be connected: if their child is still at home, the ninety days of “temporary admission” in institution each year since 2004, are necessary for the child and for the whole family. Lastly, they want to express themselves and be heard without a priori or judgments, not only by the managers during the annual evaluation but also more flexibly by the “medico-psychological assistant” (AMP) or the personal caregivers of their child and, as much as possible, in his presence. In facilities that have pursued a goal of flexible partnership between parents and team, both are developing mutual trust: that eliminates conflicts. However, the developments that are desired by parents and professionals are possible only if the professionals are numerous enough to be available and trusty in themselves.

DEVELOPMENTS IN EDUCATIONAL SUPPORT LED BY SPECIALIZED TEAMS

The situation created by multiple disabilities has a specific complexity, which requires indeed emphasizing human resources, and especially healthcare professionals that cannot be substituted by any technical system or application. Yet, it is precisely human resources which are threatened everywhere by a wrong economic policy. There is concern that staff cuts will heavily affect the health and social sector in the future.

Anyway, the medico-social sector and the specific facilities for young people with multiple disabilities, created since forty-five years, has remained in France until now strongly based on concepts such as: multidisciplinarity, continuing training and psychological support through consistent analysis of practice. All these specific resources of medico-social care should be extended to the public school system so it could fulfil the important task it has to assume, since the 2005 law: to welcome and teach all disabled young people. The school system in France is mainly deprived of these resources for years – right now, it is unable to prevent or even reduce school failure of pupils with psychosocial and economic problems – *a fortiori,* it is also unable to provide formal education to children with disabilities...

Educational support is in continuous development

After being limited to "mothering" (Tosquelles, 1966), used systematically since the fifties until the early nineties, educational support evolved gradually towards more active and diverse methods. Some were imported from Europe (e.g. the Snoezelen from The Netherlands; Basal Stimulation from Germany) and others from USA (Teacch and ABA methods developed for autistic young people). In France, the revalorisation of an educational process based on Activities of Daily Living, and the relevance of teaching concrete and natural stimuli, developed for deaf-blind children, recently opened up new perspectives for educational support to young people with multiple disabilities. So we are not allowed to say anymore “there is nothing to do but to love them”...

Specialized centres and services have opened their doors toward community facilities in the neighbourhood

Since the nineties, specialized centres and services started to relocate in the city. They were interested in participating in city life and then began to use many city resources: markets, cinema, library for young people, swimming pools, museums... Educational support has been enriched with this social integration and then gave rise to "exchange of good practices": neighbourhood children were invited to use for example the pool, gym room or pony club in the medico-social centre. Families, educators and municipal officials met each other around children with multiple disabilities. An increasing number of young people with disabilities has benefited from a "time-sharing" between a nearby school and the specialized medico-social centre, more or less accompanied by their referent educator. In theory, this tendency has developed since the 2005 law, but remains slowed down firstly by a reluctance experienced in schools to welcome among children with disabilities those whose behaviour is disruptive; and secondly because, in many cases, time in school is too short, two hours a week for example, to allow for the child to be of real benefit. Due to the complexity of their needs and their lack of verbal communication, very few young people with multiple disabilities benefit from a real timesharing with schools, even if 240 000 children with all kinds of disabilities are “received” in school...

The open-mindedness, which these developments indicate, led many teams to consider switching from multidisciplinary to transdisciplinary. In fact, required to work at the same time in the "inside" of the institution and in the "outside" in the city or at school, many professionals became aware of their need to maintain their professional identity while opening to the others’ practices. This delicate but exciting and innovative conjunction founds transdisciplinarity as one of the major developments of the educational support for young people with multiple disabilities. Recently, a growing number of teams enlarged their forces with complementary contributions of musicians, graphic artists, sports trainers, storytellers ... and of course teachers (still too rare, these gave me an impression of forerunners): anyway each tries to keep his own professional identity, while providing the child with a new outlook and new educational capacities.

However, many problems remain to be solved

Indeed, the expansion and diversification of the educational support for young people with multiple disabilities enlightens a series of long-standing issues, on which specialized teams take time to reflect in order to move forward. These questions, which I will touch only briefly here, concern certain ethical values, to which teams support teams are becoming increasingly attached these past few years, in order to meet more accurately the needs of young people with multiple disabilities and their families, despite growing material constraints which surround all of them.

Nowadays, the work of a support team is subject to being cut in pieces, reduced in presence time and interrupted too often...

Many physicians and rehabilitation specialists are working in a specialized centre only two to four hours per week, and educators, even full-time employees, are absent on multiple occasions: meetings, accidents or sickness, holidays, the accompanying measures outside, seminars and professional development courses; etc. their presence near disabled children is thus threatened by great haste, fragmentation or emergency. We recently became aware of its chopped character and of the contrast, even the contradiction, that exists between speed (or even transience) of their interventions and the extreme slowness of young people with multiple disabilities, condemned to never ending and multiple waiting times. Unable to solve it in a fundamental way, we try to reduce the impact of these interruptions by taking care to inform the children, to explain them, indicating their duration and presenting a "substitute" or what is coming next. Thus, we hope to be able to give the children a sufficient sense of continuity to feel alive, to give them some control on their own time, so that they would not consider the absence as an abandonment.

The obligation promulgated by the law of February 2005, to include all children with disabilities in their neighbourhood schools has created two reactions among professional teams: one was a deep concern that the parents, who strongly wish their child should “go to school together with the others ", should not feel to be once again socially excluded; the other reaction has been to put cognitive development at the top of their educational duty. This movement is very recent and does not yet reach all teams, especially those that are fully monopolized by multiple daily care that has to be given to the most severely affected children with multiple disabilities, when they are grouped together, far apart those who are less dependent.

Wherever we have happily evolved toward a diversified recruitment, teams are now able to notice clearly, in young people with multiple disabilities, their emerging skills of attention, memory, and interest for what is both new and firmly established in a safe environment of everyday life. As it has been said above, we are only starting to understand what they understand: the discovery of their sensitive, conative intelligence is still in its early days and an adapted pedagogy to this approach of their cognitive ability remains to be discovered. However, the encouraging findings are multiple: their love of learning is clear: the simple fact of recognizing a familiar situation on a photograph or on some simplified icons that show the expression of a feeling or of a choice ... What is surprising is the preservation of their cognitive potential, which is updated with the progress of their motivation. In adulthood, for example, with the help of the whole educational team, the majority of residents of a specialized centre have assimilated contents of a two years "health education course": during the first year they have been taught on the functioning of the human body; the second program was on their medical troubles: scoliosis, epilepsy, etc. It has been an experimental attempt where they showed to me through their questions and their greater cooperation in their own care of the body, that they understood what I said with help of their caregivers. Together we have everything to gain by betting on their cognitive abilities, and to stimulate them periodically without forcing, varying the learning subjects starting from their own interests. This experience was a first approach of what is called and, now widely spread, as “therapeutic education” (WHO, 1998). This is now an obligation in health and medico-social fields.

Awareness of limits leads teams to do a permanent self-evaluation

In the relational field, the control of feelings of daily caretakers living in close relationship with the children, initiated 20 years ago at Loczy (David & Appell, 2008), has now become well known. Every educator involved in the daily care of young persons with multiple disabilities, is aware of the limits he has to impose on his own emotional commitment; he knows that he has to adjust it constantly, in order to avoid "mothering" and to let parents keeping their rightful place.

Otherwise, it is very difficult for us to establish a real acceptance of our inability to dramatically improve the future of the child. Our dream of releasing him from the multiple constraints of multiple handicaps motivated our career orientation; that dream must give way to a patient search of breakthroughs in small steps, about which we must learn to rejoice ourselves, if we do not want to succumb, sooner or later, to despair and exhaustion that Anglo-Saxons named so accurately “burn-out”. For lack of sufficiently enhancing the small gains acquired in a singular step-by-step "companionship", exhaustion may lead to unintentional abuse or desperate renunciation, of which awareness is recent.

The great physical and mental dependency of young people with multiple disabilities not only imposes a frustrating limit to our hopes of making them radically and obviously autonomous. On the contrary, there is an also great risk – for the sake of doing well - of over-bearing individuals who can never explicitly oppose themselves to our good intentions. In young people with multiple disabilities, it is only a continuous work on ethics, as the one led for four years by the GPF (Groupe Polyhandicap France), with the help of Professor Emmanuel Hirsch (Hirsch & Zucman, 2015), which allowed us to distinguish clearly their physical persistent dependency from their psychic autonomy, they are able to acquire if they get suitable support in a warm human environment. We learnt that we have to be always aware that, being deprived of verbal expression, multiple handicapped children cannot express their will; but also that their silent smile is not a real agreement of our help: it does not mean that they always agree what we do for them; so that first, we have to take enough time to understand their nonverbal advice and their own will on daily events. Moreover, we have to offer them many opportunities of making and expressing their own choices in daily life. Since about ten years, many teams give them a real opportunity of personal choices in concrete situations, with an interesting impact on personal global development of these children.

Assessment is a part of the recent developments in educational support

The notion itself of assessment is interesting, not so much because it has been mandatory since 2002, but because educational teams do not confound assessment and administrative control anymore. A link has been firmly established between assessment and the quality of life - so important in the field of multiple disabilities. Maybe this link brought down the reluctance.

These past few years of experience in assessment allows expressing some warnings, which also coincide with those coming from the US, where the annual assessment determines the financial support for the following year...:

- Each institution should elaborate its own evaluation method, eventually received from outside, to make it suitable to its own objectives, its "philosophy" and especially the specific characteristics of the population received and the expectations of the concerned families and professionals.
- We must also be careful that the time – always very important – spent on assessment, does not exceed availability of the team and that it does not come to the detriment of educational support.
- Then we must know exactly what we want to assess. In the area of multiple disabilities, an assessment centred on autonomy progress may exclude in the future young people that are the more dependent on physical and mental plans; a potential perverse effect of this type of assessment which should thus focus more on the actual implementation of educational resources, on the joint welfare of young people with multiple disabilities, their families ... and the teams.
- Finally, it seems that the legal obligation of assessment and its implementation has increased the use of protocols for care and educational activities. Some very complex care schemes are indeed facilitated by protocols that supervise and reassure especially members of the team. However, when they invade, as too often today, the activities of daily life, they have some negative consequences: disempowerment of educators, stiffening and some loss in educational support instead of spontaneity, inventiveness, calculated risks... that no longer have their place. These new procedures have drawbacks, unknown up until now.

CONCLUSION: SOME PROGRESS CERTAINLY HAS BEEN MADE, BUT IT REMAINS FRAGILE

What can we conclude from this overview on more or less recent developments of educational support for young people with multiple disabilities? Most of them, though very diverse and of varying importance, have in common the fact that they relate indissolubly the disabled child himself, his family, and the professionals around him, tightly bounded to one another. It is probably this necessary interaction, whereby a well-being or an increased suffering of one of them has a direct impact on the other two, which is the major discovery made since these past few years in educational support for young people with multiple disabilities.

Of course, since a long time, in the medico-social and psychiatric field, the phrase that "the child cannot go well if its parents feel bad or if educators are exhausted" has often been repeated. But we have gone beyond this simplistic wording, because on the one hand, the recent developments, which have been discussed above, constitute a strong demonstration of this in a myriad of ways, and secondly, because the new benefit that can now be derived, is that the finding of "interaction" is no longer used to blame one or the other, but takes a positive and ethical meaning: deep attention, respect, caring ... together with the triad made up of the disabled person, his or her family and the professional team.

The notion of necessary interaction has of course the same meaning and the same importance in all the other fields of education and care - a breakthrough in the extremes is indeed a breakthrough for everyone, everywhere...

There is another one that is not yet recognized by everyone: the coexistence, the sharing of life, in a continuous daily relation and proximity with a very dependent person, is in all likelihood a preferred source of self-knowledge. It is the « Gnothi Seauton », the "know thyself" that Socrates considered, 2,400 years ago, as essential to the development of the human person, and that many of our contemporaries are seeking, in spiritualities that are not all devoid of interest ... or danger.

Having a better understanding of oneself, from one’s own commitment to highly dependent people, is both a priceless gift and a tough road. These two contributions supporting disabled children are very significant. However, they remain fragile and incomplete: their future depends on the value and the human resources we devote to them.

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Experience with previous European training project Euforpoly

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In 1987 a European group on exchanges on polyhandicap was created under the aegis of an NGO « Alefpa-Europe » This group gathered professionals and parents from 7 European countries. The European Helios programme granted meetings.

After having worked during 8 years on various topics such as medical aspects, communication, quality of life, adult age in persons with PIMD (Profound intellectual and multiple disabilities), the group focused on training of both parents and professionals. A meeting was held in Lille in November 1994 to take stoke of the existing resources, resources to be developed and strategies to be adopted in order parents and professionals in the services could access to the material.

In 1995, the group, coordinated by the Centre for Study and Training in Special Education- Free University Brussels, applied for a pilot project in the framework of Leonardo da Vinci program. The project was accepted for a 3-Years period and was extended for a Year.

The main objectives of this project were to contribute to prevention of stress and burn out in parents and professionals, to a better social integration of the persons with PIMD, by a reinforcement of professionals' competences (especially the less qualified professionals) and parents' competences and by promoting the parents-professionals partnerships.

We decided to:

- develop a network of resource centres through European countries and reinforce local resources
- Activate a network for information, training and advices in a so-called « en cascade » system
- Reinforce the opportunities of exchanges between parents and professionals and promote a cooperation by considering equally the expertise of both partners

The participants were professionals coping with severe and multiple disabled persons: both the less qualified professionals and the managers of the services; parents aiming to reinforce their competences, independently from a specific service and parents who aims to become a « support-parent » or a trainer; and university staff members working with various special services, training centres in the field of special education.

What were the project's results?

- Better knowledge on needs of both parents and professionals coping with polyhandicap
- Reflection on strategies to join the parents and the less qualified professionals
- Identification of resources persons/centres
- Collection of available resources and strategies to train professionals/parents
- Movement of trainers through the involved countries
- Creation of transnational modules of training

- Development of a referent curriculum for training in the field of polyhandicap
- Reports, booklets, books,…

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Quality of Life in Supporting Children with Multiple and Profound Disability; a Promising Concept[4]

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Abstract

There are three theoretical constructs that have significantly influenced the delivery of services and supports to persons with intellectual and closely related developmental disabilities (IDD). The first one is a social-ecological approach to disability, the second one is the supports paradigm and third one is the concept of quality of life. Quality of life in people with disabilities is facilitated through participation and through the provision of the right supports. In case of children with multiple and profound intellectual disabilities, collaboration with parents and family is needed. Family Assessment Portfolio (FAP) is a technique through witch participation and involvement can be enhanced.

Three theoretical constructs

There are three theoretical constructs that have significantly influenced the delivery of services and supports to persons with intellectual and closely related developmental disabilities (IDD). The first one is a social-ecological approach to disability, the second one is the supports paradigm and third one is the concept of quality of life.

A social-ecological approach to disability

The concept of disability has changed from focusing on a person's defect/disability to an ecological perspective emphasizing the person and his/her environment (Buntinx & Schalock, 2010). Intellectual disability is not just a limitation in cognitive abilities and adaptive behaviour, but also a problem of the person in his/her situation that also affects health, participation and the role the person plays in society. Understanding intellectual disability requires a multidimensional approach and should aim at reducing the mismatch between a person's skills and the demands of his/her environment in enhancing human functioning (Wehmeyer et al., 2008). A multidimensional model of human functioning is elaborated in the theoretical framework of the AAIDD (American Association for Intellectual and Developmental Disabilities). This framework can be seen in figure 1.

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[4] Text of key-note address at the Symposium of Project ENABLIN+ , University of Antwerp, 30/1-1/2/2014Who are they? Children with complexes and intense support needs: Towards a more inclusive and more active high quality life.

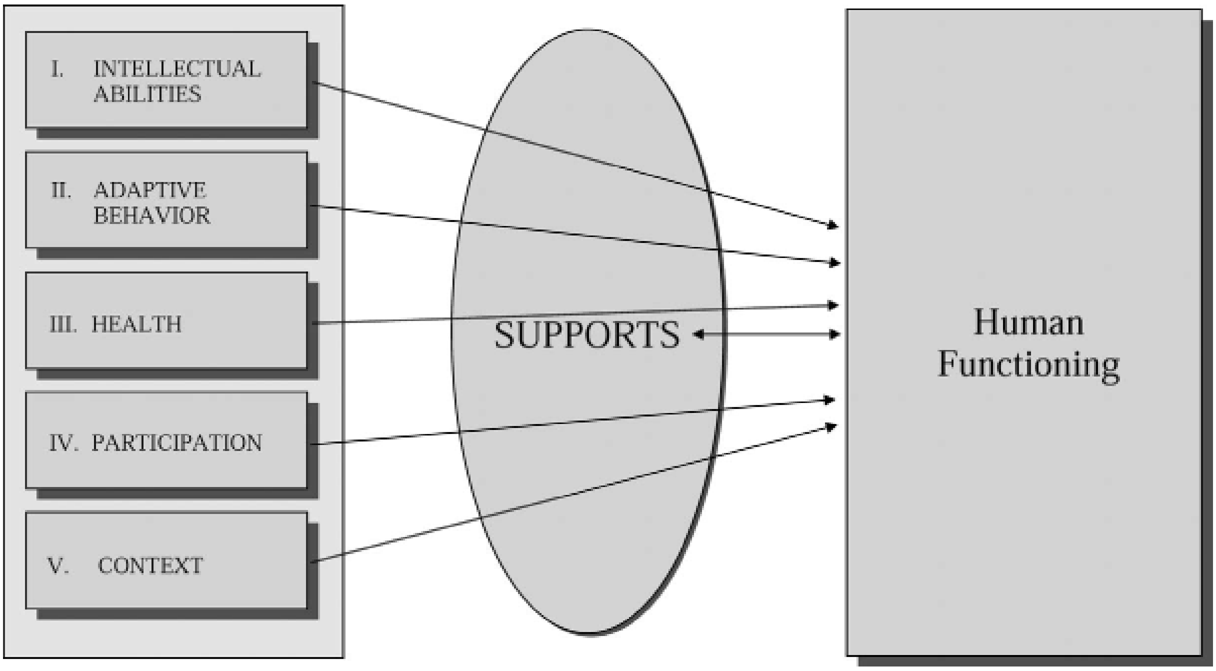

figure 1 Multidimensional framework on disability of the AAIDD

According to this framework, two components are affecting human functioning: (1) five dimensions (intellectual abilities, adaptive behaviour, health, participation and context) and (2) the role of supports.

The Supports Paradigm

The construct of support needs is based on the assumption that human functioning is influenced by the alignment between individual capacity and the environment in which that individual is functioning (Thompson et al., 2009). A person's support needs are the result of either personal capacity or the context in which the person is functioning. As Thompson et al. (2009: 135) note: "Support needs is a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning". The support needs construct focuses on the interaction between the person and his environment and puts attention to the role that individualized supports play in enhancing individual functioning (Schalock, Gardner & Bradley, 2007). The main question in the support paradigm is: "what supports are needed to help people participate in their community, assume values social roles, and experience greater satisfaction and fulfilment?" (Thompson et al., 2002: 390). From a social-ecological approach, supports are related to organizational policies and practices; these practices can facilitate or impede the support process, which is affecting human functioning or person-related quality of life outcomes. A system of supports is defined as the planned and integrated use of individualized support strategies and resources that encompass the multiple aspects of human performance in multiple settings (Schalock et al., 2010). The components of the system of supports are summarized in Table 1.

Table 1 Components and intent of a system of supports

Component	*Examples*	*Intent*
Technology-based	Assistive technology Information technology	cognitive functioning
Prosthetics	Sensory-Motor devices Environmental accommodation	sensory-motor functioning
Staff directed supports	Incentives Skills/knowledge Positive Behavioural Supports	behavioural skills and motivation
Professional services	IT, OT, PT, Speech Medical, Psychiatric Psychological	physical and emotional functioning
Natural Supports	Family, friends, colleagues Generic agencies	social integration

The quality of life (QOL) construct

The quality of life construct has evolved from a sensitizing notion to a measurable construct. Table 2 presents the conceptual and measurement framework as has been empirically validated across different cultures and countries (Schalock & Verdugo, 2002; Jenaro et al., 2005; Schalock et al., 2005; Wang et al., 2010). The concept of quality of life is multidimensional and is composed of eight domains. These domains are presented in Table 2.

Table 2 Quality of Life Conceptual and Measurement Framework

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

A number of empirically based studies have tried to identify potential predictors of QOL-related personal outcomes (Arvidsson, Granlund, & Thyberg, 2008; Felce et al., 2008; Kober & Eggleton, 2005; Wehmeyer & Garner, 2003). In all these studies there is a slight difference in how predictors and outcomes are defined and measured, but there is also consensus on the fact that outcomes are influenced by personal and environmental factors (Claes et al., 2012). In this regard, throughout the literature, personal characteristics are operationalized in terms of demographic indicators (such as age, gender, ethnicity, marital status) and related to indicators of human functioning (intellectual functioning, adaptive behaviour, mental/behavioural health, physical health, speech difficulty, mobility and support needs). Environmental factors are described in terms of inclusion, engagement, empowerment, normal rhythm of life activities, individualized supports, support staff activities and organization efficacy (Schalock, 2010b). In terms of quality of life-related outcomes, the literature shows that personal outcomes are related to the level of self-determination (Wehmeyer & Garner, 2003), choice (Stancliffe, 2001), social networks (Robertson et al., 2001; Stancliffe & Lakin, 2006; Emerson & McVilly, 2004), living status (Wehmeyer & Garner, 2003), well-being (Ruddick & Oliver, 2005), community integration (Miller & Chan, 2008), the reduction of challenging behaviour (Hatton et al., 2004; Perry & Felce, 2003; 2005), and life satisfaction (Miller & Chan, 2008).

Support strategies in the enhancement of quality of life; the use of Family Assessment Portfolios

Quality of life and the provision of supports is facilitated through the process of *person-centred planning*, a well-known and often used approach to individual program planning in the field of intellectual and developmental disabilities (Felce, 2004 ; Green, Middleton, & Reid, 2000; Holburn, 2002 a, 2002b; Mansell & Beadle-Brown, 2004; J. O'Brien, 2004). The general term emerged in 1985 and its components represent the broader ideological framework of normalization and inclusion (Holburn, Jacobson, Vietze, Schwartz, & Sersen, 2000; C. O'Brien & O'Brien, 2002). Person-centred planning covers a wide range of procedures and guidelines focused and aims at facilitating fundamental changes in the lives of people with intellectual and developmental disabilities (Cloutier, Malloy, Hagner, & Cotton, 2006; Combes, Hardy, & Buchan, 2004; Holburn, 2002 a, 2002b). The main focus of person-centred planning is to develop collaborative, goal-oriented, and individualized programs that are focused on community presence, community participation, positive relationships, respect, and competence (Cloutier et al., 2006; Keyes & Owens-Johnson, 2003; J. O’Brien, 1987; Rea, Martin, & Wright, 2002). Some of the most common of person-centred planning are the McGill Action Planning System (Vandercook, York, & Forest, 1989), Essential Lifestyle Planning (Smull & Harrisson, 1992), Life-Lifestyle Planning (J. O'Brien & Lovett, 1992), Personal Futures Planning (J. O'Brien & Lovett, 1992), Planning Alternative Tomorrows With Hope (Pearpoint, O'Brien, & Forest, 1993), and the Picture Method (Holburn, Gordon, & Vietze, 2007). Although person-centred planning processes are increasingly used in the intellectual and developmental disabilities field (Amado & McBride, 2002; Keyes &

Owens-Johnson, 2003; King, Baldwin, Currie, & Evans, 2005), person-centred planning reaches only a minority of service users (Felce, 2004; Mansell & Beadle-Brown, 2004; Robertson, Emerson et al., 2007; Robertson, Hattan et al., 2007). Robertson. Emerson et al. (2007) indicated that there is a strong influence of factors relating to the characteristics of participants in both the access to and efficacy of person-centred planning. Participants with mental health, emotional or behavioural problems, autism, and/or additional health problems are less likely to receive a plan; they are also less likely to benefit if they do receive one (Robertson, Hatton et al., 2007). Findings of other studies illustrate that people with communication difficulties, challenging behaviour, or severe intellectual disability are often excluded from the planning process (Mansell & Beadle-Brown, 2004; J. O'Brien, 2004; Reid & Green, 2002; Claes et al., 2010).

In that case, strong collaboration with parents and family is needed. Research has shown many advantages in family participation in support planning teams (Turnbull et al., 2006). It turns out that effective family/professional relationships is not an isolated event, but an ongoing process (Thompson et al., 2007). To improve this strong collaboration between parents and other actors in a support planning team, the Illinois State University developed a specific tool, the Family Assessment Portfolio (Meadon et al., 2009). The Family Assessment Portfolio (FAP) is a tool that includes scrapbooks, web-based profiles or movies that are created together with families to introduce their children to new educators. The idea came from parents in central Illinois who advocated for inclusive education. They collected information about their child and created materials that allowed presenting all kind of information to future teachers or educators in a user-friendly manner. FAPs can be used to (a) empower parents by encouraging participation in the planning process, (b) create opportunities for parents to communicate that kind of information they want to share (c) make future educators familiar with the like and dislikes of their child and (d) increase the understanding of child's most important wishes and needs (Thompson et al., 2007).

A scrapbook might include photographs of the child in different settings, a list of things that are important to know the child, things to know about family and friends etc. According to Thompson et al. (2007, p 20), when creating scrapbooks, some guidelines are important: "(1) the text should be written in the child's voice; the first person is active and therefore powerful; (2) the scrapbook should be easy to read; less is more (3) pictures should be as purposeful as possible; they should complement text; (4) the scrapbook should be fun to read; it should encourage the reader to look beyond the disability and see the child". A movie provides the opportunity to show a child's behaviour and interactions in different contexts and circumstances. A web-based profile is a web page linked to other sources of information like video clips, audio files or pictures. A web-based profile has the advantage to provide information on a flexible way.

FAPs are a new way of technology that might enhance parent's involvement in the support planning process of their child. They might be promising in the support planning processes of children with multiple and profound disabilities.

Conclusion

Quality of life in children with multiple and profound disabilities is enhanced by the provision of the right support in what is important to and for the child. As communication difficulties might occur in the assessment of wants and needs of the person, the involvement of parents is strongly recommended. The use of FAPs might enhance that involvement and closes the gap between a professional's and a parent's perspectives.

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How to assess quality of life in children with PIMD? [5]

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Summary

Because of a shortage of valid instruments to measure the Quality of Life (QOL) of people with profound multiple disabilities (PMD), the QOL-PMD was developed. In the present study, possibilities for item reduction as well as the psychometric properties of the questionnaire were examined. One hundred and forty-seven informants of people with PMD participated in the study. Fifty items were removed from the questionnaire based on pre-set criteria. Internal consistency was good for the total questionnaire as well as for the subscales. Evidence of the construct validity of the questionnaire was found. Correspondence between the groups of informants was moderate. The results of this preliminary analysis of the psychometric properties of the QOL-PMD are encouraging, but further validation of the measure is warranted.

Introduction

Over the past few decades, the concept of quality of life (QOL) has increasingly become a focus of research and application in the fields of education and special education, health care, social services and families (Schalock & Verdugo, 2002). In the field of intellectual disabilities (ID) it was initially used as a sensitizing notion, a social construct and a unifying theme. Increasingly, it has been used as a conceptual framework for assessing quality outcomes, a social construct that guides quality enhancement strategies, and a criterion for assessing the effectiveness of those strategies (Verdugo, Schalock, Keith, & Stancliffe, 2005). With this increased use of the QOL construct as a basis for policies and practices in the field of ID, the importance of a valid assessment of QOL is heightened (Verdugo et al., 2005).

People with profound multiple disabilities (PMD) are a group of people for which the valid assessment of QOL is a complex and difficult matter, especially when it regards the interrogatories ‘what’, ‘how’ and ‘who’ of QOL measurement. People with PMD have such profound intellectual disabilities that hardly any standardised tests are applicable for a valid estimation of their intellectual capacity, and they possess profound neuromotor dysfunctions, like spastic tetraplegia. In addition to profound intellectual and physical disabilities, sensory impairments are also frequently experienced (Nakken & Vlaskamp, 2002). People with PMD need support in almost every aspect of their daily life. This high level of dependency is reinforced by the fact that they cannot verbally communicate when and how support should be given. The complex interaction and the severity of their disabilities make their lives in large part different from that of other people. As such, the operationalization of QOL, the ‘what’ of the measurement, needs to be geared to their needs, possibilities and limitations in order to make its assessment valid (Borthwick-Duffy, 1990; Goode & Hogg, 1994; Ouellette-Kuntz & McCreary, 1996). Models of QOL often contain indicators such as income, status, productivity and autonomy. Viewed from the perspective of people with PMD these outcomes may be less relevant. There may, on the other hand, be some important aspects for this target group that are not mentioned in general models of QOL.

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'How' to measure the QOL of people with PMD and 'who' should be involved is a second area of concern because people with PMD do not have the required skills to speak for themselves about QOL (Selai & Rosser, 1993). Frequently, a knowledgeable proxy is asked to respond on the person's behalf, but there is serious question about whether information provided by proxies is a valid and accurate substitute for self-reports (Heal & Sigelman, 1996; McVilly, Burton-Smith, & Davidson, 2000; Rapley, Ridgeway, & Beyer, 1998; Stancliffe, 1995; Verdugo et al., 2005). Consequently, as Verdugo et al. (2005) pointed out clearly, QOL researchers are faced a quandary in relation to individuals who cannot communicate their own views about their QOL: either ignore these individuals because they cannot self-report, or obtain data from proxies that may be biased or invalid. At this moment, however, the answer to these problems can hardly be found in the literature. Few models of QOL are described that are geared to people with PMD at the level of the indicators and hardly any valid and reliable assessment instruments are available to measure the QOL of this target group.

Therefore, the main aim of this study was the development of a valid, reliable and useful instrument to measure the QOL of people with PMD, namely the QOL-PMD. The QOL-PMD was developed in several stages. In the first stage we determined clearly the construct we wanted to measure and selected as a starting point the basic domains of QOL as described in the model of Felce and Perry (1995, 1996a, 1996b). Next, an item pool was generated by interviewing 40 parents and 36 direct support staff members of 42 children and 34 adults with PMD. In these interviews we explored whether the selected basic domains are valid and relevant for people with PMD and how these domains can be operationalized for this group of people. The result of this phase was a pool of items that is geared to the characteristics of people with PMD (Petry, Maes, & Vlaskamp, 2005). In a third stage the generated item pool was assessed on its content and structure by a group of 45 international experts (e.g., researchers, support staff, family involved with people with PMD) in a Delphi format with written questionnaires and intermediate feedback (Petry, Maes, & Vlaskamp, 2007). The experts were also requested to give their opinion on the measurement approach that should be used and on the people that should be involved in the assessment. Finally, the pool of items was pre-tested in a multiple case study in a sequential design. In each stage of the development revisions were made in order to enhance the questionnaire.

The result of the preliminary work was a set of 105 items divided in six subscales, namely material well-being (n = 19), physical well-being (n = 19), social well-being (n = 21), communication and influence (n = 16), development (n = 15), and activities (n = 15). This preliminary version of the questionnaire was designed to measure the objective component of QOL of people with PMD. The items are assessed at a 3-point scale with as response categories 'agree', 'partly agree', and 'disagree'. Two additional response categories were added, namely 'don't know' and 'not applicable'. Higher scores on each item are associated with better QOL. As a measurement approach, the experts of the Delphi-study (Petry et al., 2007) preferred the use of a questionnaire, which is filled out by multiple informants. In their opinion, using a multiperception perspective will render a more accurate and complete view on a persons' QOL, as the behavioural pattern of people with PMD may vary according to different situations, settings and contexts. Based on the opinions of the expert group three kinds of informants for each person with PMD were selected: (1) one person who is involved with the person with PMD outside of employment (e.g., a parent, a sibling, a friend) ('family'), (2) one member of support staff who is involved in the direct care of the person with PMD ('direct support staff'), and (3) one member of support staff who is involved in the care of the person with PMD in an indirect manner (e.g., behavioural scientist, therapist) ('indirect support staff').

The subject of this paper is the initial evaluation of the psychometric properties of the QOL-PMD. More specific, each item was evaluated in order to check its value and to look for possibilities to reduce the number of items. Item reduction was an important issue, because the respondent burden was perceived as too high (average administration time: 1 h 34 min per informant) by the respondents in the third and fourth stage of the development of the questionnaire. On the reduced questionnaire, analyses were made with regard to the validity and the reliability of the questionnaire. Finally, the selection of multiple informants was examined.

Participants & Methods

The participants in this study were informants of people with PMD. They were selected by behavioural scientists working in services for people with PMD in Belgium and the Netherlands. The sample included 49 people with PMD of which 23 (46.9%) were female; the average age among these participants was 23.7 (SD = 12.2 years; range = 5–57 years). All people with PMD in our sample experienced motor limitations. More than half of them suffered from limitations in the movement of the lower limbs (59%) and 44% from limitations in the movement of the upper limbs. More than half of the people with PMD (59%) experienced sensory limitations. In the majority of the cases, it regarded visual impairments (54%). Auditory impairments were diagnosed in 8% of the people with PMD. Sixteen people with PMD (33%) attended a day centre and 33 people with PMD (67%) a residential care facility.

For each of these people three kinds of informants were included, as stated earlier. In total 147 informants were selected. The ‘family’ group of informants consisted of 13 fathers (26.5%), 33 mothers (67.3%), and 3 sisters (6.2%). The ‘direct support staff’ group of informants included 44 females (89.8%) and 5 males (10.2%). The ‘indirect support staff’ group of informants was comprised of 27 behavioural scientists (55.1%) and 22 therapists (44.9%) of which 44 were female (89.8%). All the informants knew the person with PMD for at least 6 months. In the ‘family’ group, 67.3% of the informants had contact with the person with PMD several times per week; 12.2% once a week; 14.3% once every 2 weeks, and 6.2% once a month. The majority of the ‘direct support staff’ group of informants (89.8%) had contact with the person with PMD several times per week. In the ‘indirect support staff’ group of informants the contact differed from several times per week (77.6%), once a week (14.3%), and once every 2 weeks (4.0%) to once a month (4.0%). Before commencement of the study, all panellists were assured anonymity and confidentiality. Informed consent from the parents or legal guardians was obtained. The research procedure complied with the ethical standards of the participating countries. Each informant filled out the QOL-PMD individually on paper.

Methods

The first step in the analysis was the evaluation of the items. A distribution of the response categories for each item was drawn. Percentages of missing values, ‘don’t know’ (DK) responses and ‘not applicable’ (NA) responses were calculated as well as item means, item variances, and item– remainder correlations. ‘Not applicable’ responses could only be given with regard to specific items (e.g.,

To gather evidence for the internal consistency of the QOL-PMD, Cronbach’s alphas were computed for the QOL-PMD scores of each group of informants as well as for the total group of informants, for the subscales and the total questionnaire. Pearson product–moment correlations were computed between the subscales and between the subscales and the total questionnaire. To get information on the strength of a correlation Cohen’s (1988) criteria were applied in which correlations between 0.10 < 0.30 are considered as small, correlations between 0.30 and <0.50 as medium, and correlations higher than 0.50 as strong.

Data on two other measures were collected to examine the construct validity of the QOL-PMD. The specific goal of these analyses was to show stronger relations among scales addressing similar constructs and weaker relations among scales addressing different constructs. Because of a lack of measures on the objective components of QOL that are geared to people with PMD and psychometrically tested, finding appropriate measures to test the construct validity of the QOL-PMD was not an easy task. Nevertheless, we selected two measures of which the relations to the construct addressed in the QOL-PMD could be hypothesized.

Firstly, a general single-item measure of QOL was assessed. More specifically, all informants were asked to rate the QOL of the person with PMD on a 10-point scale with 10 being the highest QOL. It was hypothesized that a positive correlation would be obtained between the ratings on the general measure of QOL and the total scores on the QOL-PMD as higher scores on the QOL-PMD reflect higher QOL. The strength of this correlation was expected to be medium (0.30–0.50) because this general measure on QOL assesses the subjective component of QOL of the person with PMD rather than the objective component, which is assessed by the QOL-PMD. As shown in the literature, the correlation between subjective and objective measures tends to be rather low as the subjective component has a trait-like (i.e., stability over time) nature (Emerson et al., 2005; Schalock & Felce, 2004).

The second measure that was used to examine the *construct validity* was the Mood, Interest and Pleasure Questionnaire (MIPQ) (Ross & Oliver, 2003). The MIPQ is a psychometrically sound 25-item Likert scale questionnaire with two subscales (Mood and Interest and Pleasure) designed to assess affect in people with severe and profound learning disabilities. Lower scores denote lower mood levels and lower levels of interest and pleasure. The MIPQ was included in this study because, according to its developers, it can offer valuable information regarding the subjective component of QOL among individuals with severe and profound learning disabilities, given that satisfaction might be reflected in the kinds of behaviours addressed in the MIPQ (Ross & Oliver, 2003). As such, a positive correlation between the MIPQ total score and the QOL-PMD total score would be anticipated. The strength of the correlation is expected to be medium for the same reasons as regarding the first measure. Nevertheless, the correlation between the QOL-PMD and the MIPQ is expected to be lower, compared to the correlation between the QOL-PMD and the general measure on QOL as the latter addresses the construct QOL in a more direct manner than the MIPQ does. The MIPQ was filled out by a member of direct support staff, who was frequently involved with the person with PMD, but who did not act as an informant for the QOL-PMD in this study. To get information on the strength of a correlation Cohen’s (1988) criteria were applied. Correlations were compared using the procedure described by Meng, Rosenthal, and Rubin (1992).

Multiple informant comparison

The correspondence between the three groups of informants was examined in order to gain insight in the surplus value of using multiple informants. Correspondence was defined as the intercorrelation between (sub) scale scores from different informants. The correspondence in ratings by multiple informants was examined by computing Pearson product–moment correlations between ‘family’, ‘direct support staff’, and ‘indirect support staff’. Cohen’s (1988) criteria for correlations were applied. Differences between various informants were not interpreted as reflecting the unreliability of the questionnaire, but rather as something that might be expected from the fact that each informant has different experiences with the person with PMD. Therefore, it is hypothesized that the overall correspondence between informants is medium. The correspondence between ‘direct support staff’ and ‘indirect support staff’ is expected to be the highest because they share the context in which they have contact with the person. Differences in correspondence were tested using the procedure described by Meng et al. (1992) to compare correlations.

Results

Item evaluation

In the total group of 15,435 (i.e., 105 items x 147 informants) observations, 6 observations were missing (0.04%). In 0.77% of the observations the respondents made use of the NA-response. In 4.86% of the observations the respondents made use of the DK-response. The use of the DK-response differed across subscales and across groups of informants. The DK-response was used often in the subscale physical well-being (9.16%), social well-being (6.24%) and development (5.78%) and less often in the subscale communication and influence (3.77%), activities (3.08%), and material well-being (1.90%). With regard to the total questionnaire, the group of indirect support staff (ISS) chose the DK-response most often (6.50%) followed by the group of family (FAM) (4.75%) and the group of direct support staff (DSS) (3.30%). This order was also clearly apparent in four subscales, more specific in material well-being (ISS: 2.49%; FAM: 1.81%; DSS: 1.36%), in social well-being (ISS: 9.98%; FAM: 5.44%; DSS: 3.40%), in communication and influence (ISS: 4.90%; FAM: 4.50%; DSS: 1.84%) and in activities (ISS: 4.29%; FAM: 3.47%; DSS: 1.63%). In the subscale development the family group of informants was the group that used the DK-response most often (FAM: 7.05%; DSS: 5.44%; ISS: 4.76%).

Based on the criterion we set regarding the item mean (between 0.50 and 1.50) 42 of the 105 items were removed from the questionnaire. Setting the minimal item–remainder correlation at 0.20 eliminated another 8 items from the questionnaire. A final reduction of 50 items was made of which 12 items in the subscale 'social well-being', 11 items in the subscale 'physical well-being', 10 items in the subscale 'material well-being', 6 items in the subscale 'communication and influence' and in the subscale 'development' and 5 items in the subscale 'activities'. After reduction, the questionnaire1 contained 55 items. Table 1 shows the distribution of items before and after the reduction in the different subscales.

Internal consistency

With regard to the QOL-PMD total scores, the Cronbach's alpha coefficients were almost equally high for each of the informants group as well as for the total group (range a = 0.90–0.92). Concerning the latter, all Cronbach's alpha coefficients were above the acceptable limit (>0.70). This was not the case for the Cronbach's alpha coefficients of the subscales in the different informant groups. In the family group of informants, three coefficients were slightly below the acceptable limit; in the direct support staff group of informants two coefficients; and in the indirect support staff group of informants one coefficient. The internal consistency of the subscale communication and influence turned out to be the highest for each of the group of informants as well as for the total group. Item–remainder correlations above the recommended range (>0.20) were obtained for all six subscales as well as for the total questionnaire in each group of informants and for the total group.

Construct validity

As hypothesized, the strength of the correlation between QOL-PMD total score and the general measure on QOL was medium ($r = 0.44$, $p < 0.001$). The general measure on QOL also correlated medium with social well-being ($r = 0.43$, $p < 0.001$), physical well-being ($r = 0.41$, $p < 0.001$) and communication and influence ($r = 0.35$, $p < 0.001$). A low correlation was detected between the general measure on QOL and the subscale activities ($r = 0.29$, $p < 0.01$), material well-being ($r = 0.27$, $p < 0.01$) and development ($r = 0.19$, $p < 0.05$).

As hypothesized, the correlation between the total score on the MIPQ and the total score on the QOL-PMD was also medium ($r = 0.31$, $p < 0.001$). However, the correlation between the MIPQ and the subscale communication and influence ($r = 0.45$, $p < 0.001$) and the subscale physical well-being ($r = 0.39$, $p < 0.001$) turned out to be stronger than the correlation with the total questionnaire. The MIPQ also correlated medium with the subscale social well-being ($r = 0.27$, $p < 0.01$). The correlations between the MIPQ and the subscales development ($r = 0.11$, p = n.s.), activities ($r = 0.08$, p = n.s.), and material well-being ($r = -0.03$, p = n.s.) turned out to be not significant. The correlation between the MIPQ total score and the QOL-PMD total score was, as expected, lower than the correlation between the latter and the general measure on QOL. However, the difference in correlation was not significant.

Multiple informant comparison

Family (mean = 11.41, SD = 3.51) and direct support staff (mean = 9.92, SD = 3.76) score significantly higher than indirect support staff (mean = 8.12, SD = 3.66) (FAM–ISS, p < .0001; DSS–ISS, p = 0.0418). The difference between family and direct support staff is also large although not significant (p = 0.1100). In the other subscales as well as in the total questionnaire, no significant differences between the groups of informants were found.

Overall, one can observe that the correspondence between 'family' and 'direct support staff' and between 'family' and 'indirect support staff' is lower than the correspondence between 'direct support staff' and 'indirect support staff' with regard to the total questionnaire as well as with regard to the different subscales. Nevertheless, a significant difference in correspondence between the groups of informants was only found in the subscale physical well-being (z = -3.15, p < 0.001). Regarding the total questionnaire, the correlations between 'family' and 'direct support staff' (r = 0.24) and between 'family' and 'indirect support staff' (r = 0.25) are low, whereas the correlation between 'direct support staff' and 'indirect support staff' (r = 0.38) is medium. With regard to the subscales, differences were found in the level of correspondence between informants. In two out of six subscales medium to strong correlations were found between informants, namely in material well-being and in communication and influence. For the subscale physical well-being low (FAM–DSS: r = 0.25), medium (FAM–ISS: r = 0.39) as well as strong (DSS–ISS: r = 0.51) correlations were detected between informants. Low to medium correlations were observed in the subscale social well-being. In the subscale development and in the subscale activities low correspondence between informants was found.

Discussion

In the field of ID the importance of a valid assessment of QOL is heightened with the increased use of the QOL construct as a basis for policies and practices. Because of a shortage of valid assessment instruments to measure the QOL of people with PMD, the QOL-PMD was developed. The subject of this paper was the initial evaluation of the psychometric properties of the QOL-PMD. First, the descriptive statistics of each item were analysed in order to check the value of each item and to look for possibilities to reduce the number of items. Item reduction was an important issue because the respondent burden of the questionnaire was perceived as too high. Following the criteria that were set regarding item–mean and item–remainder correlation, 50 of the 105 items were removed from the questionnaire—a reduction of approximately 50%. A major advantage of this item reduction is a lowering of the respondent burden without diminishing the psychometric properties of the questionnaire. However, further research should investigate the actual decrease in administration time.

On the reduced 55-item questionnaire several analyses were conducted that provide information about the reliability and validity of the QOL-PMD total and subscale scores in this sample. Internal consistency for each of the six subscales as well as for the total questionnaire was good for the total group of informants as well as for each group of informants, indicating homogeneity of the subscales. All subscales were found to be significantly (p < 0.001) positively correlated with each other as well as with the total questionnaire. These results are encouraging but further research, which includes examining the six-factor structure of the questionnaire is necessary. Because of the small sample size and the clustered nature of the data in this study, a confirmatory factor analysis could not be performed.

Some support for the construct validity of the QOL-PMD was found in the correlations between the questionnaire and two other measures. As hypothesized, the strength of the correlation between QOL-PMD total scores and the general measure on QOL was medium. The same goes for the correlation between the QOL-PMD total scores and the MIPQ total scores. The construct affect, which is addressed in the MIPQ, turned out to correlate the strongest with the subscale communication and influence and the subscale physical well-being. This might indicate that the basic needs of ‘being able to communicate’ and ‘being healthy’ have the strongest impact on the affect of people with PMD. In general, these results provide preliminary evidence for the construct validity of the QOL-PMD. Nevertheless, it is difficult to check the construct validity because of a lack of measures on the objective components of QOL that are geared to people with PMD and psychometrically tested.

Finally, the correspondence between the informants was investigated in order to gain insight in the surplus value of working with multiple informants. The correspondence between the groups of informants is overall low to medium, which partly can be explained by the different realities that are measured by each informant (Verhulst & Akkerhuis, 1989). The fact that each informant has his own experiences with the person is apparent in the subscale ‘social well-being’, where significant differences in scores were found between the groups of informants. Regarding social well-being, family knows the person within as well as outside the context of support, whereas support staff only has experiences within the context of support. The correspondence between ‘direct support staff’ and ‘indirect support staff’ was as expected medium, whereas the correspondence between support staff and ‘family’ was low. The fact that support staff shares the context in which they have contact with the person, most likely accounts for this difference. As such, the medium correspondence between informants might be regarded as an indicator of the transsituational validity of the questionnaire. Each group of informants has specific knowledge about the person and contributes to a complete picture of the QOL of the person. The group of ‘indirect support staff’ overall makes the most use of the DK-response option, presumably because they are involved with the person with PMD in an indirect manner and for a limited amount of time. Nevertheless, in the subscale ‘development’ their expertise has a surplus value, as in this subscale they use the DK-response less than other informants. Overall, these results support the selection of multiple informants from the different contexts in which the person lives, works, and plays. Working with multiple informants is a way of improving the reliability and validity of a questionnaire as more information from different perspectives is available (Schwartz, Barton-Henry, & Pruzinsky, 1985). However, one needs to keep in mind that significant others’ (i.e., proxies) views about QOL can be both valid and important, but they cannot replace self-reports (Verdugo et al., 2005). Therefore, the search for measurement approaches where data on QOL can be obtained directly from the person with PMD him/herself needs to continue.

The psychometric analyses provide initial evidence for the internal consistency and the construct validity of the QOL-PMD. With the development of this questionnaire, it seems that a good attempt is made to answer the ‘what’ as well as the ‘how’ and ‘who’ interrogatory of QOL measurement for people with PMD. However, several limitations to the present study on the psychometric properties of the QOL-PMD exist. First of all, the sample size of this study is small. Because of the high respondent burden, many people refused to participate in the study. The significant item reduction that was made in this study should solve this problem for future research as validation of the QOL-PMD in a larger sample is necessary. The shortening of the questionnaire should also make it easier to gather data to evaluate the test–retest reliability.

Appendix A. QOL-PMD final version

1. The person expresses his/her preferences with regard to activities and actions (e.g., personal care, nourishment).
2. The person regularly makes use of community services and facilities (e.g., restaurant, swimming pool, shops, hairdresser).

3. The person makes clear his/her feelings, needs and wishes. The person is ‘heard’.
4. The person optimally uses his/her intellectual abilities.
5. The person has privacy.
6. The person experiences no discomfort due to side effects of the administered medication.
7. The person has positive social contacts, which are meaningful to him/her with people outside the context of professional support and outside the family (e.g., friends, acquaintances, neighbours).
8. The person participates in activities that he/she can mentally cope with.
9. The person has positive social contacts, which are meaningful to him/her with group members (e.g., living group/activity group/class group).
10. The person is well rested in the morning.
11. The person participates in activities that interest him/her.
12. Children: The person receives schooling/education or developmental stimulation. Adults: The person is employed (with/without support) or receives adult education.
13. The person has at his/her disposal all technical aids and adaptations that he/she needs regarding communication.
14. The person optimally uses his/her socio-emotional abilities.
15. The person contributes to the communication process on his/her own initiative or as a reaction to a question/message of someone else.
16. The person gets the opportunity to perform activities and actions (e.g., personal care, nourishment) independently.
17. The individual’s physical health status is good.
18. The person expresses his/her preferences with regard to nourishment.
19. During daytime, the person seldom has to occupy him/herself.
20. During the last year, the individual’s problems arising from physical impairments (e.g., spasticity, deformity) have decreased.
21. The person is regularly involved in activities and actions (e.g., personal care, nourishment) with the direct support staff that he/she prefers.
22. The person actively engaged in activities.
23. The person is never asleep during daytime because of a shortage of activation.
24. The person optimally uses his/her sensory abilities.
25. The person understands what the people in his environment want to make clear.
26. The person expresses his/her preferences with regard to direct support staff/group members.
27. The person experiences no problems during daily activities due to sensory impairments.
28. The environment outside the living group/activity group/class group (e.g., garden, street, neighbourhood) is adapted to the individual’s abilities and limitations.
29. The person has good contact with his/her parents and/or other family members.
30. The person acquires new skills and/or new experiences by participating in activities.
31. The person stays in rooms that are geared to his/her needs and wishes with regard to decoration.
32. The individual’s sexual needs are fulfilled (adults).
33. The person optimally uses his/her communicative abilities.
34. The person has at his/her disposal all technical aids and adaptations that he/she needs regarding activities and leisure.
35. The person optimally uses his/her physical abilities.
36. The person experiences sufficient variation in the range and place of activities.
37. The person can follow the presence of support staff during the day.

38. The person experiences no discomfort from feeding problems.
39. The person participates during the day in several activities, which include group activities as well as individual activities.
40. The person stays in rooms that are geared to his/her needs and wishes with regard to temperature, lighting, ventilation, air humidity, acoustics and hygiene.
41. The person receives tasty and balanced nutrition.
42. The person optimally uses his/her adaptive behaviour skills.
43. The individual's mental health status is good.
44. The person stays in rooms that are accessible.
45. The person has influence on his/her direct environment.
46. The person can recognize and anticipate what is happening around him/her.
47. The person has no pain.
48. The person expresses his/her preferences with regard to mobility (e.g., posture, position in space).
49. The person lives in a community.
50. The person stays in rooms that are safe.
51. The person expresses affection towards people in his/her direct environment.
52. The person is regularly involved in activities with the group members that he/she prefers.
53. The person participates in activities that he/she can physically cope with.
54. The person participates in activities in open air.
55. The person participates in activities that are offered in leisure and cultural facilities in the community.

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"Those who do not speak ".Some considerations concerning people with intense and complex support needs

Marc Benedetti, ASFA, Isle de la Réunion

For a long time, a discussion has been going on about the definition of who needs intense and complex support, who can be called to have “multiple disabilities”. The Anglo-Saxon literature defines PIMD (profound intellectual and multiple disabilities)... Also in this project, an early controversy emerged showing the difficulties in defining a very heterogeneous population and the methods to assess their needs.

Attempting to go beyond this difficulty, it seems to me that an extract from the journal: Social Life 2013/3 (No. 3), offers an interesting perspective.

"The *French law, through the law of 2002 and the 2005 law, raises a number of principles for the participation of "the user" , which we all know they are designed for people with disabilities, but whose perspective (needs, demands) can be easily expressed and collected.*

In his article, Jean Yves Barreyre says: “It is feared that the mobilization required for persons with disabilities are for those who are less distant from "validocentrism" that regulates our societies today, while giving good conscience to all for their collective effort. This plausible scenario would lead to a paradoxical situation: a real discrimination against people with severe disabilities in an environment where everyone could welcome the efforts made in the acceptance of differences ... This paradoxical discriminatory process could operate even more easily that the change in media companies is accompanied by images, words and speeches and the "forgotten" often do not speak and do not see. They will be less present on the media screens because their difficult or absent speech, their broken or distorted picture, send an image to the able-bodied people which does not exactly comply with what the media audience tends to show, but rather prefers to hide ".

What then of "those who do not speak”, which have no access to speech or communication, or who are severely limited in their ability to perceive the world (people with multiple disabilities, deaf-blind, with severe head injuries, autistic deficits, in advanced stages of Alzheimer's disease, etc.). ?

Will they be the "outcasts" of a new legislation based on “the word”?

A definition relates to these people (children, adolescents, adults) who do not have the words to say and in whom needs assessment necessarily involves effort, competence and goodwill of specialized professionals, parents, caregivers and teachers. In this project we have a strong concern for people with multiple disabilities and people with “autism spectrum disorders " , but it would also be interesting to include all these people who are "invisible" , "inaudible", who live in the very margins of our society, in France anyway.

This definition would probably involve, beyond the general issues discussed (access to care, schooling), to focus the needs assessment on the need for communication in the first place.

How children, adolescents, adults communicate, how to establish with them a mode of shared communication?

For the rest we can return to evaluation tools, such as the "kidscreen".

Evaluation of children with disability in France

In France, as from 2005, the "GEVA" is used at the "Departemental Houses for people with a disability - MDPH (which in France are the centres of reference). In every territory (department), the MDPH is the "single counter" for the people in situation of disability. In the MDPH, an evaluation is done of his situation and according to this evaluation, a support plan is made up**.** The assessment of its situation is made by a multi-disciplinary team, which draws the information from the GEVA.

Principles of evaluation according to the GEVA

From demand to needs assessment

- The centre of the approach consists of identifying and attending the person's needs, in all its domains of life (daily activities, social life, health, work, housing, etc.)
- It **seeks to establish** a personalized support plan, consisting of a global intervention strategy: home care and support, medical and social support, services, etc. - to answer all the identified needs.
- it leans on the « life plan » of the person and refers to the definition of disability expressed in the law of February 11th, 2005 and to the International Classification of the Functioning (ICF)

The issues in the use of a medium of data collection for the evaluation of disability

== > Establish

- A common language
- A shared culture between the members of the multidisciplinary teams of the MDPH
- A medium in the dialogue between the numerous partners of the evaluation of the needs for compensation and for the support of people

== > Building on a multidimensional evaluation

- Identify the needs of the person, in order to propose answers of all kinds
- Approach several dimensions of the situation of life (personal interview, mobility, communication, everyday life, social life, training and professional life, etc.)
- Study personal factors, environmental factors and the interactions between both (obstacles and facilitators)
- Apprehension of the other steps made by the person and the supports from which he already benefits.

== > Partners' plurality ·

The person with disability and his environment are the first partners of the evaluation. It is a question of taking into account the expression of their needs, wishes, and expectations, to study the whole situation and to propose adequate answers of compensation, upstream and\or during the process of evaluation.

Figure 2 "GEVA", the conceptual framework with which to assess functioning and disability in France

What domains are evaluated by the GEVA?

Activity & participation (strand 6): heart of the GEVA

It is the central strand, which refers to the definition of disability: limitations of activities and the person's limitations of participation.

Others strand are added to clarify the situation (explain these limitations or the context of life) or give information which is useful for the definition of recommendations.

The fields of activity of the strand 6 (activity and participation):

- Application of the knowledge, apprenticeship
- Tasks and general requirements
- relationships to each other
- Mobility, manipulation
- Personal interview
- Communication
- Domestic life and Life skills
- Tasks and requirements in connection with the schooling and the initial training
- Tasks and requirements relative to the job

Environmental factors

The environment is described as facilitator or obstacle to the realization of the activities.

- Family, social and budgetary sector for the human environment
- Housing environment, living environment for the physical environment.

Implementation

Zooms in on the already implemented aids, which are present facilitators in the environment of the person.

STRAND 8 : summary of the assessment

This strand proposes a synthesis of the information collected in the other strands, which are relevant to take into account for the elaboration of a personalized "compensation" project as it, is called in France, or personal support plan. It highlights the various needs for compensation.

Reflections

Whatever the evaluation tool, it seems important to take into account the point of view developed by JY Barreyre (2012). Regarding clinical observation and shared observation, a distinction should be made between:

- On the one hand the " clinical observations " in the service of a therapeutic, educational or instructional practice, which allow to build a diagnosis, to analyze the evolution of a pathology, a deficiency, to estimate the phases of the cure, or the apprenticeships; ….
- On the other hand, "the shared observation" which allows approaching the comprehensive situation of a person assessed in his environments and to set up a global strategy of intervention with the agreement and the collaboration of the person. The objectives of shared observation are of social and political order: they aim at knowing the potentialities, the possibilities and the obstacles to the integration of people in institutions and in the mainstream environment of the French society and the conditions of realization of a civic full life.

However, the clinical data collected thanks to the specialized criteria (disciplinary or personal) can be of use to every observer or group of observers to inform, within the framework of the shared observation, the evaluations of abilities or capacities according to the environmental situations. Indeed, every observer of the situation (including the person in a situation of disability), every professional of a particular discipline, provides or can have a battery of indicators or criteria of diagnosis or evaluation adapted to the objective aimed by his particular point of view.

So, the shared observation of the children, residents or "users" of the services of a medico-pedagogical institution, will consist in determining a list of variables, shared by the professional team, which attempts to describe the situation of the disabled child, in his various dimensions (intellectual and cognitive abilities, daily life activities, the implication in the social life, the relation with the others, etc.), to feed the reflection on which will lean the elaboration of the individual project (knowing that the expectations of the family and the child must be also taken into account). This must be clearly distinguished from an observation which would lean merely on the pooling of clinical information appropriate to every actor (for example: psychiatric diagnosis, educational evaluation of the specialized primary school teacher), directly in connection with his discipline and its professional reference tables. The shared observation consists not only in translating each of these clinical elements to make it understandable by all (medical popularization for example), as it is the case today in the interdisciplinary projects meetings within the institutions and medico- social services.

The shared observation consists in this particular case in describing a crippling situation, in particular from the point of view of intellectual and psychic functioning of the person and the realization of daily life activities, within the framework of the environment in which he/she evolves, and through indicators common to all the actors. Indeed, all the professionals intervening with the child are confronted at one point or another with the various facets of its personality, with his different capacities or the limits of capacities, in the specificities of his social, family or cultural environment, etc., even if their function exposes them firstly to certain dimensions rather than to others. Therefore, the special needs primary school teacher will identify in a finer way the limits of memorization and of concentration of the child as far as these capacities participate strongly in the process of learning whereas the special needs educator will locate first the difficulties in the realization of the daily activities. All the information necessary for the construction of a life plan can be informed and shared by all the actors participating in it. So, the capacity of a child " to master its behaviour in its relations with others " is not locatable only by the staff belonging to the field of mental health and is not only taken into account in the "therapeutic" dimension of support; it must be well joined into a collective reflection, aiming at the elaboration of an individual project. Indeed, this difficulty, which may arise during classroom time, in play, during meals or still within the framework of an internship in a protected environment, can cement the current and future answers brought to the needs for the child.

In this respect, the use of the principles of the International Classification of Functioning, Disability & Health (ICF), or of others model such as the PPH – Process of Production of Disability of Fougeyrollas, in the shared observation, is recommended, as far as:

- on one hand this list does not belong to a particular discipline
- On the other hand, it proposes an exploration of the characteristics of the person in various dimensions of life situations, by taking into account the environment in which he/she evolves.

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Part II Results of research on the needs of children with complex and intense support needs in the Enablin+ partner countries

This section reports on the results of research done in the various Enablin+ partner countries in 8 European Regions. A simple questionnaire has been made by the scientific committee and was then translated into the partners' languages (appendix 1).

Needs assessment in Belgium and the Netherlands

Jo Lebeer, University of Antwerp

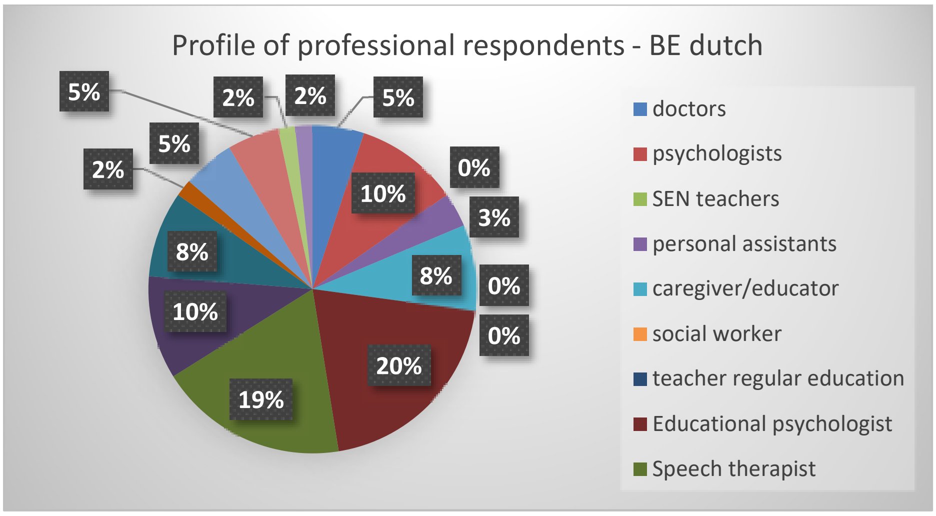
As for Belgium and The Netherlands, a mailing campaign was done twice in the last weeks of June 2014, to all 273 centres in Flanders working with children with complex support needs, as well as in The Netherlands via the electronic "Platform EMB". In addition, a mail was sent to parents-professional organisations in Flanders (Multiplus, Inclusie Vlaanderen, Gezin & Handicap) as well as in French-speaking Belgium (AP3). Some of these organisations disseminated the information in their newsletters (Multiplus, VCLB Child Guidance centre Leuven). People were requested to fill out the questionnaire in word-format, or online. Questionnaires were posted on Google docs, a separate one for professionals[6], and one for parents[7].

Profile of respondents

60 professionals filled out the questionnaire online; two sent back a filled-out "word" version by mail.

21 parents sent their forms back via online forms. One parent mailed that he preferred a direct face-to-face interview because he couldn't really explain the full needs in the questionnaires. Therefore, the coordinator went to do the interview. No responses were received from the French part of Belgium. This means we have to repeat the campaign for them. Of the 60 professionals answers, there were a lot from the Netherlands, people apparently filled out the same questionnaires as from Belgium (figure 1). Professionals' age ranged from 23-69. Their academic background was 1/3 university trained, 1/3 college trained and 1/3 vocational training. 2/3 of respondent professionals work in a special setting for children with PMID, 1/6 in special schools.

As for parents: 8/21 answered from Belgium and 13 from the Netherlands. They ranged in age from 30-70 (mean 46); they came from various professional and socio-economic backgrounds.



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[6] https://docs.google.com/forms/d/1rLRvC7Mx7ofax1lQ1_X5jUUV4s744riJGfgVp6D7LoU/viewform?c=0&w=1&usp=mail_form_link

[7] https://docs.google.com/forms/d/1zZ11MFGEZYqZmNORUTOfT_3cFnsbuI8E158VFMepKc/viewform?c=0&w=1&usp=mail_form_link

Figure 3 Profile of respondents to questionnaire in Belgium and the Netherlands

Profile of the children with PIMD

The children that were referred to (N=105) all had PMID and varied in age: 1/5 pre-school, 1/3 primary school age, and 40% were adolescents. 84% of these children were in a non-schooled setting, and only 16% were receiving school education. 57% of the children went home at night, so that means that about half of the children were in residential care. There are now also more flexible living situations: partly at home, partly in residential setting (respite care); sometimes the child is taken care of during weekends in a foster family. The older the child is, the more difficult it becomes to stay at home; this has mostly to do with increased weight of the child and concomitant increased difficulty in daily care. In addition, behavioural difficulties is a criterion to stay at home permanently or not. Half of the children with behavioural difficulties, living at home, go to a "respite house" 1-2 days a week or a weekend per month.

Parents (N=21) reported about their children ranging from 3-36 years. In addition, half of the children were in a non-schooled setting, and 3/21 were at home all the time. Only 1/21 went to a regular school. 13/21 are also at home during the night.

Professionals reported several barriers against inclusion and learning (Table 3)

Table 3 Barriers against learning and inclusion mentioned by professionals (Belgium & NL – Dutch N=60)

Barriers	medium to strong	sometimes	no
barrier technical	35,7%	58,9%	5,5%
barrier finances	48,2%	48,2%	3,6%
barrier building	28,3%	47,2%	24,5%
barrier attitude	37,5%	57,1%	5,4%
lack of assistance	48,2%	41,1%	10,7%
lack of prof support	26,8%	58,9%	14,3%
family support absence	39,6%	54,7%	5,7%
lack of training	30,9%	54,5%	14,5%
no access to regular education	45,3%	28,3%	26,4%
barrier: other	41,2%	17,6%	41,2%

The barriers reported by professionals as the most severe were financial barriers, lack of assistance and a denied access to regular education; but also lack of assistive technology and knowledge how to use them were reported frequently as well as lack of training and lack of family support.

The answers of the families were slightly different. Families reported mainly attitudes, lack of personal assistance, barriers in buildings, lack of training, lack of family and professional support, lack of technical aids as the most severe obstacles (Table 4)

Table 4 Barriers against learning and inclusion mentioned by parents (Belgium & NL – Dutch N=21)

8. Barriers	medium to strong	sometimes	no
barrier technical	42,9%	47,6%	9,5%
barrier finances	12,5%	43,8%	28,6%
barrier building	55%	35%	10%
barrier attitude	68,4%	26,3%	5,3%
lack of assistance	65,0%	25,0%	10,0%
lack of prof support	45,0%	35,0%	20,0%
family support absence	47,6%	33,3%	19,0%
lack of training	52,6%	31,6%	15,8%
no access to regular education	43,8%	12,5%	43,8%
barrier: other	42,9%	14,3%	42,9%

How are children evaluated

A majority of professionals uses a combination of standardized testing procedures, observation (standardized as well as free observation) and interviews, although the most frequently used method (74%) was standardized testing (Table 5). They were not very satisfied with these habits (only 17% reported to be satisfied, whereas 36% reported strong dissatisfaction).

Parents assess their children's needs by direct observation and interaction, with simple communication methods (signs, eye contact, symbols, body and face expression).

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Table 5–Evaluation methods, as reported by professionals working with children with PIMD (BE & NL).

Name - Designation	***Domains***	***Authors***	***Target group characteristics***	***Age of target group***	***N° of times used N=106***	***% used***	***Strong points***	***Weak points***
BSID-III (Bayley Scales Infant Development)	cognition, language, motor domain, socio-emotional and adaptive behaviour	Bayley (van Baar, Steenis, Verhoeven & Hessen – Dutch version)		children from 16 days to 42 months and 15 days	10	9,4%	standardized; allows to calculate developmental age; partly observational, so it can be used for children who are not task responding.	not suitable for goal setting;
PACT (Personal ACTivation Programme)	activities	Hiemstra, Wiersma & Vlaskamp	people with PIMD	All ages	10	9,4%	learn to look differently	time consuming
Vineland Adaptive Behaviour Scales-Z (VABS-Z)	communication, daily living, socialization	Sparrow, Cicchetti & Balla (De Bildt & Kraijer (Dutch version)	children with moderate/severe/profound ID	Original 0-90 y Dutch: 5 to18 years	6	5,7%		
Sensory Profile	sensory process patterns	Dunn		3 to 10 years	6	5,7%	complete and overview	time consuming; less suitable for profound difficulties
N-CDI Communicative Development Inventory – Dutch version	prelinguistic communication, semantics, syntaxes, morphology	MacArthur-Bates (Zink & Lejaegere 2002, Dutch)	children with language disorders > 30 months developmental age 8-30m	00;08 - 02;06	5	4.7%		
SEO-R	socio-emotional development	Došen	people with ID		4	3,8%	A good discussion-instrument, invites people to look differently at a child.	time consuming; less suitable for profound difficulties
ComVoor	communication prerequisites	Verpoorten, Noens & Van Berckelaer-Onnes	people with autism spectrum disorder or other severe communication problems	12-60 months	4	3,8%		not always useful in practice; tends to underestimate
Video interaction	overall				4	3,8%	allows personal outlook; share views; the child is central, not the protocol; the observation	

Observation scales	overall							
Parent interview	overall				4	3,8%		
NNST (Nederlandstalige NonSpeech test) Dutch non-speech	Communication prerequisites	Zink & Lembrechts	persons who use no or limited spoken language because of 1 or more disabilities	children and adults with communicative level <24 months	3	2,8%		
AMPS (Assessment of Motor and Process Skills)	functioning in daily life	Fisher, Bray Jones	children ≥ 4 years, and clients with presumed problems in daily functioning	4years+	3	2,8%		
Repos (Rotterdam Elderly Pain Observation Scale)	pain	Erasmus Medical Centre -	developed for older people with dementia, but can be used for adults with ID or communication problems	adults	3	2,8%	easy	
Profile of experience LACCS (Dutch acronym for BACCS)	bodily well-being, alertness, contact, communication & stimulating activities	de Geeter & Munstermann	people with PIMD		2	1,9%	child-adapted; oriented at goal setting, ways of communication and approaching; good picture of comprehension by the child; can be used if child is untestable; oriented at guidance of environment ; includes medical aspects	not standardized; difficult
Profile of experience	ways of signifying past, present and future experiences	Timmer-Huigens	people with ID		2	1,9%		
QOL-PMD	Quality of Life - Persons with Intellectual and Multiple Disabilities	Petry, Maes & Vlaskamp	people with PIMD		2	1,9%	Useful for children with profound intellectual disability. Able to yield new needs for support and questions; broader than health	Time consuming; questionnaires are not personalized and there miss some points
Dynamic Assessment	cognitive domain	Tzuriel	children/youth		2	1,9%	Based on what the child is able to do, or could be able to do, not on what he cannot do.	

KID-N (Dutch version of KIDS (Kent Infant Development Scale)	cognitive development, motor development, language, self-reliance, social development	Katoff, Reuter & Dunn		developmental age <14 months, for children with minimal motor abilities	2	1,9%		
EPV's (Evaluatie Pragmatische Vaardigheden)	Evaluation of pragmatic skills - functional language	Cocquyt & Zink	children		2	1,9% 1,9%		
COPM (Canadian Occupational Performance Measure)	occupational performance	Law, Baptiste, Carswell, McColl, Polatajko & Pollock	ability for self-assessment	children 8+ years & adults	2	1,9%	interviews, followed by framework	
GAS (Goal Attainment Scale)	goal planning and evaluation	Kiresuk			2	1,9%		
InventarisatieLijst Kindkenmerken LKK	abilities & needed support, for education [Inventory Child Characteristics]	Vlaskamp & Tadema	people with PIMD		2	1,9%	useful with young kids; strong and weak points	
Passive Range Of Motion (PROM)	muscles and joints				2	1,9%		
Total communication	communication prerequisites	Scheres & Oskam	people with ID		1	0,9%		
Gross Motor Function Measure GMFM	gross motor function	Rosenbaum & Palisano	Children with cerebral palsy	1/2 year-16 years	1	0,9%	standardized and clear	time consuming; less suitable for profound difficulties
Schlichting test language comprehension & expression	language	Schlichting & Spelberg		2;0-7;0 years	1	0,9%		
Developmental steps model	overall	Memelink & Wanningen		0-13 years	1	0,9%		

Memelink								
Dale scale (**disability**-adjusted life expectancy					1	0,9%		
Small steps- two typical days interview	overall	Pieterse, Treloar et al.		0-13 years	1	0,9%	clear picture of the day	
GTI Gedragstaxatie-instrument -	functional abilities [Behaviour Taxation Instrument]	Vlaskamp, van der Meulen & Smrkovsky	people with PIMD		1	0,9%		
Child behaviour Checklist CBCL	behaviour	Achenbach		1-19 years	1	0,9%		
ADOS Autism Diagnostic Observation Scale	diagnosis of autism spectrum disorder	Lord, Rutter et al.		12 months+	1	0,9%		
Ondersteuningsplan [Support Plan]	support needs	Esdégé & Reigersdaal			1	0,9%	professionals/parents and supporting specialists	
Communicatie Competentie Profiel (CCP)	communication	van Balkom & Hagen			1	0,9%	gives a nice total picture of a child's functioning	
Motor observation list	motor & cognitive	Ayres	children	5 years-0 months to 11 years 11 months	1	0,9%	standardized	
SIPT Sensory Integration and Praxis Test	diagnosing sensory processing disorder	Ayres (Miller & Benjamin)	children w. learning or developmental delays, particularly in praxis , tactile or visual discrimination	4-8 years	1	0,9%		
Orbis dossier (nursing)	flexible database for managing client records	Softwel	welfare		1	0,9%		

Modified Ashworth Scale (MAS)	passive tonus	Bohannon & Smith			1	0,9%		
Tardieu Scale	functional mobility	Held & Pierrot-Deseilligny			1	0,9%		
PEDI-NL (Pediatric Disability Inventory)	self-reliance	Haley, Coster, Ludlow, Haltiwanger & Andrellos	children with physical or physical and cognitive disabilities	6 months-7,5 years	1	0,9%		
video Gait analysis	mobility				1	0,9%		
Quality of Life list (CCE)	quality of life	CCE	people with PIMD		1	0,9%		
Heijkoop method	dealing with problem behaviour	Heijkoop	people with disabilities		1	0,9%		
SIS (Support Intensity Scale)	support needs	Thompson et al.	people with ID		0	0,0%		
ICF	overall	WHO			0	0.0%		

Summary of the most important instruments used in BE and NL for assessment

Behavioural Assessment Instrument (GTI) (Opvoedingsprogramma.nl)

This instrument developed by Vlaskamp, van der Meulen & Smrkovsky describes functioning of people with profound and multiple disabilities. Besides specific functioning, there is a guideline for supervisors. It can also serve as a basis for further handling. By taking a test for a second time, change in functional capabilities can be measured.

Inventory Activities and Situations (LAS) (Opvoedingsprogramma.nl)

The LAS will help inventory knowledge and uncertainties on the following subjects;

- Preferences relating to characteristics of operations (an object must be offered close by, the child like the colour red)
- Preferences relating to performance conditions (the child needs a couple of minutes to recognize the object)
- Preferences relating to environmental conditions (Does group size matter? Does the child has a favourite spot?)

Besides a child's preferences, there will be questions relating touch, smell and motor function and how that should be taken into account.

Inventory Child Characteristics I, (LKK I) (Opvoedingsprogramma.nl)

The goal of the LKK (Vlaskamp & Tadema) is to create a description of the functional possibilities of a child with profound and multiple disabilities. In addition, the support needs of the child will be taken into account

The LKK is targeting caregivers, teachers or remedial educationist.

*Inventory Child Characteristics **II (LKK II)** (Opvoedingsprogramma.nl)*

The second part is a small report, which include of 3 categories;

- A child's relations at home and at the day care/school.
- A child's health (eating and drinking habits and mental health will be taken into account.)
- A child's social environment

Quality of Life-Profound Multiple disabilities (QOL-PMD) (Multiplus.be)

The QOL-PMD (Maes, Petry & Vlaskamp) is used the measure the quality of life of people with profound multiple disabilities and consists of 55 items with 5 categories

- Physical wellbeing
- Material wellbeing
- Communication & influence
- Social-emotional wellbeing
- Development and activities

The questionnaire will be filled in by parent(s) or family, professional caregiver or teacher and therapist, remedial educationist or psychologist. With an external moderator leading the consultation, a support plan can be established. The questionnaire can be used for the screening the quality of the care in the organization

Inventory Person and Care (IPZ) (Opvoedingsprogramma.nl)

It is a semi-structured questionnaire with the aim to create a coherent description of a person with profound and multiple disabilities, the relation with his (professional) caregiver and the care provided, with the situation in which care is given. The inventory is targeting (professional) caregivers/parents, to create a complete image.

Two versions of the IPZ are available, for day care and residential care. The questions are incorporated in 10 categories, which include the following;

- Life, characteristics and his needs
- Relations between the person, his parents and professionals
- The situational aspects at home or goals and situational aspects of the replacement home.
- Goals and situational aspects of care provided at individual, group and institution level

Based on the outcome of the questionnaire, a perspective may be defined and the priority of educational process - the main goal- can be specified. Evaluating the perspective, IPZ-data has to be updated, by reviewing the old and new date.

Communication passport *(www.communicatiepaspoort.be)*

A communication passport is a document with personal information about people who have problems with or are unable to talk. It provides a summary on ways to communicate, the behaviour and interests. It's created in collaboration with the holder and its parents (or partner).

It provides safety and comfort to the owner and helps him to integrate.

Scale Motor Development Mentally Disabled (SMZ) (pearson.nl)

SMZ measures the spontaneous gross motor function of mentally disabled in daily life and at games and relaxation. It can be used for people with a severe mental handicap as well as people with less severe mental handicap.

It has 22 items which are all related to daily life, like sitting, walking and swimming. The items are increasing in difficulty and in many cases start and cut line can be used.

Checklist Pain Behaviour (CPG) ww.oncoline.nl

This checklist is developed for children/youth with express limitations, children with severe mental disabilities not able to verbally communicate with others.

Using the CPG nurses, doctors and caretakers assess pain behaviour, even when the observatory does not know the child. The CPG is validated for post-operative pain as well as daily, chronic pain. It consist of 21 items divided over 4 subscales

- Facial expression (9 items)
- Social behaviour/mood (4 items)
- Vocalization (4 items)
- physiological signals

Every item is rated with a four-point scale
Based on the scores on the items four scale scores are calculated, as well as a total score.

Questionnaire Alertness (Lijst Alertheid) opvoedingsprogramma.nl

The goal of this questionnaire is to answer the question ‘When is the best time to start with an exercise?’ Because it is expected to vary by person, with this questionnaire an individual alertness profile can be draft. At first there has to be looked for moments of alertness, in the next step reactions to various stimuli. Based on this information an alertness profile will be written.

MOVAKIC (hagonderzoek.erasmusmc.nl)

Movakic is a digital questionnaire and will be filled in by physiotherapists and occupational therapy, who know the child.

The questionnaire consists of questions about motor skills, which are divided in three poses (lying, sitting and standing) in 13 different situations
The situations will be questioned through 4 items;

- maintaining the pose
- Activities in pose
- Transfers from pose
- Movement in pose

Relevant situations are answered per individual child, the order of chosen situations depends on the difficulty for the child.

MOVE-method (www.methodieken.nl)

MOVE is used to practice motor skills, to teach children to sit, stand and walk.

The exercises are done with equipment, like a chair, and a walker.
The main goal is to increase the mobility therewith the child’s self-reliance.
At the start, an intensive individualized program is used, when it is possible, it is integrated in daily life.

The basic skills are trained in six steps with goal to increase self-reliance or to decrease dependency. Exercises are suited the child’s everyday life. The training is intensive and repetition is very important, this takes a lot of patience. With every exercise, safety should be kept in mind.

Children with multiple disability in France

Eric Zolla, Christine Plivard, Anne-Marie Boutin, CESAP, Paris, France

Who are they? How children with complex and intensive support needs are defined in France

The French word ***polyhandicap*** was first used in the 70s and 80s to describe the now internationally recognised term, PIMD, a person with **Profound Intellectual and Multiple disability**. That is a serious disability with multiple features and diverse aetiologies, with the shared feature of a malfunction of the central nervous system. It occurs early or in the course of development (degenerative diseases, acquired pathology.

- ✓ Brain damage leads to major functional alteration from which leads to serious disabilities: severe mental deficiency, motor deficiency more or less associated with sensory deficiencies (visual, auditory…), frequently epilepsy, which is sometimes severe, and changes to psychological and cognitive development.
- ✓ Brain damage, usually early, may be of genetic origin – as is the case in numerous unusual diseases – or may related to a prenatal brain injury during pregnancy (hypertension, infection…), more rarely perinatal (IMC), or post-natal as the result of cranial trauma, infection (meningoencephalitis), cerebral anoxia. In 30% of cases, no cause is discovered. The lesion may be stable or progressive. Multiple disability may be the result of a common pathology, but in a great proportion of cases there is an unusual or rare disease, which evolves into a situation of multiple disability heavily medicalised.
- ✓ A situation develops that inevitably leads to extreme physical, psychological and social vulnerability…

According to Dr. Lucile Georges-Janet, it is clear that this definition covers a wide range of different situations and it is not always a case of fixing the limits for multiple disability, whether regarding Cerebral Palsy, which suggests a better intellectual level, or regarding deficiency psychoses (where motor problems are less evident), ground-breaking cases are not unusual.

This idea, coupled with the multiplicity of aetiologies, clinical tables (the concept of Multiple Disability is not yet referenced in ICD-10) and their variable appearance, makes studies around their prevalence considerably more complex and explains their rarity in a distribution ranging from 0.7% to 1.29%.

To summarize, the CESAP decided to refer to the definition to which it contributed and which from now on is offered by the *Groupe Polyhandicap France (GPF).*

The specific life situation of someone presenting a cerebral malfunction, early or occurring in course of development and having for serious consequences multiple progressive disturbances of motor efficiency, perception, cognition and in building relations with the physical and human environment.

This is a progressive situation of extreme physical, psychological and social vulnerability, over the course of which some may present transitory or lasting signs in the autistic spectrum. Because of this complex situation, the education and existence of a person with multiple disability requires specialist techniques for medical monitoring, learning ways to relate to people and communicate, development of the ability to enable sensorimotor and intellectual capacities, all aiming at exercising maximum autonomy.

The idea of multiple disability in French law

French legislation recognises the term and uses a definition very close to that of the GPF.

Children and adolescents with multiple disability are defined in the regulations by D 312-83 (CASF) as follows: "children or adolescents presenting a serious disability with multiple manifestations associating severe or profound motor and mental impairment and leading to severe restrictions on autonomy, perception, expression and relationships. Eventually, multiple disability aggravates other deficiencies or problems and require specialist medical monitoring techniques, learning ways to relate to people and communicate, development of the ability to wake sensorimotor and intellectual capacities, all aiming at exercising maximum autonomy**.**

The idea of serious multiple disability for French Hospitals

Multiple disability is defined by the association of French Hospitals according to four criteria (Source: PMSI[8]):

- Profound mental deficiency or severe dementia
- Motor disorder on the order of partial or total paralysis, partial or total ataxia, severe tremors, dyskinesia or dystonia;
- Reduced mobility as a result of a motor problem;
- Extremely restricted autonomy characterised by permanent dependence on a third party or apparatus.

Similar but distinct ideas

In France, multiple disability is distinguished by several relatively similar ideas:

Rare disabilities

Rare disability is the combination of 3 types of rarity:

- Rarity in the population: a prevalence of less than 1 case for 10000 people;
- Rarity of the combination of deficiencies;
- Rarity and complexity of the technical nature of handling the disease.

(source: http://www.gnchr.fr/)

In French legislation (source: http://centreressourceslaplane.org/) - Decree of 02/08/2000 published in the Official Journal nr. 186 12/08/2000, *Rare Disabilities* are defined as follows:

Article 1

Corresponds to a "rare configuration of deficiencies or associated problems, frequently including an intellectual deficiency and of which the rate of prevalence cannot be superior to one case for ten thousand inhabitants. Its treatment requires the establishment of specific protocols, which are not simply a question of adding up the techniques and measures employed or treatment of each of the deficiencies considered."

Article 2

Are afflicted with Rare Disability, as mentioned in the 1st article, and present deficiencies from the following categories:

- The combination of a serious auditory deficiency and a visual deficiency;
- The combination of a serious visual deficiency and one or more other deficiencies;
- Serious dysphasia, whether or not combined with another deficiency;
- The combination of one or more deficiencies and a serious chronic or developing deficiency, such as;
    - A mitochondrial ailment,
    - A metabolic ailment,
    - A developing ailment of the nervous system,
    - Severe epilepsy.

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[8] **Medicalization programme for information systems (PMSI)** ,a quantified and standardised information system in French hospitals, designed to measure an establishment's activity and resources

Plurihandicap/Multihandicap

The French "*Multihandicap*", sometimes called "*plurihandicap*", can be defined/is defined by the combination of several deficiencies having approximately the same level of gravity. This makes it difficult to identify a principal deficiency and poses particular treatment problems, because the remaining abilities do not always make it possible to use the normal compensatory measures. For example: a sighted person can use sign language with a deaf one, but not with one who is deaf-blind. (Source: http://www.crmh.fr)

Cerebral Palsy is an internationally used terms whose limits and definitions are subject to numerous variations according to the school of thought, ideas, and evolving understanding about its development.

According to the most recent collective international definition, (Rosenbaum and coll., 2007), "Cerebral Palsy (CP) is a term that designates a group of permanent problems in the development of movement and posture, responsible for limiting activity and is attributable to events or non-progressive damage to the developing brain of the foetus or infant. In Cerebral Palsy, motor problems are often combined with sensory, perceptive, cognitive communication and comportment problems, epilepsy and secondary musculo-skeletal problems."

The term *infirmité motrice cérébrale (*IMC), cerebral motor problems, is used more widely in France and is sometimes used in place of Cerebral Palsy. However, for Guy Tardieu, IMC brings together mainly non-progressive motor problems resulting from a cerebral lesion, as a "consequence of an early pre, peri, or postnatal lesion", that can be accompanied by sensory problems and partial problems of superior function, with the exception of intellectual deficiency." (Tardieu 1969).

The term cerebral palsy is therefore more general because it also groups forms with intellectual problems where one speaks together with the most severe cases, of multiple disability. In France, the term motor disability of cerebral origin, infirmité motrice d'origine cérébrale (IMOC), is also widely accepted. (Source: http://www.frc.asso.fr/)

More information about the definition of this target group can be found in Appendix 2.

Prevalence and incidence rates of children with PIMD in France

In France, prevalence of multiple disability remains stable at 1.2/1000, undoubtedly because of the mainly antenatal nature of the causal lesion. According to the GPF the prevalence of multiple disability in France is not negligible, with about 1000 new cases each year (prevalence 1.1/1000), including all aetiologies (acquired pre and perinatal multiple disability linked to progressive illnesses)

There are an estimated 19,600 children with multiple disability (from 0-20 years) in France, of which 10% occurred postnatally and 10% as a result of hereditary-degenerative or neural-metabolic diseases.

Year	Population at 1 January	Number of live births in the year	1.2/1000	
			Prevalence rate (in relation to general population)	Incidence rate (in relation to birth)
2001	60 941 000	803 234	73 129	964
2002	61 385 000	792 745	73 662	951
2003	61 824 000	793 044	73 189	952
2004	62 251 000	799 361	74 701	959
2005	63 731 000	806 822	75 277	968
2006	63 186 000	829 352	75 823	995

2007	63 601 000	818 705	76 321	982
2008	63 962 000	828 404	76 654	994
2009	64 323 000	824 621	71 188	990
Estimated number of children born with multiple disability in 9 years:				8 756

Source: INSE

Children with multiple disability in French care homes (2010)

Distribution of places end 2010 (extract)

Type of housing	IME	Establishment for children with polyhandicaps/multiple disability
Boarding facility (complete, by week, individual units)	31.1 %	46 %
Temporary care	0.3 %	2 %
External/day care (without accommodation)	67,4 %	50.6 %
Family	0.8 %	0.5 %
Other types of housing	0.4 %	0.9 %
TOTAL	**100 %**	**100 %**
Number of places	69 592	5 637

[1] *Source : DRESS, Etudes et Résultats n°832, Février 2013, l'accueil des enfants handicapés dans les établissements et services médico-sociaux en 2010*

How children with PIMD are assessed in France

Each profession uses specific tools, but they are not usually adapted to the specifics of multiple disability, for example: Orthophony (Assessment of cognitive and learning function in the child)); Physical development/therapy (Early childhood Developmental Motor Scale– Brunet-Lezine) or WPPSI; (The Wechsler Preschool and Primary Scale of Intelligence), Occupational therapy (Clinical occupational therapy assessment) (CESAP) ou MACS (Manuel Ability Classification Système) etc.

CESAP, with the Handas organisation, (today APF) has developed the P2CJP for psychologists:

P2CJP (Cognitive Skills Profile in young people with multiple disability)

People with multiple disability present sensory, motor and intellectual problems which make it very difficult to assess their cognitive abilities. It is essential that psychologists have tools at their disposal that can help identify their abilities and evaluate them, to help design a programme to support, educate and take care of them in collaboration with a multi-disciplinary team. This tool can also be used to support collaboration with families.

Almost 150 children and young adults took part in this research, all in institutions managed by Handas or CESAP. All participants were evaluated under the supervision of a psychologist from the institution, often in collaboration with the team. Sometimes parents were contacted directly. The large number of participants clearly shows that this study responds to a need.

The tool designed as a result of this study is called the P2CJP (Profile of Cognitive Abilities of a Young Person with Multiple disability). It is composed of two complementary parts, a Reactivity Grid (GR) and a Cognitive Skills Profile (PCC), which are to be used in tandem. The P2CJP is designed to be part of the complete medico-psychological assessment, a source of important information, but not as a diagnostic tool.

The Reactivity Grid (GR) aims to identify what forms of communication the child or young adult uses or exhibits, with the objective of defining them as accurately as possible. By observing the person with multiple disability, the aim is to assess their communication skills so as to develop and find the best way to use them in care and support. This grid has also proved popular with various health professionals, who found it helpful with reaction indicators allowing better evaluation and therefore monitoring the children and young adults.

The Cognitive Skills Profile (PCC) is composed of 69 questions concerning a wide range of abilities (memory, attention, verbal and communication, sensory, spatial, learning, socio-emotional, and reasoning). Responses to the questions make it possible to establish a profile of the child or young adult and so evaluate their level in the measured areas. This tool can also be used as part of monitoring of the child or young adult, to put figures on their development landmarks, but also to determine what skills the professionals can rely on to improve the aid provided.

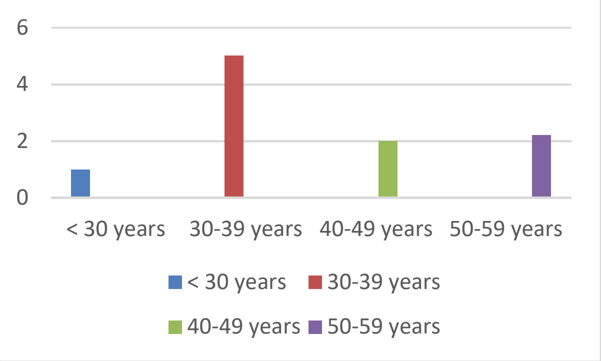
The P2CJP has been validated using classic psychometric methods. Its aim is to help the psychologist not only to achieve a better understanding of the patient's skills, but also the nature and manifestation of the problems presented by the children and young adults being monitored. Having been validated, it can therefore be used in the context of cognitive evaluation for this population.

This tool is distributed by CESAP to psychologists on request and presentation of their registration number.

Results of needs analysis questionnaires in France

In France, CESAP sent the questionnaires (appendix 1) to parents and professionals in July 2014. 23 usable files were returned: 13 completed by parents, 10 by professionals.

The **parents** who returned the 13 files are aged between 30 and 60 years, with half aged between 30 and 40 years. Their professions are diverse: 2 nurses, 1 childcare assistant, 1 teacher, 1 chef, 1 manager, 1 retired person, 1 without profession, and 2 family caregivers. It should be noted that in France there is currently a great deal of thought about the status of "family caregivers" which parents now declare as a profession



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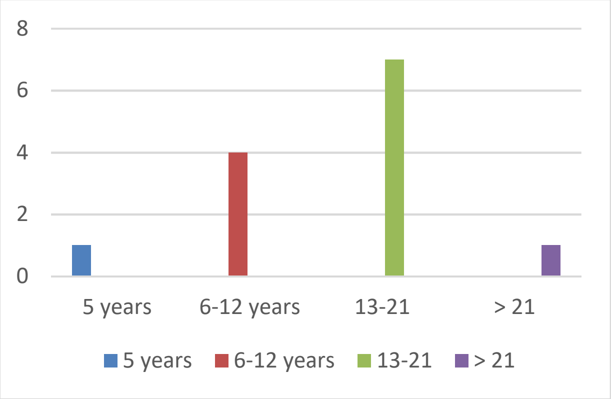
Their **children** are between 5 and 33 years old, with 5 children (5-12 years); 7 adolescents (13-21 years), and 1 adult. The majority of the children live with their families, with outside day care for children with multiple disabilities; the adult lives in residence specialized in adults with multiple disabilities



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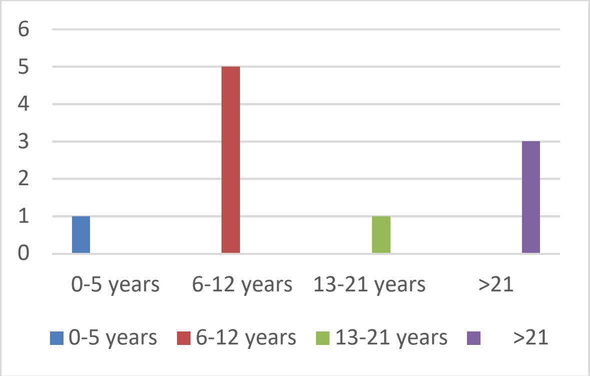
The **professionals** who returned the 10 files are between 30-50 years old, with half of them between 40-50 years old (see: graph of age of professionals).

Their professions: 3 doctors, 1 social worker, 1 educator, 1 paramedic, 3 institution/department heads, and 1 psychologist.



These children/adolescents,

- attend different types of establishments for children and adolescents with disabilities (care and accommodation; day care centres) in different ways: full time, part time (several hours a day), several days a week, temporary respite care, adjustment…
- are with their families with the assistance of home care services,
- some go to ordinary schools, often part time, at pre-school age.

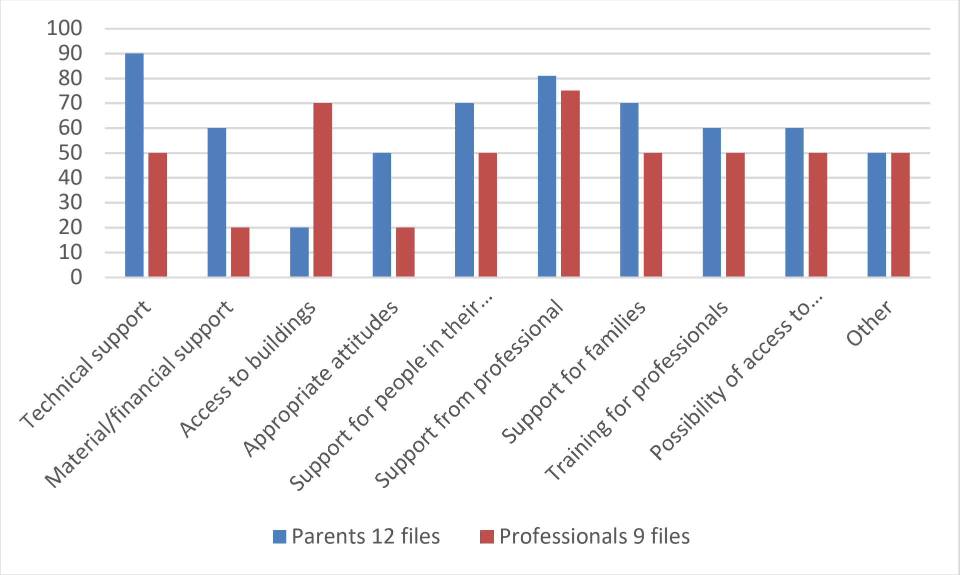
In the parent files, the children/adolescents all had significant motor and cognitive limitations, with serious dependency for daily life. Only one could walk unaided for a short distance, 2 others moved along the ground, the others could not move from place to place autonomously; none used oral language; 5 among them used other methods of non-verbal communication; 60% had major health problems, including epilepsy; they did not have access to ordinary school learning processes (reading, writing, mathematics…) and require adapted teaching.

The children/adolescents under professional care all had **motor** (assisted mobility in wheelchairs and other equipment encouraging movement) and major **cognitive limitations,** some also had **sensory** deficiencies and psychological problems with **behavioural problems**; they are very dependent for daily life, except 15 of them who had no motor problems and 8 who are more autonomous. They all have **communication problems**, with almost non-existent or seriously impaired oral language, which is more or less compensated for by other modes of non-verbal communication. They all have major **learning problems** requiring adapted teaching and many have sometimes severe health problems: more or less stabilised epilepsy, digestive, respiratory, nutritional, orthopaedic problems, etc.

Half of the **professionals** saw the main **barriers** primarily as lack of access to buildings and ordinary education and secondly as the lack of access to leisure activities. A third of them saw the lack of material and financial support, appropriate attitudes, professional training as the main barriers, and finally (22%) saw the lack of support – technical, in daily life, for professionals, and for families.

For the most of the **parents (75%), the perceived barriers** are the lack of financial support, with 50% expressing the lack of daily support in daily life, technical support, and access to buildings; for 40% the lack of training for professionals, appropriate attitudes, for 30% the lack of access to ordinary education and support for families; finally, for 25% it was the lack of access to leisure activities, professional support, with one parent pointed out the lack of a system for respite care for families.

For the **needs assessment**, the professionals used several referenced tools, but since few of these were suitable for the problems of these children/adolescents, they instead adapted them or created new ones.



Results of assessment tools evaluation

The referenced tools used are**:**

- WISC IV
- the Brunet Lezine /PEPR (psycho-educational profile)
- the P2CJP (profile of cognitive skills in children with multiple disabilities)
- SAN SALVADOUR pain assessment grid
- the GEVA grid (reference guide for official assessment of needs) and GEVA SCOL (derived from GEVA to assess educational and teaching needs)
- the B. EGRON grid (assessment of individual educational needs)/ targeted transmissions for health needs.

Adapted or created tools

Most often, needs assessment is undertaken by **shared observation.**

- Different categories of professionals share their own training reference documents in a single more or less formal reference document.
- Communication assessment results are established with the families with the help of tools created by the professionals.

Satisfaction with these tools varied:

- People currently appreciate the P2CJP tool as one of the rare validated tools for cognitive assessment in children with multiple disabilities.
- An educational record is created by a specialist teacher by revising ordinary national school records. The fact that it was created from a 'standard' but took into account the specifics of the children/adolescent was regarded as a strong point; the weakness was the fact that it was not suitable for all children.

All **parents assessed the needs** of their child by **direct observation; 60**% from the child's expression, which was not always judged easy to decode; and finally, 45% with professional assistance.

5 of them used tools

- To monitor bodily constants;
- But above all, tools related to communication (LSF and pictograms); parents regarded the strong point of using these tools as that they allowed their children to express themselves and interact; the weakness being that they worked better for dual relationships and were more difficult for generalizations.
  Pictograms were not always useful for the child's problems of concentration and adaption, and their visual problems; the child was not always able to use them.
  The LSF is complex if there are motor problems.

Conclusions: What needs regarding children with CISN are still unsatisfied in France?

General needs / Society

- To help society in general to remove preconceptions about people with multiple disability
- To provide the means for recognizing sensitive/emotional intelligence in infants and adults with multiple disability
- To encourage recognition of the expression of sexuality in people with multiple disability and that of adolescents
- To encourage a cultural life and creative skills in people with multiple disability

What do French medico-social institutions need?

- To (re) capture a sense of time and attention, and of the *value of daily life*
    - Cf. for example, work on daily basal stimulation, which aids learning. The problem is a lack of trainers in this field in France, which means that not enough professionals can be trained.
- To try to reduce the number of daily changes in relationships (build continuity into the management of French medico-social structures).
- To curb the proliferation of administrative procedures, which can lead to malfunction.
- To continue to develop the idea of high quality care and to fight against bad treatment

Schooling/educational needs

- Continue to develop educational opportunities in ordinary school (inclusiveness) or in teaching units (school teachers in the institutions)
- Recognise the ability of "life-long learning"

Professional needs

- Provide the means to evaluate education approaches offered by institutions,
- Help develop teaching, observation, and communication tools to improve evaluation.
- Improve suitable, specific approaches to psycho-behavioural problems.

The needs of the families (support)

- Encourage early support after families have been informed of a disability. Reduce the impact of this announcement by providing the first steps in managing the situation. For this, the person informing the parents should have an "ecological" knowledge of the sector
- Simplify and increase the visibility of administrative references (knowing rights and duties)
- Develop support for daily life at home
- Develop knowledge transfers about care and education
- Recognize the abilities and support needs of parents and siblings, so they can be taken into account

- Help strengthen the real/symbolic link between parents and families with a child with multiple disability

Professional needs (training/demography)

- Take account of the needs of young professionals in the early stages of general training, who need continued training at the beginning of their professional lives, to refine their skills with people with multiple disability.
- Take into account professional demography: the demographic deficit is increasing, mainly in the medical and paramedical professions. The GPF's last Skills study underlined the inequalities in the framework provided by different establishments and the differences between their recruitment needs. While medico-psychological assistants are still the best-represented skills, **the analysis of unfilled posts showed major recruitment needs in physiotherapists, speech therapists and psychiatrists**. The study also showed that outsourcing is increasingly being used by facilities. This mainly concerns the recruitment of speech therapists and physiotherapists but also physicians and covers several forms: temporary, holiday or payment on a per-service basis. They also have a massive dependence on interns or, in smaller proportions, subsidised contracts and volunteers.

The needs of children in unsuitable situations, or for whom there is no solution for care

In France, everyone receives a minimum allocation in the form of benefits. But some children (and adults) are still in unsuitable situations for lack of a place in special facilities or without family support structures, and some remain with their families without any assistance with their environment and without sufficient care.

Two types of population should be underlined here: children presenting serious behavioural problems and/or presenting serious health changes.

Care needs

- Reconsider the question of care (authority/safety/protocols and the care received by people with multiple disability
- Encourage access to ordinary care

In regard to other countries (ENABLIN+ project)

- Exchange support methods with other countries
- Understand the assessment methods, objectives and results of the different support methods.
- Compare and exchange information about the appeal and methods used by different support methods, choice of institution/department etc.

The situation of children with multiple disabilities in Romania

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For the past ten years, the percent of people with SEN in Romania increased with 40%. In 2012 in Romania out of the people with SEN 8.8% were children and 91.2% were adults. Associated disabled children represented 21%. (ONPHR, 2013)

Legislation and finances: Law No. 448/2006, Curriculum 2008.

Activities: teaching abilities for independent living, for social and professional integration, activities acceptance in community, for education, for mental health, for the development of basic co1mpetences, personalized educational/intervention plan

Forms for care giving: residential placement, day-care, special school, integration, protected workplace, centre for daily activities

Needs Assessment Questionnaire Results Romania

I .PROFESSIONALS

Who are the respondents?

Our staff-members tried to reach professionals from whole Transylvania, involved in supporting children with complex and intense support needs. 300 respondents completed the questionnaire. The age group was 23-63. 48,78% were aged between 20-29 years old, 29,27% between 30-39 years, 14,63% were between 40-49, 4,88% were between 50-59 and 2,44 were over 60 years old.

The respondents’ professions were diverse:

- 56,1% were special education professionals
- 2,44% social workers
- 14,63% psychologists
- 2,44% physiotherapists
- 7,32% kindergarten/school teachers
- 2,44% speech therapists
- 12,20% mid school teachers

These specialists are involved in the care system for: a) 62 children aging between 0-5 years; 161 children aging between 6-12 years and 100 children aging between 13-21 years.

The most frequent impairments in the presented age groups were:

- Cognitive impairment	41,9%

- Motor function impairment	15.79%
- Sensorial (visual. hearing) impairment	4.02%
- Health problems	1.24%
- Severe language and communication problems	21.67%
- Severe learning disabilities	16.72%
- Severe motor problems	5.26%
- Severe self-care and self-support problems	6.81%
- Severe behaviour disorders	11.76
- Participation disorders	12.07%

Where are the children?

The respondents reported that during the day the children with complex and intense support needs are in

a) Special day-care centres/centres for rehabilitation (39.2%),
b) included within the mainstream school system (24.39 %), and
c) in special schools (31.71 %),
d) kindergarten 2.44%,
e) university 2.44%.
During the night children are at home with their family (89%) and at an internat (10%).

Environmental barriers and what are they a result of?

- **Money and financial support** is the most highlighted problem, in 48,78% of the cases is a very important issue, in 48,78% of the cases is a secondary problem, only in one case money doesn't represent a problem.
- **Technical supports** are missing in 39,2% of the cases, in the rest of cases the existing technical supports are minimal, insufficient.
- **Access to buildings** still represents a major problem for 36,59% of the cases. The problem has been solved in the special institutions and schools, but still an issue in public transportation and other buildings.
- **Professionals' support** is missing in 31,71% of the cases, the rest reported as being inaccessible because of the lack of financial support or distance/access to the professional help.
- **Families' support** is missing in 31,71% of the cases, in rest is insufficient or inadequate.
- **Proper attitudes** represents a problem for 29,27% of the cases, but increased very much in the last decade.
- **Leisure activities** are totally lacking for 24,39% of the cases, for rest of the surveyed population is insufficient or inadequate.
- **People support within daily life** is increased very much, only 21,95% reported as being an issue.
- **Access to mainstream schools** is very satisfactory, only 19,51% of the surveyed population considered it as being a problem, but not missing.

Assessment and evaluation tools

The following tools are used by the professionals:

- Structured observation
- Denver Developmental Screening Test (DDST)
- Tests which include painting
- Speech and language tests
- Cognitive profile test (KPT)
- Sindelar Program
- Bender Gestalt A and B version

- Frostig Test (DTVP)
- Portage Test
- Child psycho-drama
- Correction tests and tasks

II. PARENTS

Who are the respondents?

The Babeş-Bolyai University conducted the survey with parents of children with complex and intense support needs, and parents of children with disabilities more generally from Transylvania region in Romania. 90 respondents completed the questionnaires.

The age group of the responding parents was between 27 and 54 years, as following:

- 4,44% between 25-30 years
- 51,11% between 30-39 years
- 35,55% between 40-49 years
- 6,66% between 50-59 years.

Referring to the education level of the responding parent:

- 4,44% were primary school graduates (general school (8 classes)
- 73,33% were secondary school graduates (high school)
- 22,22% were high school graduates (colleges or universities).

Who are the children having complex and intense support needs?

1. Relating to the children’s situation:

- 6,67% are between 0-5 years
- 62,2% are between 6-12 years
- 31,11% are between 13-21 years old.

All the parents (100% reported) multiple disabilities, 75 % reported over 5 types of disabilities.

The most frequent appearing disabilities are cognitive developmental problems 53,33%, limitations in language and communication 51,11%, learning disabilities 42,22%, motor function impairments 37,78%, self-autonomy problems 31,11%,, behaviour difficulties 31,11%, different types of health problems 31,11%, sensorial impairments 28,89%, severe motor problems 24,44% and participation problems in 22,22%.

Referring to the health problems, the parents reported several types of diagnoses: epilepsy, Down syndrome, autism spectrum disorder, asthma, severe myopia, mild mental retardation, Tourette syndrome, squinting, ADHD, hydrocephalus, three cases of liver problems, rachitis

Behaviour problems were linked to obsessive-compulsive disorder; in one case, it was reported difficulty in stealing food and concentration difficulties, cases of aggressiveness.

In motor impairment in one case extrapyramidal syndrome was reported, one is related to severe neurological deficiency, in one case spastic legs were reported, in one case ataxia was reported connected with tardiness and two cases of imbalance problems, one case of hemiparesis.

Environmental barriers and what are they a result of?

- **Money and financial support** is considered the most important issue, 62,22% of parents considered as major barrier, 37,78% considered is a problem, but nut of utmost importance.
- **The inclusive leisure activities** are considered very important, 48,89% of the parents considered it important, even more important than money and material support.
- **Professionals' support** and **families' support** is needed in 42,22% of the cases.
- **Proper attitude** is considered as lacking in 37,78%, **peoples support** within everyday life in 33,33% of the cases.
- **Technical support** seems to be a smallest problem, only 26,57% of the parents reported as needed**.** **Access to buildings** in even less solicited, only in 20% parents reported problems to access the buildings. **Schooling** is ensured in 88,88% of the cases, only 11,11% of the parents reported that they problem with the access to schools. **Personal care** is needed only in 8,89% of the cases.

Where are these children learning?

According to the respondents, during the day, their children are:
a) 4,44% are in mainstream school, inclusive/integrated classes;
b) 24,44%in a day-care centre/centre for rehabilitation;
c) 42,22% are attending special schools;
d) 6,67% are home schooled.
Three children are learning in 2 locations (in mainstream school and day-care centre).

One child is attending mainstream school, day-care centre, special school or is home schooled, depending on his momentary health condition.

One child is attending mainstream school, foundation day-care and special institution for complementary

Where are these children living?

Parents reported that the children are living during the weeks (nights) as following:

a) 86,67% are living at home ;
b) 6,67% is sleeping in boarding schools;
c) 2,22% are living in special institutions;
d) 8,89% are in day-care centres.

One child is living in all four locations, depending on his momentary health condition.

What kind of support are provided to the children now?

The types of support that are provided to the children in this moment are:

- Material support of the State (Child protection services and County Council), according to level of deficiency: 42,22%
- Special supports (free meal, free transportation, school materials, specialists, therapies): 40,0%
- No support: 17,78%

Evaluation/identification of children's needs

Parents report that they identify the needs of their children:

a) 6,67% through direct observation and professional help;
b) 17,78% through direct observation only;
c) 13,33% through direct observation and indicated by their child;
d) 22,22% throughout direct observation, professional help and indicated by the child;
e) 26,67% only by the child's indication;
f) 6,67% throughout direct observation and professional help;
g) 6,67% with professional help only.

Did the parent's use instruments for evaluation? What type of instruments? Level of satisfaction with the instrument

According to the parent's declaration, only in 26,67% of the children were used instrument of evaluation, in all cases there were instruments provided or used by specialists. The satisfaction rate regarding the used instruments is thus presented: no parents were very satisfied, 66,68% of the parent were satisfied, 25,00% less satisfied and 8,33% were unsatisfied with the applied instruments.

In 73,33% of cases no evaluation instruments were used.

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Legea nr 448/2006 privind protecţia şi promovarea drepturilor persoanelor cu handicap publicat în Monitorul Oficial, I/1006 din 18 decembrie 2006 (Law No.448/2006 regarding the protection and promotion of the rights of handicapped persons, issued in the Official Monitor of Romania, No.I/1006, December 18, 2006).

Needs Assessment Questionnaire Results Bulgaria

Apostol Apostolov & Agneta Morfova, Karin Dom Centre, Varna

I. PROFESSIONALS

Who are the respondents?

Karin Dom conducted an on-line survey with professionals, involved in supporting children with complex and intense support needs. 75 respondents completed the questionnaire. The age group was 28-58. The respondents' professions were diverse. The three most represented professions were psychologist, speech therapist, and special needs educator.

Where are the children?

The respondents reported that during the day the children with complex and intense support needs are in a) day-care centres/centres for rehabilitation (65%), b) included within the mainstream school system (53 %), and c) in special schools (50 %). During the night, children are at home with their family (89%) and at residential facility (10%).

Environmental barriers and what are they a result of?

Technical supports are seen as a considerable barrier – very much (38%), more often than not (31%). **Money and financial support** are seen as another substantial barrier – very much (49 %), completely (25%), more often than not (15%). **Access to buildings** is another significant barrier – very much (32%), more often than not (28%). **Proper attitudes** are also a barrier – very much (46 %), completely (29%). **People support within daily life** - very much (39%), more often than not (26%), completely (21%). **Professionals' support** – more often than not (36%), very much (35%). **Families' support** - more often than not (31%), sometimes (25%). **Professionals' training** – more often than not (32%), very much (28%). **Access to mainstream schools** - very much (28%), more often than not (24 %).

Assessment and evaluation tools

The following tools are used by the professionals:

- 37,5 % use AEPS™ - system for evaluation and assessment of child development and preparation of individual plan/programme
  15,6 % use the Bulgarian tool Manova-Tomova: a tool for assessing intellectual abilities.
- 15,6 % use Raven's Progressive Matrices: a tool for assessing intellectual abilities
- 15,6 % use structured observation
- 12,5% use the Wechsler IQ test
- 12,5 % use the The Denver Developmental Screening Test (DDST)
- 9,4 % use the Stanford–Binet Intelligence Scales
- 9,4 % use Projective tests
- 6,3 % use tests which include painting
  6,3 % use interviews with parents
- 6,3 % use speech and language tests

- 6,3 % use basic norms for child development
- 6,3 % use ASQ (Ages and Stages Questionnaire)

II. PARENTS

Who are the respondents?

Karin Dom conducted an on-line survey with parents of children with complex and intense support needs, and parents of children with disabilities more generally. 27 respondents completed the questionnaire. The age group was 28-54. 20 respondents were of higher education, 7 respondents were of secondary education.

Who are the children having complex and intense support needs?

The parents were asked to answer in relation to their family situation. The age group of the children is 0-5 (63%), 6-12 (35%), 13-21 (4%). There was a question also in relation to the situation of the children. Most parents report that their children have limitations in language and communication (69%). The other substantial group is the group of children with difficulties in personal autonomy (50%). Learning difficulties – 46 %. Limitations in motor functions – 35%. Severe participation problems – 35 %. Limitations in the cognitive area – 23 %. Severe mobility problems – 15 %. Limitations in the sensory field – 12 %.

Where are the children?

According to the respondents, during the day, their children are: a) included within mainstream school (35%); b) in a day-care centre/centre for rehabilitation (27%); in special schools (23%). During the night, parents report that their children are at home (100%).

Environmental barriers and what are they a result of?

Technical supports are not seen by parents as a considerable barrier – not at all (31%), very much (23%), more often than not (15%). **Money and financial support** are seen as a major barrier – completely (27%), very much (23 %), more often than not (23%). **Access to buildings** is also not seen as a significant barrier – not at all (38 %) very much (23%), completely (12%). **Proper attitudes** are a substantial barrier – very much (42 %), completely (23%). **People support within daily life** - very much (31%), more often than not (15%), completely (15%). **Professionals' support** – more often than not (23%), very much (19%). This category is not seen as a barrier by 19%. **Families' support** is nor reported to be a significant barrier – not at all (31 %), sometimes (19%), sometimes (25%), completely (15 %), very much (15%). **Professionals' training** – very much (27%), sometimes (27%), completely (15). **Access to mainstream schools** – very much (31%), completely (15 %). In this category, 23 % of the respondents do not see access to mainstream schools as a barrier.

Evaluation/identification of children's needs

Parents report that they identify the needs of their children: a) through observation/direct contact (81%); b) by the help of professionals (58%); c) as indicated by their child. Only 5 parents report that they use any assessment tools. One of the parents notes that "mother's observation over time is the best instrument".

Needs assessment – results of Italy

Marina Rodocanachi, Anna Dal Brun and Sabrina Vincenti, Fondazione Don Gnocchi, Milano

In Italy, the questionnaire was distributed to 54 professional and 11 families: **21 professionals** answered the first part and 19 also the second part; **9 parents** filled the first part and just 3 also the second part.

Professionals' age ranged between 24 and 62 years. There were 11 special educators, 2 medical doctors, 2 psychologists, 1 educational psychologist, 1 developmental physiotherapist and 2 speech therapists

P**rofessionals** answering to questionnaires were dealing overall with 344 children with complex needs: 87 aged 0 to 5 years; 171 aged 6 to 12 years and 86 aged 13 to 21 years.

Parents answering represented 9 children: 2 aged 0 to 5 years, 6 aged 6 to 12 years and 2 aged 13 to 21 years. Their age range was between 40 and 57 years. There were 4 mothers working at home, 3 employee, 1 professional and 1 health assistant. *(*Figure 4*)*

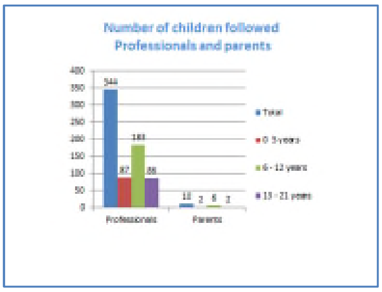


Figure 4 Children of professionals and parents answering at questionnaires (Results of questionnaires by Italian partner)

According to **parents and professionals,** children had **severe limitations** both in motor and cognitive areas with most of them having limitations also in sensorial area. Other areas of development interested where participation, language and communication, autonomy in daily skill and learning. *(Figure 5-8)*

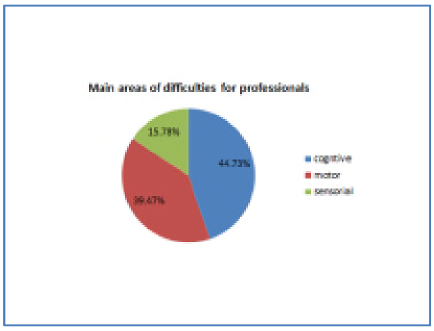


Figure 5 Main area presenting difficulties: professionals

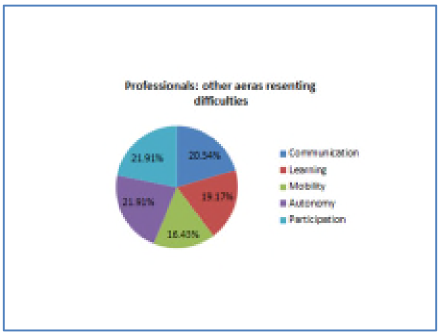
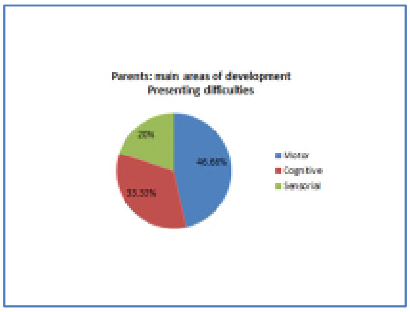


figure 6 Other area presenting difficulties: professionals



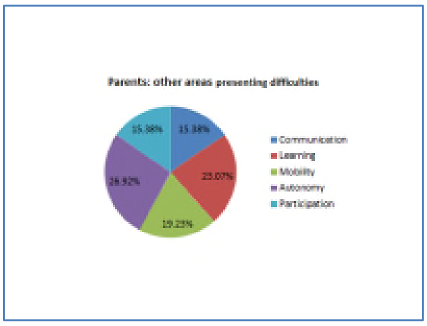


Figure 7Main area presenting difficulties: parents

figure 8 Other area presenting difficulties: parents

Most of the **children followed by professionals** and all except one from **parents** were in normal school, just a few of them (9 children) were both in normal and special school (integrated projects) and just one child from professionals was in family and one among parents answering was in Institution. (Figure 9)

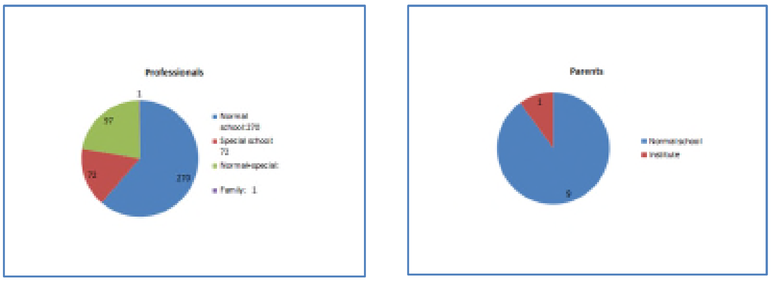


Figure 9 Where are the children according to parents and to professionals?

According to **professionals** the most frequent **barriers** are related to proper attitudes, followed by the lack of financial support, technical support, families' support and professionals' training: Access to building and access to mainstream school were not perceived as a barrier except than in 2 on 19 professional and access to leisure activities just in 3. **Parents** felt as **barriers** especially finance support, access to buildings, proper attitudes, professionals' training, access to leisure activities and family support. None of the responders indicated professionals' support as a barrier and just one parent-indicted access to mainstream schools and bureaucracy as a barrier. (Figure 10)

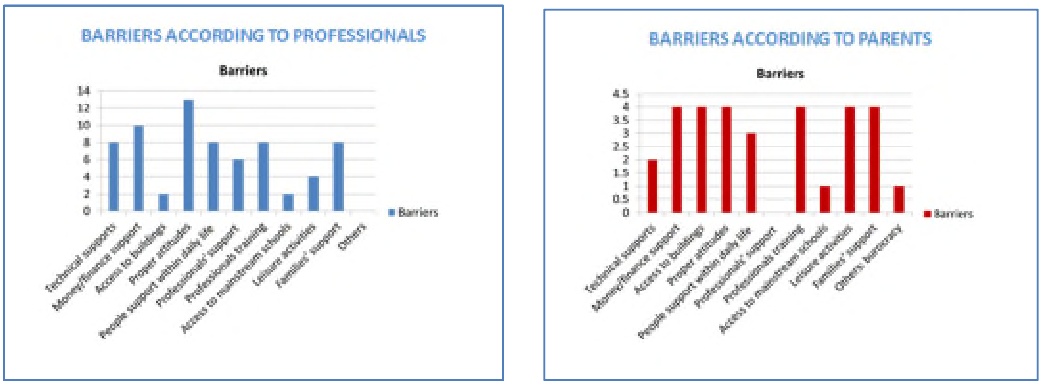


Figure 10 Barriers according to professionals and parents

Concerning **evaluation models, professionals** use either free or structured observation in different areas of development; other instruments indicated were:

- AAC instruments
- Family Centred care questionnaires
- Autism scales and questionnaires
- Team case discussions
- Home visits and talks with families
- Psychological systemic approach with families
- PEI, PDF (individualized educative plan; dynamic functional profile)
- Mediated learning experience approach

Evaluation **tools** indicated by **professionals** were:

- Evaluation Grids (professionals being very satisfied of them)
- Evaluation Scales for Autism, for autonomy, for evaluation of needs, for development, for cognitive non-verbal intelligence
- Italian cerebral palsy protocol of video registration for very severe neuropsychic disability (GIPCI)
- Observation cards for AAC, early communication, PCS symbols

- Self-made instruments for observation

Parents evaluated their child’s needs mostly through observation, professionals assistance and active intervention with the child and they used as tools AAC instruments and visual images. Parents declared to be very satisfied concerning postural system but less satisfied with the use of sensors.

Children with intense and complex support needs in Portugal

Marie-José Saragoça, Adelinda Candeias, University of Evora

Needs assessment questionnaires – results of Portugal

In Portugal, we had 15 participants responding this questionnaire: six parents and 9 professionals.

The parents were 4 females and 2 males, aged between 47 and 59 years. They have qualification between the 2nd Cycle and Secondary Level and they have diverse occupations (Administrative, medical assistant, home-working mothers, insurance employee, and military). One of the mothers is unemployed.

The professionals were 7 females and 2 males, whose ages ranged between 26 and 50 years, with the following qualifications: 5 B.A., 3 M.A., 1 Ph.D. At the moment these professionals are working as: Special Education Teacher (1), Psychologists (4), Physiotherapists (2), Occupational Therapist (1), and Teacher (1).

According with the parents, their children are young people with complex and intense needs, mostly with ages ranging from 19 to 21 years. Only one youngster is aged between 13 and 18 years. These youngsters spend most of their time in settings for people with disabilities. They also spend some time within their families or in the Occupational Activity Centre (Figure 11).

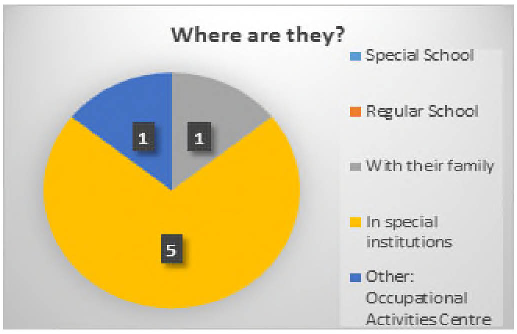


Figure 11 Children as reported by parents (Portugal)

The children and youngsters monitored by the professionals are mostly aged between 6 and 12 years and most of them are integrated in regular schools (Figure 12).

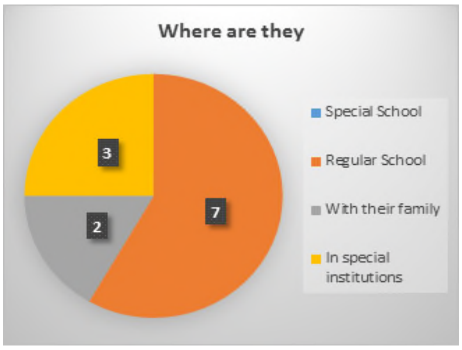


Figure 12 Children's placements as reported by professionals (Portugal)

According with the parents, the **areas presenting more difficulties** are the ones in the cognitive domain, followed by the motor domain and the ones of communication and language.

Regarding the cognitive domain, parents refer to particularly severe learning difficulties such as never having learned to read and/or write. As for the motor domain, parents report difficulties mainly at walking down stairs and walking properly, muscle atrophy, fine motor difficulties and walking difficulties (in racing). In the field of communication and language, parents report difficulties in making oneself understood, speaking difficulties or not speaking at all. In the sensory domain parents report difficulties associated with the condition itself: being blind and having Autism Spectrum Disorder. Other health problems mentioned by parents refer to heart diseases, celiac disease, thyroid and breathing problems and epilepsy (Figure 13).

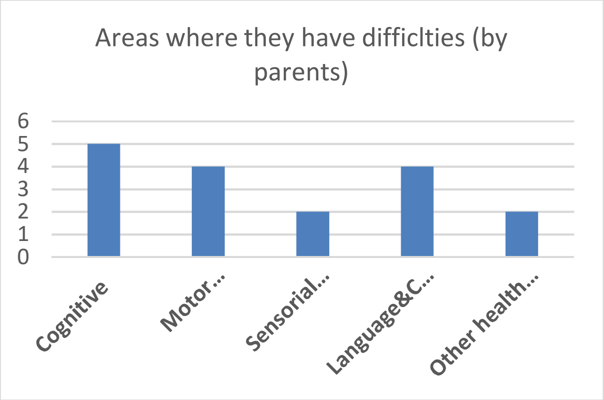


Figure 13 Areas of difficulties in children, as reported by parents (Portugal)

Parents also refer that the most **severe difficulties presented by these youngsters** are evidenced particularly in terms of Learning Disabilities, Personal Autonomy and Participation.

Concerning the Learning Difficulties, most parents stated that the children could neither read nor write. They know the letters and the numbers, but they cannot form or even read unfamiliar words. One parent also mentions that these difficulties compromise the behaviour. They also refer to attention and concentration difficulties. The difficulties in autonomy refer mainly to difficulties in moving alone, in feeding, dressing, making their personal hygiene or in going to the toilet by themselves. The difficulties in participation consisted primarily of group activities, difficulties related to attention /concentration deficit that affect the execution of tasks and deliberate refusal to participate in activities that are proposed to these youngsters (Figure 14).

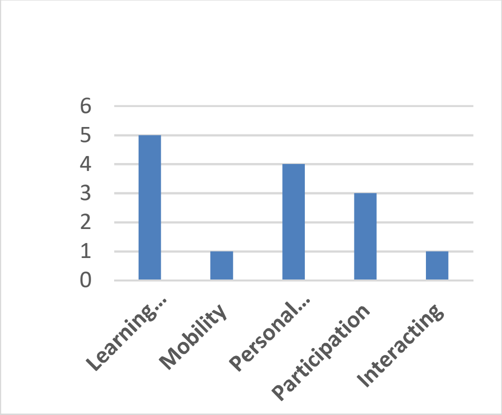


Figure 14 Severe Problems identified by parents (Portugal)

Children and youngsters monitored by the professionals have severe difficulties in mobility (particularly in terms of walking) and interaction (difficulties in interpersonal relationships) are less referred to.

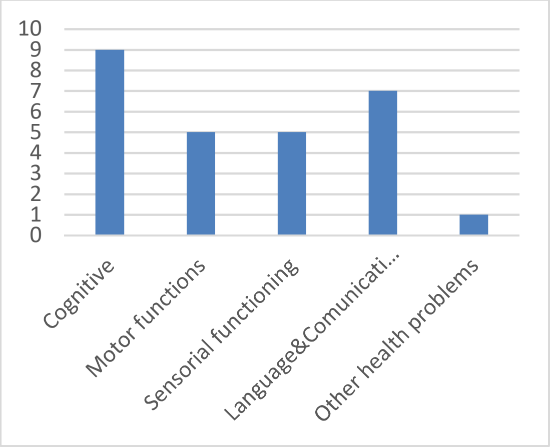


Figure 15 Areas where they have difficulties (by Professionals in Portugal)

The **difficulties presented by these children and youngsters** stand mainly in the cognitive domain and in communication and language, followed by the motor and sensorial domains (Figure 15).

At the cognitive level the following difficulties, related with cognitive deficit, are mentioned: Asperger Syndrome, Autism, Attention Deficit and Hyperactivity. At the level of Communication and Language the professionals essentially refer to problems related with dyslexia, dyspraxia, dysgraphia and Autism Spectrum Disorders. As for the motor domain difficulties related with Hypotonia, Steinert's Myotonic Dystrophy and Cerebral Palsy are mentioned. Problems of low vision and deafness are referred to in the sensorial domain.

The most **severe difficulties** are evidenced mainly at the level of Learning Difficulties and Interacting Difficulties, followed by severe difficulties of Participation and Personal Autonomy. Severe mobility difficulties are the least mentioned. Regarding severe learning difficulties, the professionals mention problems mainly related to Troubles of the Autism Spectrum, Cognitive Deficit, Hyperactivity, Attention Deficit, and Dyslexia. In this area, professionals do still refer to the fact that some children and youngsters do neither read nor write and have difficulties to understand what you mean to communicate. As for severe interacting difficulties, the professionals mention problems mainly related to difficulties inherent to the frame of the problems of the autism Spectre and to the global development delay, namely severe difficulties in language development, stereotypies, obsessive interests and lack of emotional and social competences. In what concerns severe participation difficulties, the professionals refer to severe difficulties in communication and social interacting, with implications in the participation in the classroom environment and lack of interest in school subjects (very often due to frustration resulting from misunderstanding subjects). Severe difficulties at the personal autonomy level are seen mainly in the sphincter control and in the need of support for basic hygiene and feeding care.

Concerning the barriers that parents feel more often, they highlight those related to money / financial support (referring to the fact that family incomes are insufficient to give the necessary care to their children, with reference to a situation of unemployment, and the support from the Portuguese government), family support (parents report the lack of support, monitoring and routing in the diagnostic and post diagnosis phase, also mentioning that there are no structures that assist families to have time for themselves) (Figure 16).

Next there are the barriers at the level of technical aids (also due to financial difficulties, it is not easy to find the specific type of the needed support to respond to real needs, neither at the public, nor at the institutional level), access to buildings (difficulties in accessing to public services, and they are concerned even with some security issues), personal assistance in day-to-day living (there are references to the need to tailor work schedules to the children' routines because it is especially the parents who provide this support) and support from experts (also conditioned by financial issues, still stressing that this support should be more diverse and intensive).

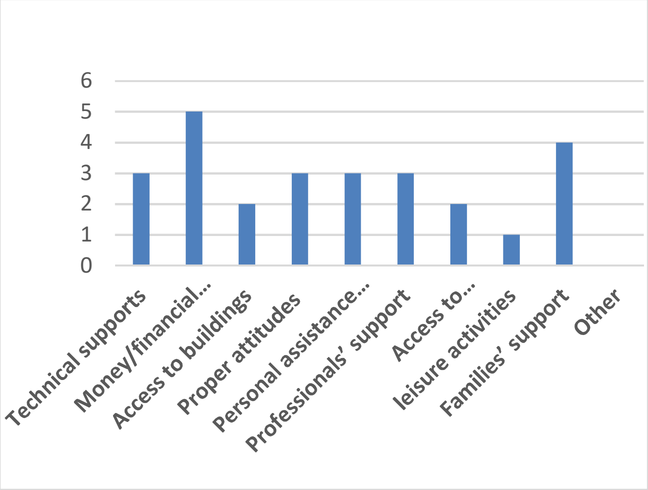


Figure 16 Environmental Barriers identified by parents in Portugal

The most frequent support **barriers for children and youngsters monitored by professionals** are the ones associated to the specialists' support. In this field, the professionals' view is that there is a lack of therapeutic support (psychology, physiotherapy, speech therapy, among others). Barriers concerning financial support, (above all at the level of therapies and transportation), leisure activities (at school) and family support (psychological monitoring should be free and technicians who can support families to deal with the children's disabilities are lacking) are also mentioned by a large number of professionals (Figure 17). There are still references to access difficulties, namely schools with steps, public services with no proper accessibilities, damaged pavements with no space for wheel chairs. As for the access to regular teaching, some professionals point out that the teaching strategies lack diversity and that the regular teachers are not sensitive enough to change materials and lesson plans in order to include students with SPN.

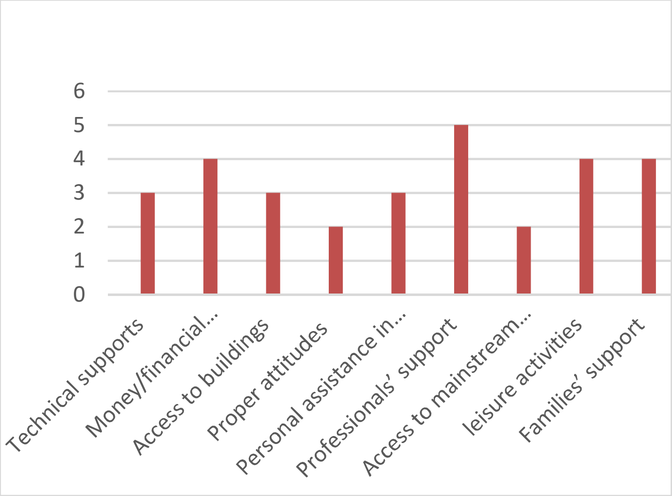


Figure 17 Environmental Barriers identified by professionals in Portugal

About Assessment **of Children and Youngsters' Needs**, all the **parents** who participated in the questionnaire identify their children's needs through their own direct observation. However, the majority also base the evaluation on the professionals. There are also two cases in which the young people themselves identify their own needs (Figure 18).

None of the parents use any instrument to assess their children's needs or records their progress.

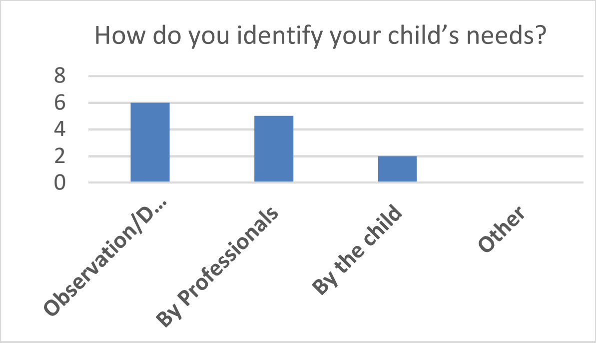


Figure 18 How parents in Portugal identify their children's needs

To assess the needs of people with intense and complex support needs, **professionals** use Formal and Informal Models, according with the student's individual educational program (IEP) and in reference to ICF-CY. They also do direct Spontaneous Observation and Direct Provoked Observation. The needs assessment is made according to the student's features and articulated with the special education teacher. Some of the tools used in this assessment are Physiotherapy Assessment Scales (Assessment of Neuromuscular systems, Muscle-skeletal and Cardio-breathing systems and life-quality assessment); Psychological assessment tools suitable to each child (Portugal Table).

Table 6 ***Assessment Tools used by professionals in Portugal***

Name - Designation	***Authors***	***References***	***Satisfaction***	***Strong Points***	***Weak Points***
ICF	WHO	WHO	Satisfied; Not very satisfied	Easy Language; Language uniformity	Not all technicians are qualified ; Not used by Health
WISC-III	Wechsler		Fairly Satisfied	Quality and quantity of provided information; evaluates several cognitive competences	Long in application
CARS Childhood Autism Rating Scale	Eric Schopler, Robert J. Reichier, and Barbara Rochen Renner		Satisfied	Quick application	Doesn't detail the information
Complex Figures of Rey			Roughly satisfied	Quick application	
Raven's Progressive Matrices	John Raven		Satisfied	Easy application	Little information feed-back
Projective Tests			Roughly satisfied	Quick application	
CAT Children's Apperception Test	Murray		Fairly Satisfied	Facility for the students to adhere to this tool	Application limitations to students with expression and communication difficulties
Toulouse-Piéron			Roughly satisfied	Quick application	
Palpa-P Psycholinguistic Assessments of Language Processing in Aphasia	Kay, Lesser, & Coltheart		Satisfied	It gives us a detailed profile of the difficulties	
Family Drawing Test	Lois Corman		Satisfied	Facility for the students to adhere to this tool	Objetivity
Occupational Therapy Evaluation Grid	He/she him/herself		Satisfied	Easy to fill in and easy to understand	It must be complemented whenever necessary with more specific tools
Physiotherapy Evaluation Grid	He/she him/herself		Fairly Satisfied	Wide applicability	Difficult to measure
Berg's balance scale	Berg		Roughly satisfied	Wide-ranging	Difficult application
Rivermead's motor evaluation scale	Rivermead		Roughly satisfied	Wide-ranging	Difficult application
Barthel's Index	Barthel		Satisfied	Easy application	
Mini Mental State	Folstein		Satisfied	Dynamic	
Ashworth's scale	Ashworth		Satisfied	Easy application	
Borg's Modified scale (Dyspnoea)	Borg		Satisfied	Easy application	

Pain Assessment scales	Direção Geral de Saúde		Satisfied	Easy application	
Sensitiveness Assessment scale			Satisfied	Easy application	
Worksheets	He/she him/herself				
Tests	He/she him/herself				
Powerpoints	He/she him/herself				
Boardmaker Boards	He/she him/herself				

Discussion

Students with multiple disabilities have a combination of marked limitations, which put at serious risk their development leading them to experience severe difficulties in the learning process and participation in the various contexts in which they live: education, family and community. These limitations and their level of functioning result from the interaction between their health conditions and the environmental factors.

According to Orelove, Sobsey and Silberman (2004) and Saramago and colleagues, (2004, p.213), children with multiple disabilities:

> *"... exhibit marked limitations in the cognitive domain, associated to limitations in the motor domain and/or sensory domain (seeing or hearing), and may also need specific health care. These limitations prevent the natural interaction with the environment, putting at serious risk the access to development and learning. "*

Students with multiple disabilities may exhibit very different characteristics, which are determined, essentially, by the combination and severity of the presented limitations, by the age in which they arise and by the lived experiences.

Therefore, they are students with unique and exceptional learning needs. They also need ongoing support in most daily activities, such as feeding, hygiene, mobility, dressing and undressing.

Although it is a heterogeneous population, it is common to manifest pronounced limitations in terms of some mental functions, and display great difficulties in communication and language (such as difficulties in comprehension and production of spoken messages , verbal interaction with partners, in conversation and in accessing information) and on motor functions, particularly in mobility. They may also have limitations in seeing or hearing functions, and often coexist serious physical health problems, including epilepsy and respiratory problems.

Concerning activity and participation, the greatest difficulties of these students lie at the level of:

- the processes of interaction with the environment (with people and objects);
- understanding of the surrounding world (difficulty in accessing information);
- the selection of relevant stimuli;
- understanding and interpretation of the received information;
- skills acquisition;
- concentration and attention;
- of thought;
- decisions taking about their life;
- problem solving.

The barriers to their participation and learning are very significant, that’s why they require:

- intensive support in daily activities and in learning;
- partners who accept them as active participants;
- identical experiences in different environments;
- common environments where significant opportunities exist to participate in multiple diversified experiments;
- opportunities to interact with people and significant objects (Saramago et al, 2004).

Consequently, these students need specific services support, in their natural settings, whenever it is possible, in order to respond to their specific needs. These supports must be embodied in their individual educational programmes (DGIDC, 2008).

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Part III New developments in assessment towards inclusion

Evaluation towards inclusion: does it make a difference? Evaluation of children with intensive & multiple needs in Italy

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The process towards inclusive education in Italy

Until 1971 many children with disability in Italy were out of the school system and just a minority of them attended special schools. Don Gnocchi Institute opened in these years one of the first special school in Milan and stated that any child with disability had the right to be educated.

Inclusive education begun in Italy between 1971 and 1977 thanks to some important design of law approved by the Italian parliament who stated the rights to have an inclusive education for children with disabilities.

- **1971, Law 118 approved from the Italian Parliament: *«Education in situation of handicap must be carried on in normal classes inside the public national school system»***
- **1975, Falcucci's Document outlines philosophy and principles of integration**
- **1977, Law 517: mainstreaming is generalized to the different school levels**

During the period 1977 -1992 special school begun to close and mainstreaming education became a reality among the public school system through the approval and regulation of the presence of an individualized support teacher for the disabled child set into a regular school and of the right of any person with disability to be included in mainstreaming education from kindergarten to University.

- **1982, Law 270: establishes and regulates the role of the support teacher for children with disabilities inside normal classes**
- **1992, Law 104 on the rights of persons with disabilities.**
- **1994, legislative decree**: **it establishes and regulates the competencies of health districts in term of functional evaluation and diagnosis for disabled children in relation to inclusion in normal classes**

The basic principles included in the legislative dispositions are that mainstreaming is a determinant factor for disabled children to go over marginalization and that learning and socialization in normal schools are complex processes with obstacles that have to be removed.

Mainstreaming and complex and multiple disabilities

Mainstreaming has been growing in public schools in Italy through years, but there are few data about the proportion of child with severe and multiple disability included among the whole population.

In the school year 2012-13 the rate of inclusion was 2.7% (222.217 students with disability on a general student population of 8.943.701, Statistics *from MIUR, Ministry of Instruction, University and Research, fig. 19)*

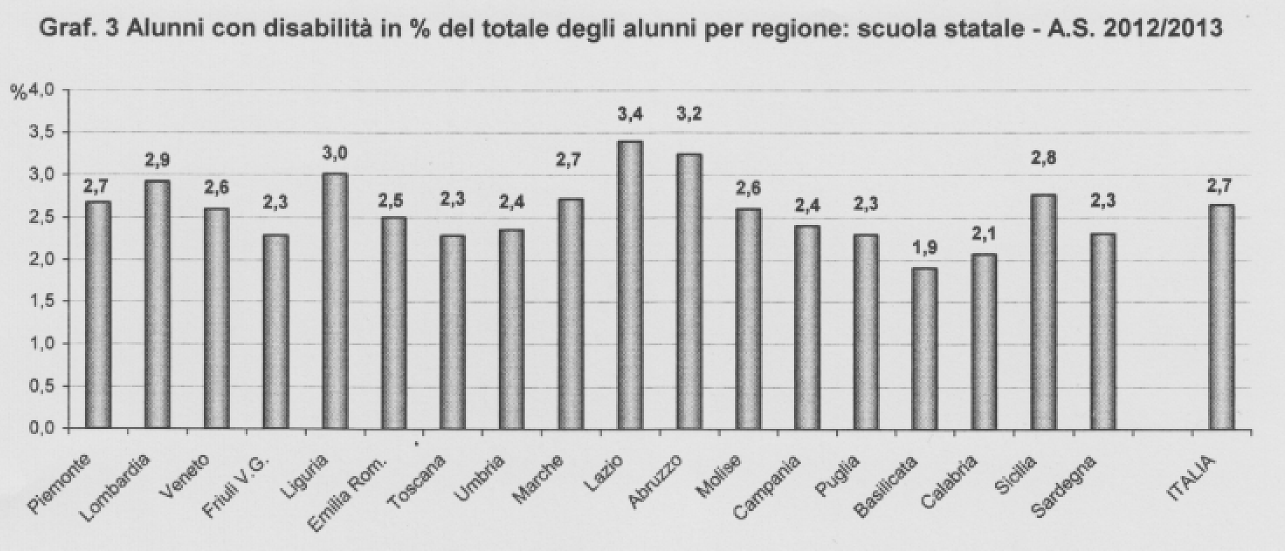

Figure 19 ***Students with disabilities in School year 2012-2013 in Italian Regions and in Italy***

The Ministry of education use functional labels to classify the different kinds of children with disability included in regular classes, without taking into account the severity (*School year 2011-2012 – statistics from MIUR according to main functional impairment: 66.7% mental retardation; 4.1% motor disability; 2.9% sensory, hearing; 1.7% sensory ,vision; 24.6 % other kind of disability with no other specification)*

The only recent Italian data found on severity of children included in regular school are from ISTAT (Italian statistical Institute) who classify severity according to the level of impairment in mobility, self -help in toilet and self- help in eating. Three levels of inability means severity (around 7% of children with disability included in normal schools are classified as having severe disabilities according to these three parameters in school year 2011-12).

According to the Italian system a support teacher is nominated for each child with disability included in normal classes, with a number of hours assigned according to the functional diagnosis elaborated by the medical team. Figure 2 describes the number of children with disability assigned to one support teacher from year 2003 to year 2013 (a mean of two children for one support teacher) and Figure 3 represents the number of hours of support teacher a week for child in primary and secondary school in North, Centre and South of Italy.

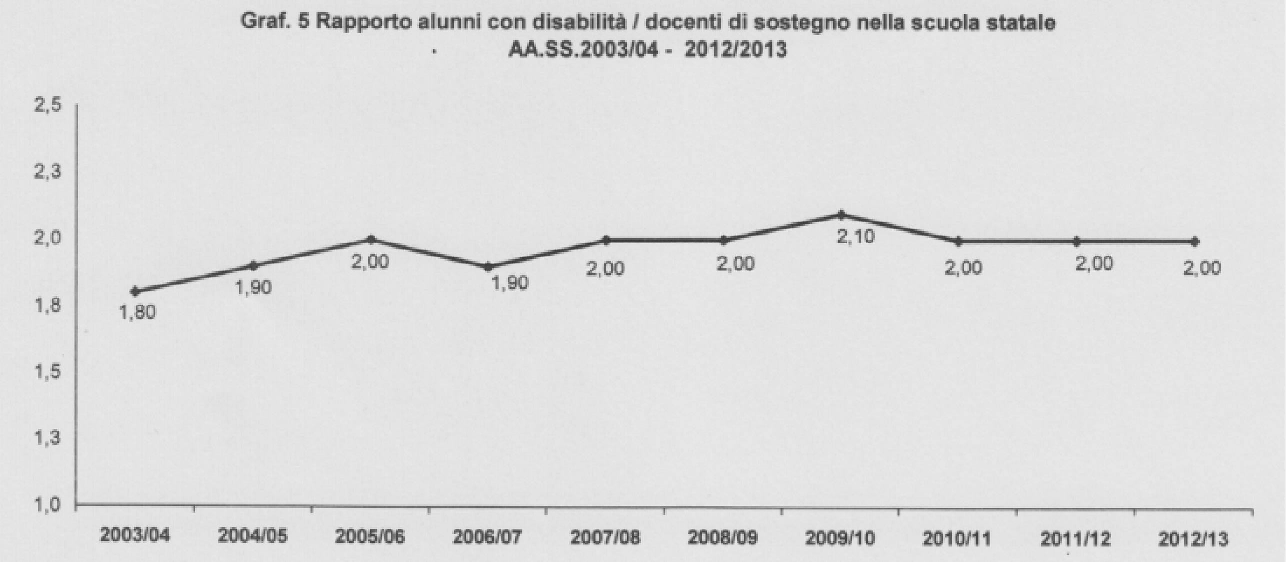

Figure 20 ***Number of children with disabilities for one support teacher in Italy 2003 to 2013***

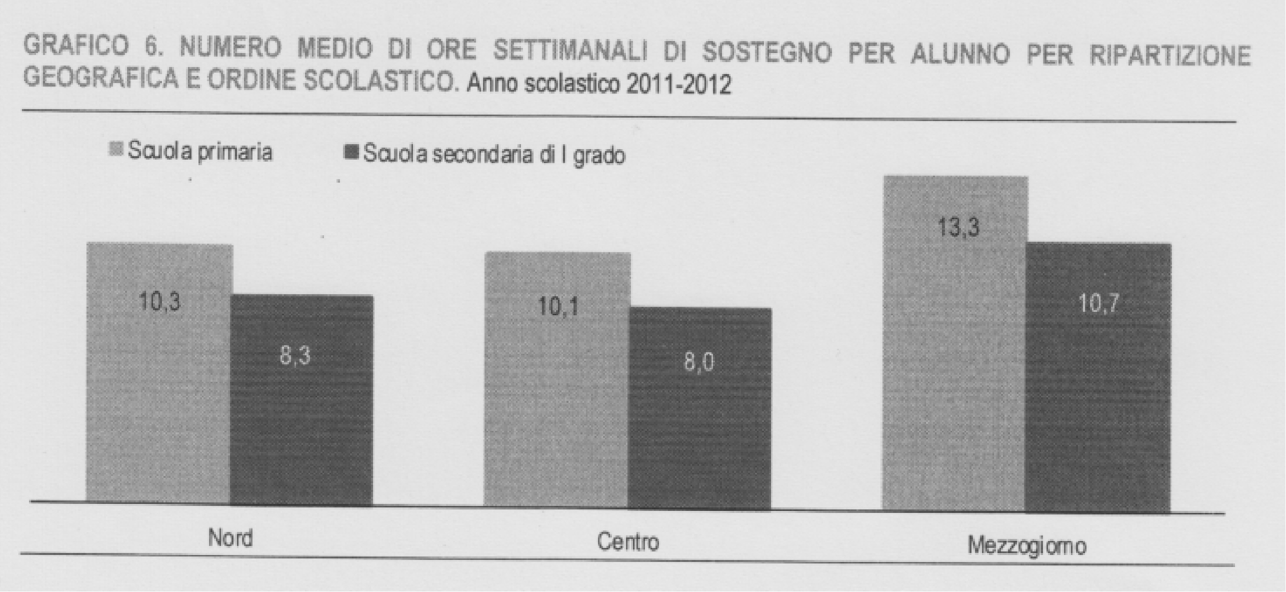

Figure 21 ***Mean number of hours of support teacher a week for child in primary and secondary school in North- Centre and South of Italy***

Statistics from MIUR report don't specify the number of special schools still existing in Italy, but only the comprehensive data of about 5000 children still educated in special schools on 201.000 in mainstreaming education, which means that just a 2.48% of all disabled children that are out of mainstreaming course. Beside we have no data on the characteristic of these children, according to the experience of Don Gnocchi Special School we feel that the majority of these children have complex and intense support needs.

Evaluation towards inclusion: the Italian model

The process of evaluation of children with disability for inclusion into normal school includes different actors and a complex system, with generates some instruments shared among school, health system and family in order to choose the teaching methodology and plan the objectives of learning in the different functional areas.

The principal actors, who cooperate, are:

- The Health system (the child specialized medical multidisciplinary team of reference who is responsible for the child evaluation and who takes contacts with school and families during the school years - the public health commission who is responsible of certification for the right to have a support teacher)
- The public administration in terms of regional bureau and local administrations who are responsible for the economic charge of inclusion
- The School with the support teacher, the board of teachers for children with disability inside the school and the teaching staff
- The family who has the right to ask for inclusion and to share and approve the educational individualized plan

The instruments for inclusion are:

- **The certificat**e which include a clinical diagnosis and a **functional medical profile** of the child drown up from the health rehabilitation team who knows the child

- **The proceeding from the local Public Health Commission** which states the right to have an individual teacher, the level of severity and the validity period

- **The functional diagnosis (DF)** redacted from the rehabilitation team describing the characteristics of the child in terms of functional areas (Cognitive – Emotional - Behaviour - Speech – Language and Communication – Sensory - Gross and fine Motor control – Neuropsychological – Self- help - Social relationship) and stating the kind an number of hours of support teachers, of caregivers and health assistance and the aids and technical supports the school must have to include the child

- **The Functional Dynamic Profile (PDF)** written after a first period of observation at school, in cooperation among teachers, family and the rehabilitation team. It includes the prevision of development of the child, his difficulties and resources and the potentialities that have to be sustained, reinforced and developed.

- **The Individual educational Plan (PEI):** redacted after some months of inclusion, which includes the areas of intervention, the short and medium term objectives, the modality of intervention and the modalities of evaluation and the outcomes.

Critical aspects and good practices

Some critical aspects in Italy are the collection of data on the population of children with intense and complex support needs, lacking in Italian statistics and making these children not recognizable as an entity.

Furthermore, financial resources for a high number of hours of support and health assistance are often lacking and regular teachers not always cooperate with support teachers to include the child among peers.

Another Italian problem is the lack of training for teachers and professionals and the need for new model of training for the different kinds of severe disabilities. Empowerment of parents is also necessary.

Though inclusion in mainstreaming education is widely diffuse and applied in Italy since many years, there are still problems for inclusion of children with severe disabilities into regular school, with cases of bad practices. As the few special school still existing accept nowadays the most severe children, there is a concrete risk to emarginate these children inside a kind of “well-functioning ghetto” and an on-going debate is now on in Italy on the possibility to go back to special schools as inclusion of a child with intense support needs into regular school often fails.

Nevertheless, the Italian school system has built, during 36 years from the introduction of the law, a lot of experience on inclusion. Experimental models and pilot experiences of inclusion in regular schools for severe cases of disability exist, though not all over the country. One model is the pilot experience of the ”strengthened schools”, active in some Italian districts, in which inside normal school coexist small classes of at least 2-3 children with severe disabilities with normal classes in a kind of open classes. Interaction between normal and disabled children are strengthened through the presence of experimental laboratories, teachers are specialized for teaching to severe children through experimental methodologies and individualized educational plans. The individual project for each child is in network with families, health district and social services.

Parent’s networks and associations are very active in Italy and cooperation between school and health system towards inclusive education is regulated by law, but there is a need for to expand and consolidate the good practices, for training and support to specialized teachers, professionals and caregivers and for parents’ empowerment. Going back from inclusion to special schools don’t seem to be a good solution for children with complex and intense needs, but a lot of work has to be done to improve the Italian model and not to lose it.

The ICF (International Classification of Functioning, Disability and Health) as a reference in the assessment of functioning and needs of children with multiple disabilities

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Abstract

Since 2008, in Portugal, the International Classification of Functioning, Disability and Health (ICF) and its later version for children and youth (ICF-CY), is the reference document in determining the eligibility of children to benefit of specialized supports.

Before, a medical report was required for the child could have the support from special education.

In this presentation, it is explained how the ICF is operationalized in the Portuguese educational system, and are showed the required documents in the assessment and intervention process with children and youth with special educational needs (SEN), namely, with children with multiple disabilities.

We also present some studies, that have been developed in Portugal about the implementation of the ICF in Portugal, especially the advantages and constraints of the ICF application in education, as well as some the needs point out by special education teachers for a better implementation of the whole process of assessment and intervention by reference to the ICF.

Keywords: ICF, assessment process, functioning, special educational needs.

Portuguese situation in numbers

In Portugal, at the school year of 2012/2013, there were 17 Reference Schools for the bilingual education of deaf students; 336 specialized units for students with multiple disabilities (or multi-sensory impairments); 256 specialized support units for Autistic students; 32 Reference Schools for the education of blind/low vision students and 25 Resource Centres of Information and Communication Technologies for the Special Education (http://www.dgidc.min-edu.pt/educacaoespecial/).

Some numbers about Special Education at the same school year were as follows:

Indicators	School year 2012/2013
Students with an IEP (Individual Educational Programme)	**50 750**
In mainstream schools	**49 149**
On pre-school	**2 175**
On fundamental school	**42 530**
On secondary level	**4 444**
On special education schools	**1 601**
Students with a specific individual curriculum	**11 219**
Students with the support of the Specialized support units for students with multiple disabilities (or multi-sensory impairments)	**1 864**
Students with the support of the Specialized support units for Autistic students	**1 357**
Students in the Reference Schools for the education of blind/low vision students	**556**
Students in the Reference Schools for the bilingual education of deaf students	**258**

(http://www.dgidc.min-edu.pt/educacaoespecial/index.php?s=directorio&pid=3)

The introduction of ICF – International Classification of Functioning, Disability and Health ICF – CY (Children and Youth), in Portugal

On May 22th, 2001, the 54th World Health Assembly adopted the International Classification of Functioning, Disability and Health (ICF) to be used by all WHO member countries of which Portugal is a part.

The International Classification of Functioning, Disability and Health (ICF), in Portuguese official language, appears in 2003. ICF appears referenced in the field of the Portuguese education in the Decree-Law Nº. 3/2008 of January 7th (and the amendments introduced by Law Nº. 21/2008 of May 12th) as a highly innovative aspect of the new paradigm of Special Education in Portugal, namely in the way we look at the child with permanent Special Educational Needs (SEN).

The operationalization of the ICF thus becomes an indispensable element in the identification of students (DGIDC, 2009) that need to be supported by specialized education. Indeed, the ICF is the reference document that leads the whole process of evaluation and classification of SEN in Portugal. ICF aims to create a unified and standardized language and a working structure for describing health and health-related states.

ICF – Children and Youth Version

Taking into account the particular characteristics of the stages of childhood and adolescence, the need for an ICF version that contemplates these peculiarities was felt immediately.

Thus, in 2002, a WHO working group was formed, led by Rune Simeonsson to develop a version tailored to children and youth, which can be used in areas such as health, education and social development.

In 2007, WHO launched the International Classification of Functioning, Disability and Health - Children and Youth version (ICF-CY) that focuses on specific features and more meaningful contexts for children and young people.

The release of the ICF-CY (children and youth) doesn't have the official version in Portuguese yet. The WHO Collaborating Centre for the Family of International Classifications is also preparing the official version in Portuguese. A trial version translated and adapted by the Centre for Psychological Development and Education of the Child, from the School of Psychology and Educational Sciences of the Oporto University is, however, available online.

The Need for a Classification System

The need for a classification system able to clearly and reliably identify children who, indeed, need specialized assistance, it was a need felt for a long time. The classification and categorization of children are often considered essential to ensuring equal opportunity in the allocation of education and social services (Florian et al., 2006, 36).

In 1999 an Outlook of the National Education Council (Outlook No. 3 / 99) made reference, inter alia, the need for a classification system capable of identifying the specific needs of children/youth.

In 2005, in Portugal, Ministry of Education and the National Council of Education, indicated that "1 in 16 students had special educational measures" (DGIDC, 2009, 8), a figure that had a tendency to increase. Special education was provided to students whose first language wasn't Portuguese, and also to students from ethnic minorities or at environmental/social risk.

The absence of a rigorous system of reference, identification and assessment of the needs of children harmed the educational response set for pupils with real special educational needs and, also, the degree of attention to students who needed other kind of intervention.

As far as schools organization is concerned, it also brought problems since it faced a progressively greater number of students who (supposedly) required special educational measures.

In 2006, the Portuguese Government adopted the First Action Plan for the Integration of Persons with Disabilities or Disability (PAIPDI) for the years 2006-2009. In this document there are already some references to the ICF and to its application in the assessment and description of the functioning profiles (Resolução do Conselho de Ministros n. º 120/2006).

Having thus the ICF support as a reference, the latest legislation in Portugal concerning the Special Education, defined the specialized support to provide various levels of education and training, aimed to remedy the special educational needs of "students with significant limitations in terms of activity and participation in one or more areas of life, due to permanent functional and structural changes, resulting in continued difficulties in communication, learning, mobility, autonomy of interpersonal relationships and social participation "(DL 3/2008, artº. 1).

Characteristics of the ICF

The goal of the ICF implementation in specialized assessment is to identify the functioning profile of the student and to identify barriers and facilitators in order to define the appropriate educational responses.

ICF doesn't focuses on "consequences of disease" (as in the International Classification of Diseases - 10 (ICD-10). Instead, its attention is directed at a system of classification and multidimensional interactive which does not rate the person, but the characteristics of the person, the characteristics of the environment and the interaction between these characteristics.

As it is stated in the introduction of the document itself, the ICF can be applied to various areas, for instance, for statistical purposes (as in collecting and recording data); for investigational purposes (e.g. quality of life or environmental factors), for clinical purposes (needs assessment, rehabilitation, ...) as an instrument of social policy planning (social security systems, ...) and also for educational (organizing educational programs, development of social actions, ...) (WHO, 2001,5).

The various components of the ICF are all in dynamic interaction. Consequently, an intervention carried out on a particular element may cause changes in one or more elements.

This interaction can be summarized in the following scheme:

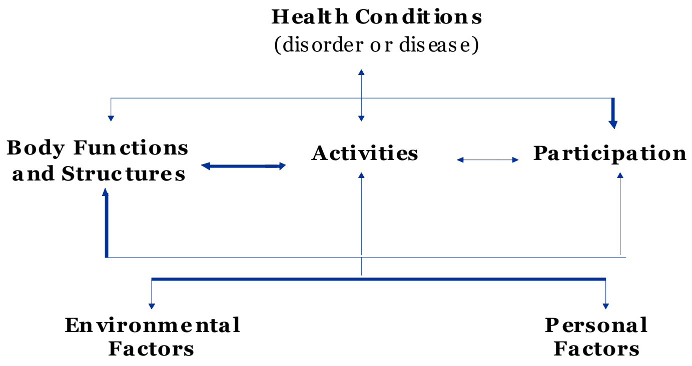

Figure 22 Interactions between the components of ICF (WHO, 2001, 18)

Thus ICF proposes a biopsychosocial model of disability and functionality (opposed to a purely medical or social model), approaching the subject from a biological, psychological and social perspective. ICF seeks to look at each individual as a whole, in which a problem is perceived, explained and operated upon from various perspectives.

The functionality of an individual in a specific domain is an interaction or complex relationship between health condition and contextual factors (i.e. environmental and personal factors). There is a dynamic interaction among these entities: an element in an interaction can potentially alter one or other elements.

Assessment/Intervention Process in Portuguese Educational System

Implementation of ICF - CY in specialized assessment

The whole assessment/intervention process is organized in five main steps (Candeias, Rosário & Saragoça, 2013):

Step 1 – Referral procedure

When a student has special needs that may justify the adoption of educational responses in the context of Special Education, a referral is made to the Director of the School, by completing a "Referral Form". This referral can be done by parents or carers, teachers, early intervention services or other community services, but the teachers/directors of the class are usually the ones to do it.

Step 2 - Constitution of the multidisciplinary teams

The Director of the School leads the Referral Form to the special education teacher team. Together with the Department of Psychology and Guidance (when available), they analyse the situation, define the need for specialized evaluation, and when it is appropriate the assessment process begins by reference to the ICF, the Technical and Pedagogical Report is drafted.

The assessment process begins with the constitution of the multidisciplinary team that will undertake an assessment of the student’s specific needs. In this team, there is always a special education teacher, the teacher/director of the class, parents/carers and the educational psychologist. Technicians (as speech therapist, physiotherapist, …), health services, social workers, may also be a part of the team – if the child needs their support. In the team meeting the "Roadmap Assessment" is completed, which decides: what to evaluate, who assesses and how to assess.

In the meeting the ICF categories, on which is considered necessary to obtain new or more information according to the specific condition of each child/youth, are selected.

The assessment, by reference to the ICF-CY, should consider various components - functioning and disability components and the contextual factors - and the interactions that occur between them.

Each technician will assess the categories of their competence that have been previously defined in the meeting team (Roadmap Assessment). This evaluation is done by reference to the ICF, for example, the psychologist will assess the "Mental Functions" and the special education teacher evaluates the corresponding part of the "Activity & Participation", using formal and informal assessment instruments (e.g. medical exams, pedagogical and psychological assessment scales, observation grids, student's products, among others).

Step 3 – Elaboration of the functioning profile

After the evaluation carried out by different technicians, the assessment team meets to analyse all gathered information, and with the help of a checklist the Technical and Pedagogical Report is elaborated, which identifies the student's functioning profile, taking into account the functions and body structures, activity and participation and environmental factors that influence this same functionality (facilitators and barriers). This report also explains the reasons of the special needs and their typology, as well as the answers and educational measures to be adopted that will underpin the Individual Educational Program's (IEP) development.

Step 4 - Preparation of the IEP and implementation of special educational measures

The IEP is developed jointly by the teacher/director of the class, by the special education teacher, by parents and whenever necessary, by other participants in the process. The IEP includes: (a) student's identification, (b) personal and academic relevant history, (c) functioning indicators, level of acquisitions and difficulties, (d) environmental factors that act as facilitators or as barriers to participation and learning, (e) definition of educational measures to implement, (f) the description of contents, general and specific objectives to be achieved and the strategies and resources to be used, (g) level of student's participation in educational activities of the school, (h) the schedule of the different activities, (i) the identification of the technicians involved, (j) the definition of the process of evaluation of the individual educational program implementation, and (k) the date and signature of the participants in the IEP preparation and the responsible for special measures implementation.

The coordination of IEP is a teacher's responsibility - the teacher of the primary school or the director of the class (depending on the student's educational level).

The whole process, from the referral procedure to the preparation of IEP, is expected to last 60 days, maximum.

Studies and Reflections about the experience of implementation of ICF in Portugal

Study 1. Qualitative study – special education teams in 3 schools in the Alentejo region

This study (Candeias, Rosário & Saragoça, 2013) investigates the views of special education teams' perceptions about ICF implementation in three schools with various levels of education (preschool, basic education and secondary) in the Alentejo region. Such study concluded that for an effective and efficient implementation of the ICF it is necessary to train teachers, particularly with regard to assess the functioning of students with special educational needs, teamwork and time management, once this new model requires new skills on the part of teachers involved.

Study 2. Quantitative study – special education teachers in the Alentejo region

This study (Candeias, Saragoça & Gato, 2010) used a qualitative methodology and investigated the teachers' attitudes towards the: knowledge of the ICF; received training and advantages and limitations that ICF introduced in the assessment/intervention with students with SEN.

In regard to training, data analysis identified that: about 41% of teachers received training before starting to use the ICF. The training had an average duration of 25 hours (minimum of 5 hours and maximum of 46 hours). The teachers wanted the training to have an average of 30 hours (minimum of 20 hours and a maximum of 58 hours). 65% of teachers expressed a need for more training in the ICF. With this study, it was possible to note some favourable and unfavourable attitudes toward to the use of ICF, i.e.:

Favourable attitudes:

- It is a useful instrument that favours the identification of facilitators and barriers to activity and participation;
- It is a biopsychosocial classification of functioning;
- It allows to draw a functioning profile;
- It helps to plan the educational intervention;
- The decision making is shared;
- The work in a multidisciplinary team;
- The interaction between professionals / creation of a common language.

In addition, unfavourable attitudes:

- Training in the ICF is not considered sufficient;
- Training in the ICF not focused in the practice;
- It is a slow process;
- No use of ICF by all stakeholders in the process (e.g. Health area).

It was possible to conclude that:

- All aspects of a person's life (development, participation, and environment) are incorporated into the ICF instead of solely focusing on his or her diagnosis;
- Its applicability to different fields (education, health, social security, employment, ...) will provide unified and standardized language that will work in multidisciplinary teams – but in Portugal, where it has only been applied to education, this led to a professionals embarrassment in different fields, because it lacks a "common language";
- The application of the ICF involves the team work, where all contributions are considered important to a comprehensive assessment of the child's needs - Decision-making will be the responsibility of a team and not a single person;
- The application of the ICF It allowed the creation of instruments that help to systematize the assessment process – example: "Assessment Roadmap" which defines what needs to be assessed (at different components of the ICF), who will assess the different categories and how they will be assessed (information sources and tools to use).
- The application of the ICF has the advantage of empowering all actors in the process, clarifying the role of each one.

It was also possible to point out several constraints:

Inadequate training of professionals in the field;

- The lack of an official Portuguese version of the ICF-CY (children and youth version);
- As the model is not applied (yet) to other areas such as health, one of the advantages of ICF (standardizing language) becomes a barrier;
- The greatest difficulties of the ICF use can be found in the absence of a reliable set of instruments (with the aim to assess the different body functions and activity and participation level) and absence of strict criteria to establish the limitation degree.

Finally, the study emphasized the major urgent needs:

- Training in assessment;
- Training in assessment by reference to the ICF;
- Development of assessment tools and compilation of existing instruments;
- Teachers and other experts training in the field of teamwork and time management, because this new model requires new strategies of work.

Study 3. Qualitative and quantitative study – 926 Groups of schools; 252 students' processes; 35 focus groups; 577 survey respondents

The main results of this study (Simeonsson et al., 2010) were:

- Schools are now able to describe differently from students who need special education services;
- Schools are able to capture and record the individual needs of students and based on them decide on the educational responses to adopt;
- The biopsychosocial model, operated by the ICF, allowed a greater understanding of students and their needs.

However:

- The functioning profile formulated by reference to the ICF is still not fully serving the development of Individual Educational Program;
- There are teachers who do not yet understand the reasons for the use of the ICF in the assessment and eligibility of students;
- The lack of professionals to evaluate and describe the body functions and structures, a more efficient coordination with the Ministry of Health is here in question;
- Education professionals miss training and assessment tools;
- The multidisciplinary teams are focused on the functional characteristics rather than the disabilities of the students.
- There is a purposeful look about environmental factors, however there is still a low identification of barriers;
- Specialized assessment has involved the use of diversified sources of information and the use of informal methods of assessment according the biopsychosocial model.

Study 4. Quantitative Study with special education teachers from Portugal

This study (Saragoça, 2012) with 913 Special education teachers aimed to characterize the training needs of special education teachers towards the use of the ICF-CY framework in the assessment and intervention process of children/young people with SEN.

From the study were obtained the following results:

The most appropriate training modalities	Professionals to be involved in the training	Contents in which training is needed
◆92,9% - Teachers initial training ◆76,6% - Training Workshops ◆69,6% - Training courses Only 24,4% - e-learning	◆84,5% - Regular education teachers should also receive training in ICF ◆90,2% - Technicians (speech therapists, physiotherapists, psychologists) ◆77,8% - Involvement of the School Management But… 23,3% agree/strongly agree that training should involve only special education teachers.	Above 65%: ◆Case studies discussion ◆ Assessment instruments ◆ Evaluation methods ◆ Differentiation between eligible and non-eligible students for special education ◆ Distinction between performance and capacity qualifiers ◆Selection of the codes to be used

The major conclusions were:

- Teachers want to have training in ICF in their initial training courses (graduation degree);
- Teachers want to have training in ICF in specialized training courses;
- Teachers want the training to involve Health professionals;
- Teachers consider that teams from schools should be more dynamic and do more internal training (also involving parents/guardians);
- Teachers consider that it is needed an investment in in-service training, accredited (Training Workshops and Training Courses) and that
- It is needed a greater involvement of the Schools Management.

Work in progress

Currently, members of the Portuguese Enablin+ team are working in:

- A diagnosis of the training needs of special education teachers and regular education teacher towards the ICF through 2 questionnaires – about the attitudes towards implementation and attitudes towards training in ICF, and
- The development and implementation of a training model oriented to the attitudes’ change based on coaching.

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Part IV Parents' perspectives

The role of the family in social networks

Jacques Lodomez, president of AP3, a parents-professionals association of people with multiple disabilities

When considering the family as a system, it is obvious that the birth or the arrival of a child with a disability will have repercussions on each of the family members and will require a restructuring and reorganization of the system. It is important to consider also that each of us may have different needs which must be taken into account. Parents and sometimes other members of the family of children, adolescents, adults with disabilities face significant psychoaffective, social and physical overload. This overload causes partial or permanent stress states. It is evident that this stress challenges many parents today.

Some factors may obviously reduce this stress:
- satisfactory relationship with the child, the disabled person and the other members of the family,
- material resources, personal and emotional resources of the family and of each of its members,
- the resources at the level of the community that avoid the isolation of families.

In summary: an adequate satisfaction of the needs of parents, siblings and professionals.

Among the basic needs of the family, we can mention:
- the need to have proper guidance during the announcement of disability
- the need for information: early assistance services, associations...
- the need for training parents before that of the disabled person
- the need for technical and material aid...

Responding appropriately to those needs will allow the family to reach a certain normalization of life.
The need for emotional support is an ongoing need of families. This support must be dynamic and adapted to the different moments in the life of the family.
During the revelation of the diagnosis, it's certainly at this stage that the emotional guidance must be the most intense. This often coincides with the birth of a different child, but it can also occur during pregnancy or during the first years of life. Indeed, no family is prepared to have a child with a disability. This is obviously a shock to parents but also for the rest of the family. The announcement of the disability is a crucial moment; it must be done by a competent person and in the presence of both parents. Depending on this the couple "explodes" or it "tightens"; there are not 36 solutions.

This first stage of shock is generally followed by a period of intense activity, search for "knowledge" and "understanding" what happened, to know the diagnosis, treatments, prognosis...
Little by little, parents must achieve a "grieving process", mourning the loss of the ideal child in their eyes, the loss of the much-desired child. It is a process that can be long, but that is quite normal for finally accepting the child as it is. From this moment, it is important to provide parents with a space to meet other parents, in order to be able to express more freely their feelings and experiences and to share with other parents who have gone through similarly painful moments. The parent turns primarily to a parent before confiding in a professional.
It is clear that this support must go together with information, looking for appropriate services: "early intervention", special school or integrated normal school, associations specific to their child's disability. A relationship of equals must be established between parents and professionals.

After the revelation of the diagnosis, comes another moment of destabilisation of the family. They have to find a structure, a special school,… It may reopen a wound that was latent and may cause a new breakdown of the family unit. The child grows, we must adapt the habitat, choose specific hardware, adapt the “rolling thing” (the car or wheelchair). The couple may need to make a choice in their professional working life. One of the two may stop working or have to work part-time.
Once again the resources and capabilities of the family and immediate environment will be an important aid.

The next step is adolescence. The child grows in size, has gained weight and remains very often dependent of someone else. For parents, nursing care becomes increasingly heavy. Confronted with a certain “burden or care”, parents are beginning to ask themselves questions:

- What will be done tomorrow?
- After us, what will happen? Who? Where to? ...

It is clear that we cannot load the siblings with the responsibility to take over from the parents and yet it is at this time that the family needs to breathe, to find "respite" (foster, assistance at home...)

Finally, the child reaches adulthood. The parents’ wound reopens again but in a much stronger way, causing anxiety. We are now confronted with a lack of institutions, an emptiness that was not anticipated. Indeed medicine has made huge progress, in keeping children alive who, a few years ago, would be doomed to a certain quick death. Adults with disabilities arrive at retirement age (new) but there is nothing or almost nothing there to host them. Somehow, parents try to keep the adult at home near mom and dad if they are still alive.

- There are few or no services available to help at home
- The future of the person with a disability after the death of parents
- Some parents come to wish that their child die before them

At this age, problems also arise of legal guardianship, if parents have not taken measures before. Again, the family must be able to benefit from support on the part of professionals.
This passage from adolescence to adult life, is accompanied at the same time by ageing of the family and sometimes a difficult rupture.

In summary, the family of a disabled person will need material assistance so that the child can stay as long as possible in his home:

- assistance at home, appropriate “babysitter” or personal assistant
- equipment and appropriate adaptations to the house but also to preserve the physical health of the parents
- need moments of respite
- ease of transportation of the disabled person.

If one reflects somehow, one realizes that the so-called “valid” world’s perception of the disabled person has evolved. I believe that non-disabled human beings eventually realize what it means to be a disabled person. Some examples: respect of special parking places reserved for the disabled, accessibility of buildings. The disabled person has the right to be treated as a full person and enjoy a quality of life for personal and social development with the rights granted by the United Nations’ Convention, ratified by national statutes and the European Commission of human rights.

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Who are they? Girls with Rett syndrome

Hugo Pilate, Belgian Rett Syndrome Association

Imagine the unimaginable… you give birth to a darling baby girl. Every day you watch her flourish, you watch her grow. Then somewhere between her being 6 to 18 months old, her development stops and even regresses.

“Madame, Sir, your daughter has Rett syndrome. She as a genetic defect that will leave her mentally and physically severely handicapped. She will always be completely dependent on others.”

Can you imagine how the world of parents, who get this message, collapses? Then you will equally understand how important a parents’ association’s support is to parents with a Rett child: with our magazine, information meetings, group sessions of music therapy, swimming, hippotherapy, financial support for the purchase of expensive aids that can strongly improve the life-quality of Rett girls.

What is Rett syndrome?

Rett Syndrome is a very rare disorder, occurring mainly in girls, approximately in 1 on 10.000 girls. Starting with normal development, ‘something’ changes between 6 and 18 months. The cause of Rett Syndrome was first discovered only in 1999: a mutation of the MECP2 gene of the X-chromosome

Various phases

- Initial normal development that then suddenly stops between 6 and 18 months
- less playing, less contact – words are forgotten, languages deteriorates
- walking becomes more difficult
- Fast decline during a number of weeks or months
  typical hand-wringing
- Stable period
- Continued motor decline

Typical features of girls with Rett Syndrome

- Hand-wringing
- Some walk, mostly they don’t
- They don’t talk with words but with their eyes
- Epilepsy
- Scoliosis
- Dependent on others for all small and big things in life

But it’s not only loss

- Happily enjoying life
- Radiant eyes
- Optimists
- Having fun with music and TV
- Happy with wat they have and can do
- Life qualities that we can all learn something from

Lessons from a personal story

Our daughter Inge was born on the 18th of October 1984, as the second child in our family. The diagnosis Rett-Syndrome came in 2001, when she was already 17 years old. Before this period we didn't know what the cause of the increasing retardation in her development was .

For every child, development starts at birth and is a lifelong challenge.

For children with Rett-Syndrome development is an even greater challenge because they constantly have to fight against the loss of their abilities.

This was also the case for our daughter. She started life as a normal baby and is now a young woman with complex and intensive special needs.

The first year of her life she seemed to have no problems.

When she started to walk, however, we discovered that she had a problem with her left leg. We consulted a paediatrician who told us that we didn't have to worry but that we should have patience. After one month we went directly to an orthopaedic surgeon. Within a week, at the age of 15 months, an urgent operation took place because of a double hip dislocation. Eight weeks in a plaster cast, followed by 12 months in a Pavlik -orthopaedic device, day and night.

The surgery happened during a period, when development normally progresses very fast: the change from a 'horizontal life' towards a 'vertical way of living'. Could this lead to retardation? What could be the impact of the anaesthesia? Nobody told us anything. The medical problem was solved, but that was it.

At the age of nearly 3, Inge went to a mainstream pre-primary school. A class with nearly 25 children. The first year there seemed to be no problems. During the second year, the first signs of retardation became visible as well as a progressive loss of fine motor skills. My wife, a special education teacher, who at that time worked with children with mild or profound intellectual disabilities, organized an assessment at a rehabilitation-centre for children with developmental disorders. After screening, a retardation was confirmed. Inge started to follow two sessions of 1 hour each week, to tackle these problems. Thanks to the effort of the grandparents, we could organize this therapy.

The third year in class, the teacher gave Inge special attention and adapted exercises, together with two other children of her class, who also had difficulties with the pre-primary school programme. Thanks to these efforts, Inge could participate fully in kindergarten. There was a good cooperation between parents and teacher.

Then came a leap to primary school. As parents, we could choose between the mainstream school in our neighbourhood with a remedial teacher who would give support to Inge when necessary, or a special school for children with learning difficulties and children with mild intellectual impairment. We immediately chose for the special school, because we were aware of the increasing retardation of Inge's development. The class-group was smaller (10 children), the teacher was specialized which made learning more easy. A special programme was set up together with the school.

When plotting Inge's retardation in digits, her IQ measuremenet at age 4 started at 128; and then it slowly decreased, at 5 years old 117, at 6 years old 97, at 7 years old 70, at 15 years old 35….

At the beginning most of the problems were situated in fine motor skills, leading to dyspraxia.

At the age of 7, due to a series of unexpected severe epileptic fits, the retardation accelerated rapidly. Some of the skills she learned before this difficult period were more or less maintained. So she always liked to make puzzles, she still could make puzzles between 100 and 200 pieces. Other skills seemed to have been 'frozen'. Learning new things, mentally or physically, became very difficult. Only in 1 to 1 settings, with a teacher or therapist, could have a result. They organised this as much as possible. The most fantastic result in this period was, that the physical education teacher taught her to swim! Due to a sustained training and thanks to a special bond between them.

This is very important condition for development: when there is a special bond between teacher, trainer or health care provider and the child, then a child can make progress; then development is possible, or at least, one can maintain abilities despite the progressive physical degeneration due to Rett syndrome.

She still goes swimming with me, twice a week: a part is training (she swims between 10 and 16 lanes), and a part is quality-time: sauna, Jacuzzi, bubble bath. She participates once a year at the Special Olympic Games, in a swimming contest.

At the age of 11 she developed scoliosis, a severe abnormality of the back. The use of a brace was necessary to keep her walking. The first “Milwaukee-brace” was made conform to 'the academic specifications'. It was efficient but not comfortable. Later on, another orthopaedic technician developed a brace, equally efficient, but much more comfortable, because he was taking into account all our and Inge’s suggestions. We found a lot of solutions during subsequent visits!

At the age of 12, an intensive individual special programme was set up due to the continuing retardation, together with the previous teachers, the remedial teacher, the speech therapist and the physiotherapist (engaged outside the school to diminish the stress on the school’s physiotherapist). When invited by a new special education teacher and the actual head teacher, we received the message that Inge had to leave school, for the remaining 6 months of primary school. They “obliged” us to go to a school specialized in children with severe intellectual disability. Why this decision for the last 6 months? It was presented as a decision of the whole school community “in the best interests of the child”. Later we received other information. Why there was no match between Inge and these people? The director said really bad things about her, e.g. that she was intentionally oppositional. He said the school couldn't cope with her very fluctuating achievements at school. It's until now, our biggest mistake to act as asked. Inge really deleted this period out of her memory.

In the new school there was a total no-match with the new teachers, the other children, and the school. It is still difficult to look back on this period. Development stopped, she and we were unhappy. She was afraid, anxious. This clearly reinforced a period of regression.

We looked for a new school. At the age of 12, Inge started in a boarding school for people with mild or severe disabilities. There she could stay to finish school. After a year of trying out, looking for good solutions, an adapted programme was put together. It was a success: a good match with several teachers, the class-group, the children in the living group, the educators. The team gave custom-made-solutions, a warm, tender environment, in respectful relation with Inge and good communication with the parents. It was also a fine period, in which she was making progress again, she recovered, and developed good social skills with the other children.

Again there was space to develop, to learn, to take care of her skills. During the weekend at home, Inge got full attention from her family.

At the age of 20 she finished school and there was an opportunity to go to a day-centre for persons with intensive support needs, who are not able to function in adapted working conditions. Again a big leap. What would it bring for her future? Could she find adjustment in this new setting?

In the early years, there was a permanent discussion about Inge’s abilities, our expectations, the structure and organisation of the centre. Their vision was not always compatible with our view.

But we had to take care that it would not turn into a conflict. More young residents mean more parents with parallel expectations. They needed to be more flexible to integrate the complex and intensive needs of the different adults with disability: beside the provision of care and time allocation, more active programmes, more individualisation, new activities.

Also Inge needed to adapt to her new environment. A world different from school, a slower rhythm than in school, with older co-residents and this time probably for the rest of her life. A new environment, complementary to her family life, where we activate her: swimming, riding a tandem, walking, playing cards, board games,...

In the day-care centre, she can participate in several group activities adapted to her capacity: woodworking, shopping, cycling… . Weekly, she follows an individual training by an occupational therapist for manual training, reading, educational computer games. Every day she goes to the physiotherapist to stabilise the scoliosis and to train motor skills. She has a lot of social contacts in the group, she likes the different workshops. Now, we are in a stage that the complex and intense support is at a good level.

The organization makes it possible for her to go on holiday: winter sports in Austria, walking holiday in Austria, bicycle holiday in Belgium or the Netherlands, music festivals like 'Rock for Specials', they have a farm where adapted work is possible for a part of the population.

In summary: does Inge belong to the target group? And is there support to develop her? Surely she has complex and intensive support needs. As regards motor impairment, there is daily support and therapeutic assistance. As regards cognitive impairment, she receives weekly individual therapy sessions and some daily activities. With respect to speech and language impairment, social contacts are provided, at the centre as well as at home. She has no behaviour problems, no hearing problems. She has additional needs because of her scoliosis. Daily life self-care (hygiene, toilet visit, dress up, transport, ..) require assistance. However, compared to many other girls with Rett syndrome, who need assistance to feed them, are tube fed when necessary, or whose communication and speech are nearly absent, Inge can be considered relatively fortunate.

A new challenge emerges for us: how to organise family meetings, when providing the necessary care turns out to be too complex or too heavy for us as parents? The recent ideas and new approach of the Flemish government are making us concerned. The government is emphasizing the need for more community (read: less professional) care and support. Parents’ groups are forced to organise this themselves. Hopefully this still will be organised by the government for those persons with complex and intensive dependency needs.

What are some points of attention on the way to ENABLING and INCLUDING these young people, the way to an active, high-quality way of living?

The life of our child is a continuing story of looking for, and working out adapted solutions, in a changing world, with different, sometimes changing actors. Enabling and including never stops.

The need of coordination

The involved person, the parents, the family , the school , the teachers, the therapists , the doctors (general practitioner , neurologist, orthopaedic surgeon, dentist,) , psychologist , educationalist, educator. Every actor has a role in the process of enabling and including. But who is taking care of the coordination, who has the overview? Who is responsible for the integration of all these aspects? Let the good coordinator stand up! Parents are not able to do this. Neither does the contact person at the centre of child guidance, because he does not know all the relevant elements. He or she can play a very important role, however, until the end of the school career. The social worker does not have the time nor the skills. Perhaps the general practitioner, but Will he take the responsibility to coordinate all the medical aspects and to bring them together with the other aspects? Specialists are mostly looking for a diagnosis, a remedy, but often don't engage into a long term engagement.

The need of expertise centres

Parents are, after a severe diagnosis or confronted with a severe problem in development of their child , very vulnerable and insecure. The important role of an association of parents and/or experts is, to bring these parents in contact with persons with similar experiences, who can deliver an active contribution to the treatment process: the feeling of solidarity , the possibility to rely on expertise, the feeling not to be isolated, and to get concrete suggestions and practical tips.

Expertise centres are necessary : for Rett-syndrome , there is such a centre at the Maastricht University (the Netherlands). There is a need for platforms for therapists, healthcare workers, and other involved professionals to communicate , to share best practices , ... Not every one of them is an 'expert' in all the possible complex support needs of multiple disabilities. They need to adjust and expand their knowledge. There is also a need for platforms for parents, to share experiences, to share emotions, to get concrete solutions.

The pendulum movement in healthcare

Look out for, what I will call “historical mistakes” : on the one hand a provision of care completely taken over by the government , with practically no role for parents or family, and on the other hand the approach that parents or family have to find out and organise everything themselves . A sort of trial and error process or searching. A clash of theories and concepts about daily needs of the needy. The right approach is anywhere in the middle! The cooperation of several actors, professionals as well as volunteers, parents and family , are the guarantee for more quality of life.

Rather than fighting against each other, there is a need to find a match between all actors. This is a long-time work, which requires above all an open mind and a search for mediation. When there is a NO MATCH, it results in an arrest of development and less well-being.

The need of a wide range offer

- a MAINSTREAM OFFER vs CUSTOM MADE SOLUTIONS : look for the best. Special persons deserve the best support: open the offer, don't block the offer, not as assistant, but also don't do this as parents.
- A MAINSTREAM SCHOOL with internal support and/or external offer
- A SPECIAL SCHOOL with or without supply of internal or external therapist
- A GROUP APPROACH vs INDIVIDUAL SUPPORT – TRAINING
- A common SPORTSCLUB or YOUTH MOVEMENT vs SPECIAL clubs / activities

Try to find the balance, from the point of view of the person with his specific abilities and dysfunctions. Go for the best results. Look for opportunities, search possibilities, try out, give space to new ideas.

A community really shows its strength when it lifts up the quality of life of its weakest members , to a higher level , not only by paying attention to them , but by providing the necessary resources and the space to realise a variety in offered possibilities. More than care, more than financial support, real chances to develop.

Rett Parents Association

The Belgian Rett Parents Association was founded 25 years ago. Its objectives are to:

- Guide and support parents and families with Rett children
- Gather and spread information on the Rett Syndrome
- Bring people together that are involved with the Rett Syndrome and motivate them to continuously learn from each other
- Improve the general and social well-being of Rett children

We want to achieve these goals by organising a range of activities:

- Home visits to new parents
- Publishing a magazine: Rett Gazet
- Publishing a handbook and flyers
- Annual new year diner with parents
- Fundraising for contributions
- Editing a website, Handi-Rettguide and e-mail contactpoint
- Organise an annual family day
- Organize hippotherapy

These are all activities that the girls enjoy

The highlight of the year for all Rett families and their caretakers is the family day. There is music therapy, swimming for the Rett children. An expert guest speaker is invited to inform parents, therapists and care takers about the latest scientific progress and other relevant matters. There are also adventure games for siblings (brothers and sisters). There is a barbecue, a horse wagon ride, swimming for all, walking and most importantly spending time with people who understand what it is to live life with Rett.

Our children are like all others - a perspective from Portuguese parents

Associação Dar Resposta[9]

Before any definition or description, the children that we talk about, are our children, our most precious beings, for whom we give life, move worlds and break barriers. As parents, we experience before anyone else the ambivalence of feelings and the whirlwind of thoughts. Doubt and uncertainty unite to hope, promoting expectations. Every little achievement of our little big heroes gives us the strength to continue, and look beyond the disability, remembering that above all, our children are like all others. They have the right and should have the same opportunity to draw a path in life, make vocational decisions and choose from an equal number of options like other children do, in the same age groups.

Children with complex needs do not present a single or concrete definition. First of all, the complaints that precede diagnosis are sometimes unclear, too confusing, do not make sense and there is no reference standard or it is unknown. The environment around the child and family can become chaotic, unorganized, with no path or meaning. Preliminary diagnoses meddle with complementary diagnostic and assessment tests, often vague and sometimes confused, mainly when there are other complications associated with it. The answers that come up with a more conclusive diagnosis are first accompanied by an ambivalence of feelings of relief and anxiety simultaneously.

Hereafter starts a period to define the strategies of intervention and treatment. This period is equally complex, either by the nature of the problem, either by the multiplicity of needed support. Unfortunately, this support is not always available.

The needs become intense, frequent and recurrent, due to worsening of the clinical condition or due to the emergence of intensive support that promotes or enhances the preserved abilities. Permanent monitoring presence can also be considered and in this concrete situation, the involvement of parents / families becomes preponderant. It´s an engaging and in-depth process which involves the largest possible number of people and resources.

Complex and intense needs imply diverse support, covering different technical areas, different approaches and different intervention models. Moreover, the support structures also require support. Being a full-time caregiver can be exhausting so it is important to provide and ensure a good support network to

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[9] Dar Resposta is a parents', relatives' and friends' association of people with disabilities, created in september 2009 in Portugal. It's a social and nonprofit solidarity Association, whose intervention is addressed to citizens with disabilities, with a special focus on children and youth with autism spectrum disorders (ASD).

these persons. Technical and Specialized Professionals require specific and appropriate training in complex and intense support needs. That training should be ongoing and constantly improved in close coordination with the clinic evolution of diagnostic.

However, despite all the constraints that may be associated with disability and all the limitations that entail a more severe pathology, by being close to them, we find out that in those children and youngsters there is still a huge will of life. And living means: to be involved with the society that surrounds us, to try to create and to dream. These children and young people have an enormous resilience and willingness to overcome obstacles, which leads them to be determined and to improve skills. We know that if given the opportunity, full inclusion in the different domains of life (employment, leisure, access to several services in society) is not only possible, as it will be a contribution to their autonomy and independence.

In short, the definition of the Target Group is not just the disease or condition itself, or its bearer, but involves everyone and everything who are directly and indirectly involved and which can be as opponents or helper in treatment (Associação Dar Resposta, 2014).

Conclusions

We started from the questions “who are they?”, with the underlying questions: “what are the needs of children with intensive and complex support needs” and “what are the training needs of those who care for them or support them?”. We sent out questionnaires to professionals and parents in 8 European regions in 8 languages (EN, FR, NL, IT, PT, HU, RO, BG); we organized regional conferences, parents and other experts, organised focus groups and did individual interviews. What can we conclude from this research?

1. What’s in a name? The internationally accepted name of “children with PIMD” (or in Anglo-Saxon world accepted name) – profound intellectual and multiple disability – is not such a useful name when it comes to defining the kind and degree of needs. What is relevant is that there is a group of children who are in a state of disability in which they are for most part of the day, and for some 24h, dependent on assistance and support for various or all aspects of life: body care, hygiene, mobility, nutrition, communication, social relations, learning. That is why we prefer the term “complex and intensive support needs”, which defines the group not in terms of their deficiencies, but in terms of their living conditions. The term PIMD still has an IQ delimitation, the term CISN does not. Neither does the term CISN make a distinction between ability to walk or not. The term CISN is more encompassing than PIMD and includes it.

2. The concept of “quality of life” as defined by Schalock et al., with its subdivisions personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being and material well-being, represents best the essential goals to strive for, in policy making, planning services, education and other areas of life. In many countries, the struggle to obtain a minimum decent quality of life is an ongoing struggle: although there are wide varieties in welfare levels among the partner countries, the struggle is the same. Striving for quality of life is the same regardless the degree of disability; also people with very severe disability, who are for example unable to talk, to walk, to feed themselves, and are completely dependent, experience a desire for quality, the need to belong, to love, to be loved, to feel appreciated, to take part, to do interesting things, to relate, to taste, etc. These are universal needs. However, the problem often lies in a lack of awareness of people around them, who underestimate these needs because they don’t take the time to communicate.

3. Measurement of functioning. Static and standardized test batteries are widely used all over the partners’ countries, mostly because they are requested by administrations to determine the provision of services or compensations. However, they appear to cause many problems when the question is to understand the real needs, the real potential, and the actual and potential level of functioning. Most of the children with CISN have very low IQ’s because their very limited capacity to respond. An IQ measurement therefore says little about real intellectual capacity. Similarly, low test results tend to lead to underestimation of potential, with the risk of causing a lack of investment. Alternative methodologies have been developed, which are more qualitative, more functional, more flexible and more action-oriented. They are not yet widespread, because they are more time-consuming, but in the end are more in line with the striving for quality of life.

4. Continuous support systems vary widely from country to country, but there are common challenges. For example, though a child (and later as an adult) with CISN is well taken care of in the Netherlands, and has a right to life-long support, they are almost all in separate institutions. The government supports families, but the tendency is to reduce governmental budgets and move more responsibility to community care. A similar situation exists in Belgium, although there is no right to support, which often leads to very stressing situations in families. Although Bulgaria has much less financial resources to meet the needs, it is in a process of building a system of continuous support.

5. Stress on family system. Everywhere the stress on the family system is particularly high in the case of children with CISN, the more so in countries with less material resources. With the tendency of many governments to cut budgets, and stress community-based support, the risk is to increase family stress. Societies with a strong tradition of family culture and networking have an advantage.

6. Activity degree. Everywhere the low degree of activity is a problem in the case of children with CISN. Because they have multiple impairments, they rely on the assistance of other people to do something or to be involved in any kind of activity. This not only requires the actual presence of someone, but also that someone who should believe that activity is possible and important. The number of hours lost by doing nothing is a common complaint everywhere.

7. Assistive technology is available, but staff is lacking to instruct users (child, family and supporting staff) how to use them.

8. Participation degree. The degree of inclusion (participation in mainstream society, e.g. inclusive education, inclusive leisure activities) varies widely in Europe. Italy and Portugal are top inclusive countries, where most of the children, even with CISN, are included in regular education. At the other end of the spectrum is Belgium where almost none of the children with CISN participate in mainstream school life. Inclusion is explicitly stated as a right in the UN Convention of People with Disability. Yet, in practice, that right is not everywhere granted. In most countries, there are initiatives, also promoted by the government, towards inclusive education and participation in other domains of life. For the category of children with CISN, this entails many questions how to do it in practice. There is a need to find ways how to combine education and care or support.

9. Need to believe in possibilities. What appears from parents' experiences, is the need to find people who really believe in the child's possibilities to develop, to learn, to be active and to participate, and who make a real "connection" with a child, and who act accordingly. It can make a significant difference, whether the child "finds" such committed people, or not. If it doesn't, life is passive and of low quality.
10. Need for training and sharing expertise. The conclusions from this needs' analysis research also point to a need for training in the various domains outlined above. Expert knowledge is unequally distributed, is not always present within one country, and should be shared internationally.

Contributing authors

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Apostol APOSTOLOV PhD is a sociologist, conducting research in the areas of youth, multiculturalism, children with special needs, and education. In the period 1999-2008 he worked in British academia as a researcher and lecturer. In 2006 he gained his PhD from the European Research Institute, the University of Birmingham. He then took a Research Fellowship post at the University of Oxford, where he worked on a project, researching and promoting multi-agency work in children’s services. After Oxford, Apostol returned to his home country – Bulgaria – where he began work in the non-profit sector. Currently, he is based at Karin Dom Foundation, Varna - a centre for children with special needs. There he is working as a Business Development Consultant, being responsible mainly for the development of the Foundation’s Training Centre. He leads on various projects, including research and evaluation of the Foundation’s Early Intervention Programme.

Enikő BATIZ, graduated at the Faculty of European Studies of the Babeș-Bolyai University in Cluj-Napoca, Romania, specialising in European Studies; master in School Psychology in 2004. Since 2005-2006 teaching assistant at the Department of Applied Psychology of the Faculty of Psychology and Education Sciences at Babes-Bolyai University. Ph.D. student in Psychology at the “Psycho-Diagnosis and Scientifically Validated Psychological Interventions” Doctoral School of the Babeș-Bolyai University in Cluj-Napoca, under the academic supervision of professor Szamosközi Stefan Ph.D. Trained in the Feuerstein Instrumental Enrichment Basic Program and in the Learning Potential Assessment Device Program in the 2010 Summer School in Cluj-Napoca, both co-organized and supervised by the Feuerstein Institute in Jerusalem. She works with dynamic assessment of children, in the corrective interventions and cognitive development and in training activities for developing the competencies in applying both the mediated learning and cognitive enrichment methods.

Marc BENEDETTI. Psychomotor therapist by training, he worked, from 1977 until 1989, with children with complex and intensive support needs, and with severe challenging behaviours, in the region of Lyon, mainly in a Centre of Early Intervention, and occasionally in a department of paediatrics and of child psychiatry.

Since 1989 a resident of the Isle of Reunion, he joined the team of the CREAI (Regional Centre for the Childhood and Adolescence in Difficulties). In the early 2000s, he participated in the elaboration and the implementation of a similar project. At the request of Ministry of Social Security, National Solidarity and Ministry of health and quality of life of Mauritius Island, he participated, with Dr Th.Gillain, in the elaboration of an evaluation system: evaluation of the needs for the elderly and disabled in the Mauritius Island. Today he practices as a consultant with local associations (projects development, analysis of the practice, trainings). He has been working for 2 years with ASFA and was in charge to link the association and all other partners of the project Enablin +.

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Claudia CLAES, PhD. is a lecturer at the Faculty of Social Work and Welfare Studies of University College Ghent and visiting professor at the Department of Orthopedagogics, Ghent University (Belgium). She made her PhD with Robert Schalock, past president of the American Association of Mental Retardation. Her research interests include quality of life in the field of intellectual disability, person-cantered planning, and individualized supports. She is coordinator of E-QUAL, an expertise centre on quality of life studies associated to University College Ghent. She is a guest editor for a couple of journals on Quality of Life research. Contact: University College Ghent – E-QUAL, Voskenslaan 363 – 9000 Gent (Belgium) Claudia.claes@hogent.be

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Elisabeth HOUOT. Ergothérapeute de formation, elle a commencé à travailler, il y a 25 ans, auprès de jeunes enfants "Imoc" et polyhandicapés. Elle s'est installée il y a 15 ans à la Réunion, où elle a obtenu un diplôme de cadre de santé et s'est tournée progressivement vers des fonctions d'encadrement d'équipe. Après avoir obtenu le diplôme de directeur d'établissement spécialisé, elle dirige aujourd'hui le Centre d'éducation motrice. diradj.cem.sessad@asfa.re

Inge KROES has worked as a supervisor of children with special needs, as a psychologist in special education. She participated in a national study in the field of education-care. She now works as a course instructor and a psychologist specialist in supporting people with disability. She supervises children and young people and their parents in their development.

Jo LEBEER MD PhD, is a clinical consultant in dynamic assessment, enhancing of learning potential and inclusive education of children and adults with developmental disabilities or acquired brain damage. He made his PhD on the subject of plasticity and the ecology of development in children with brain damage.

Associate professor at the University of Antwerp, Faculty of Medicine (Belgium), in disability issues; he co-founded INCENA (Study Centre on Inclusion & Enablement). Visiting professor at the Centre for Cognitive Development, Diego Portales University, Santiago de Chile and at the Department of Psychology at the Babes-Bolyai University in Cluj-Napoca, Romania. He has been trained as ICF-trainer by the WHO and in Feuerstein's Structural Cognitive Modifiability and Mediated Learning Experience and has been giving seminars and workshops in many European and South-American countries as well as in Hong Kong. Coordinated several European Projects: Inside, In-clues, Daffodil and participated in Distincproject. www.sclm.uantwerpen.be

Jacques LODOMEZ, president of AP3, a parents-professionals association of people with multiple disabilities

Bea MAES PhD is professor of Special Needs Education at the Catholic University of Leuven. She is the founder of Multiplus, a centre for evaluation of children with multiple & severe disability. She is the president of the Special Interest Group of the IASSID (International Association of the Scientific Study of Intellectual Disability).

Aneta MORFOVA, completed her bachelor's degree in special pedagogy in 2003 with specialization in speech therapy at the University of Shoumen "Bishop Konstanitn Preslvaski". In 2006 she completed her Master's degree in speech therapy at the University of Sofia "St. Kliment Ohridski". Since 2007 she works as a speech therapist with children and adults with various language, speech and communication disorders.

Mia NIJLAND has worked in elderly care, care of the disabled, rehabilitation centres, day care centres, youth care and education. She was supervisor of people with special needs, group leader and team leader and now many years pedagogue, advisor and project leader in the domains: live, learn and work for children, youth and adults.

Reka ORBAN made her PhD on the history of special education in Transylvania (2008). Started to work as a special education teacher in an integrated special class for children with cognitive disabilities. Speech therapist. Since 2001 teaching assistant and since 2008 lecturer at the Department of Applied Psychology of the Faculty of Psychology and Education Sciences at Babes-Bolyai University. Experience with older People with Complex and Intense Support Needs from 1994, after joining the Faith and Light Community in Cluj-Napoca. Between 1998 and 2011 she was the responsible of the community and from 2011 she is one of the vice province coordinators. She works with learning disabled children as well as with cognitive delayed and with multiple disabled children, developing their cognitive abilities.

Katja PETRY finished her Master of Educational Sciences, option special education, at the University of Leuven in 1999. She obtained her PhD in Educational Sciences in 2006, with a dissertation on 'Measuring the quality of life of people with profound multiple disabilities: development of a questionnaire'. Currently, she is a senior academic staff member of the Parenting and Special Education Research Unit of the Faculty of Psychology and Educational Sciences of the University of Leuven, Belgium. She is specialised in the field of special needs education and sick children.

Christine PLIVARD is a physiotherapist with a specialisation in Psychomotor therapy; she also has a Masters in Training Engineering. She is Director of training, documentation, and resources at CESAP (Study & Training Centre for People with Polyhandicap), Paris, France. She the author of "L'évolution de la formation continue des professionnels de terrain", in Polyhandicap : processus d'évaluation cognitive (2013), under the direction of Régine Scelles et Geneviève Petitpierre. She also wrote "Comprendre et se former pour accompagner le jeune polyhandicapé dans ses apprentissages", In "Polyhandicap … le défi des apprentissages", La nouvelle revue de l'adaptation et de la scolarisation, Special issue n°6, July 2011

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Diana VARELAS has an MA in Clinical and Health Psychology. She Collaborated on a project for enabling parents of children with disabilities: Pais em rede: Oficinas para Pais, in Evora Region (Project funding by the High Commissariat for Health (Alto Comissariado para a Saude) and Fundação Calouste Gulbenkian) (2011-2013). She was a member of the Portuguese team in European projects since 2011 and coordinated the DAFFODIL Autumn Course.

Carla VLASKAMP PhD. Emerita professor in Special Needs Education ("orthopedagogics") at the University of Groningen, The Netherlands. She made her PhD in 1993 on the subject of an educational programme for children with profound intellectual and multiple disabilities, which she developed. This programme received much attention in Belgium and The Netherlands. She received the European 'Sint Vincent Prize' and is a Fellow of the International Association for the Scientific Study on Intellectual Disabilities.

Eric ZOLLA is Assistant Director General of CESAP (Study & Training Centre for People with Polyhandicap), Paris, France. He has a DESS degree in Cognitive Ergonimics, DEA of Sociology, DESS Social Policy and Management Strategy. He is the author of "Déficience visuelle et adolescence", in Réadaptation, 517 (2005); "La Gestion des risques dans les établissements et services sociaux et médico-sociaux", (2013, Ed Dunod); and "Réussir la relation d'aide : la bonne volonté ne suffit pas", in L'action médico-sociale au service des personnes handicapées, pour un juste renouveau (2013, edited by Elisabeth ZUCMAN, Ed Érès).

Élisabeth ZUCMAN MD PhD, is a doctor in physical medicine & rehabilitation; she was co-founder of the CESAP (Study & Training Centre for People with Polyhandicap), Paris, France. Honorary professor at Cnefei - National Study & Training Centre for Children with Special Needs (1985-1992), Paris. Honorary President of Groupe Polyhandicap France (GPF);and formerly advisor to CTNERHI (National Technical Centre for Study and Research into disability and maladjustment. Author of: "L'accompagnement des jeunes polyhandicapés évolutions, adaptation", In « Polyhandicap … le défi des apprentissages », La nouvelle revue de l'adaptation et de la scolarisation, Hors série n°6, juillet 2011. "Auprès de la personne handicapée, une éthique de la liberté partagée" (Vuibert 2007, Ed Erès); "Personnes handicapées, personnes valides : ensemble, semblables et différentes" (2012, Ed Érès). "L'action médico-sociale au service des personnes handicapées - Pour un juste renouveau", edited by E Zucman (ed) Co-Auteurs : M. Bille, G. Courtois, R. Delbos, J. Gaudinat, - Marie-christine Tezenas du Montcel, E. Zolla –Ed Érès (2013).

Presentation of Enablin+ Project Partners

Partner 1 University of Antwerp

P1 BE
University of Antwerp, project INCENA (Inclusion & Enablement); coordinator
Contact persons: Jo Lebeer & Beno Schraepen, INCENA Study Centre for Inclusion & Enablement
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Who we are?	The Centre who effectively participates in this project is called INCENA (Inclusion & Enablement). This belongs administratively to the Faculty of Medicine & Health Sciences, Department ot Primary & Interdisciplinary Care/ Disability Studies Research Group of the University of Antwerp. It also has a home at the Department of Social-agogical Work of the ArtesisPlantijn (AP) University of Applied Sciences, which belongs to the AUHA, the Association of University and Higher Education Colleges of Antwerp. INCENA provides bachelor training of “special needs educators” at the AP University of Applied Sciences; we contribute to undergraduate training (bachelor and masters of medicine and nursing) at the Medical Faculty in disability matters, and we provide various courses in continuing education in the domain of disability with rehabilitation professions, special and regular teacher training, educators & other support staff, project development in the domain of social inclusion and inclusive education.
Activities	Training in post-graduate and undergraduate levels, development of didactic materials, coaching projects, research and networking.

Since 1993 we have been organizing professional post-graduate training in Feuerstein's Structural Cognitive Modifiability, Mediated Learning Experience, Instrumental Enrichment, Trainings have been given in BE,NL, F, RO, NO, IT, CH & Réunion. We have done in-service training of teachers, educators & rehabilitation staff of children, adolescents and adults with learning difficulties and/or disabilities in the area of : modifiability of learning, plasticity of development & ecology, inclusive education. Workshops have been given in BE, NL, F, D, UK, ES, PT, IT, RO, HU, CZ, LV, NO, S, CH, TR, Hong-Kong, Brazil, Chile, Uruguay & Argentina. Courses in Mediated Learning Experience for parents of children with learning or developmental difficulties, and awareness raising activities about "learning enhancement and inclusion" have been done. We also have organized post-graduate training in the International Classification of Functioning, Disability and Health (ICF), in Behaviour Management for Caregivers of adolescents & adults with intellectual disability and/or autism; and a course about enhancing quality of life & inclusion in Down syndrome.

We developed didactic materials for teaching learning prerequisites; of trajectories for training educators of children, adolescents and adults with learning difficulties & training manuals. We set up and coach pilot projects in inclusive education and learning enhancement for children with developmental difficulties in mainstream schools; and we coach schools in transforming towards an inclusive, living and learning organization. We do research in the ecology of development of children & adults with neurological impairments; dynamic assessment of learning processes; implementation of ICF, epidemiology of autistic spectrum, follow up of down syndrome, ethical issues in disability.

International networking

Internationally we participate in several international networks: Inclues Network for Inclusive & Cognitive Education, International Feuerstein Institute (Jerusalem); International Association for Cognitive Education & Psychology IACEP; European Academy of Childhood Disability EACD www.eacd.org. We have collaborated in different European projects since 1992, all in the area of learning enhancement and inclusion: first a series of conferences within the HELIOS programme 1992-2000), project INSIDE (1998-2001); In-clues (Clues for inclusive & cognitive education) (2003-2006); Daffodil on dynamic and functional assessment (2008-2011) www.daffodilproject.org; Distinc (2010-2013). We were co-founder of the European Disability Forum and we function as a Disseminator of the inclusive assessment project of the European Agency for Development in Special Needs Education.

National networking

For the Enablin+ project, INCENA closely cooperates with professional and parents' organisations working in the field of profound and multiple disability in Belgium (among others: Multiplus, AP3, Belgian Rett Syndrome Foundation, Inclusie Vlaanderen, ApHRAM, GRIP, Lus vzw, Gezin & Handicap, etc.); with the Kinsbergen Centre , with schools and institutions giving support to children with PIMD; with the Cerebral Palsy Reference Centres of the various University Hospitals in Belgium; the BACD (Belgian Academy of Childhood Disability); with the Ministery of Education Policy Development Department, with the VAPH (Flemish Agency for People with a Disability), etc.

Role in the project Project coordinator+ collaborate in all work packages: needs assessment; research of good practices, competence definition, module development, pilot trainings, international training, publication and dissemination

Partner 2 Bureau Nijland Kroes

P2 NL Buro Nijland-Kroes, Expert Centre for Education & Care , Wijhe
contact person Mia Nijland mia@nijlandenkroes.nl , in collaboration with CALIBRIS
Wijhe. Tel 06- 23 67 9393

Participation in daily life is not obvious for children and youth with (complex or intense) dependency needs. For example, participating in education or work is not easy. They are also more limited in choosing leisure. Particular daily decisions are often (perforce) made for them instead of with them. Sometimes they need organizations that could help them. Nijland & Kroes is that kind of an organization. We provide support for the children and youth, but also for the parents, professionals or other educators.

We provide advice on (multiple) difficulties in care- or education. We also offer individual or psychological assessment, a separate environment which acts as a second home, coaching or training. We do research, develop training modules and instruments and professionalizing staff. Our way of working is ordinary, workable and adapted. We aspire to organize the possibility of including children and youth with a disability in normal schools. With these activities we promote social inclusion. The team of Nijland & Kroes consists of 15 staff. These are behavioural scientists, applied psychologists, coaches, trainers and other professionals. We are a team with a professional approach and a personal touch.

In our organization we strive towards the greatest participation and independency that is possible for children en youth. We would like them to take part in family and peer activities, to become autonomous.

Our motto presents our way of thinking: ‘Where normal and special meet’. Where meetings take place, there is always space for movement and change. Whether it’s about an advisement, an answer or solution, in our meetings we focus on the child in his or her situation and relatives. In this dynamism, Nijland & Kroes functions as a bridge. Through conversations and dialogues, we draw goals en help them to expend and achieve them. We offer opportunities in lasting results for development, education and connections. Our practical way of thinking and working suits perfectly in recent social trends and political decisions. In this way we contribute to a professionalization of care and education which is future-proof.

During the past year, Nijland & Kroes co-developed a specific EMB-training (oriented at people with multiple and profound disabilities) training offer for parents and professionals on MBO-level 3/ 4 (high school vocational training level). The new training is available for employees of schools and care institutions, who work with people who need intensive support in their daily life (also referred to as “the EMB group” in Dutch or PMD in English). Fascinating work that requires good staff. Nevertheless, we prefer the emphasis on the possibilities and opportunities of this target group. Supporting them needs interprofessional cooperation. We want to use the offer both for the target group and the facilitators who work with them, in their strength. A good ‘fit’ between the two is needed and contributes to well-being, optimal development and participation in society. Facilitating such a ' Quality-fit ' is what we seek with the new training. The offer is the first industry-certified training for *support assistants* in care and education. Interested parents can also participate.

The results of Enablin + will be included in the training and vice versa. This cooperation and the mix of input from all parties, will help keep the vocational training and future-proof. Also we hope that way the storms of transitions, youth care and appropriate education to resist and beautiful to create opportunities for the target group. Netherlands and Belgium are the active partners from Enablin + initially for training.

For further information please see the website:

www.mbo-emb.nl

Twitter: @MBO_EMB   Facebook: MBO-EMB

The role of Nijland & Kroes in the project is:

1. Leader of workpackage N° 3
2. Support associated activities of the other workpackages
3. Host a partner meeting in NL

The project has appointed 3 staff members directly working on the project (1 senior en 2 junior) including 1 manager, 1 employee support staff and management. The project can also be supported by students of Applied Psychology and Special Education for research of different tasks such as: research of best practices, needs assessment, development and en management support.

In the project Nijland & Kroes collaborates with Calibris, the national knowledge centre for vocational learning of care and wellbeing also responsible for the certification of learning on the job centres and establishment of qualifications. In line with these tasks they are also establishing qualifications in “zorg en welzijn en sport” (care and welfare and sport). This is all to support the on-the-job vocational training programmes.

They support employers to have sufficient staff with the right skills available. Independent of the situation Calibris acts as a consultant, initiator, intermediary, director, financier or researcher. They operate in a dynamic environment with a variety of stakeholders facing complex tasks and profound change. All with a clear goal in mind; a competent workforce and a well-balanced labour market.

Alongside Calibris we will also cooperate with the Windesheim and Saxion Colleges and Special education in the Netherlands. Nijland en Kroes have large network of professionals in care and education sectors as well as parents that are able and willing to contribute. We have followed a boy with multiple disabilities for many years. This boy is the real life case that underpins our holistic and interdisciplinary view and practical approach.

In parallel to the project Enablin+ we have been involved with the development of a curriculum (as part of “Mytyl schools” for children with cerebral palsy) for professionals in care and education. This could be a great example for the project.

Partner 3 CESAP

P3 FR CESAP, Comité d'Etudes, d'Education et de Soins Auprès des Personnes Polyhandicapées, Paris. Contact person : Eric Zolla ezolla@cesap.asso.fr

Founded in 1965 by a group of doctors , social workers and officials of the Assistance Publique - Hôpitaux de Paris (AP - HP) , the Comité d’Education et de Soins Auprès des Personnes Polyhandicapées (« Committee of Education and Care Beside of people with multiple disabilities ») is a non -profit association public consists of anyone interested in the issue of multiple disabilities (families , doctors, professionals) and who works towards three mainly lines :

1. Promote the early care of children with multiple disabilities and their families and assure this care over time by managing structures
2. Promote research and study on multiple disabilities . These studies and research intended to support both researchers from various disciplines (medicine , psychology, sociology , education, etc. .) As CESAP professionals and other associations of medical and social field.
3. Promote the development and training of the professionals who care for people with multiple disabilities through its training center " "CESAP formation, documentation, ressources"

CESAP is the founding member of the Groupe Polyhandicap France (GPF) - http://www.gpf.asso.fr/ , a member of “comité de liaison et d’action des parents d’enfants et d’adultes atteints de handicaps associés » (CLAPEAHA) - http://asso.orpha.net/CLAPEAH/ or the Association Nationale des équipes Contribuant à l’Action médico Sociale Précoce (ANECAMSP)- http://www.anecamsp.org/

Partner 4 Babes-Bolyai University

P4 RO

Babes-Bolyai University, Department of Applied Psychology, Faculty of Education Sciences & Psychology, Cluj-Napoca, Romania
Head of Department: Prof. dr. Istvan Szamosközi
Contact person Mrs Dr. Reka Orban reka.orban@ubbcluj.ro

The Department of Applied Psychology of the Babes-Bolyai University is involved in:

- providing guidance for training educators of children, adolescents and adults with learning difficulties
- Intervention: personalized and differentiated education for children with developmental difficulties in mainstream and special schools
- Research: in Dynamic assessment of learning processes

Networking: Internationally we participate in several international networks: Inclues Network for Inclusive & Cognitive Education, International Centre for the Enhancement of Learning Potential (Jerusalem)

The role of UBB in the Enabling+ project will be: leader of WP4 : testing the in-service training. This involves developing pre-and post-evaluation of the modular courses, implementing the courses, and publishing results. UBB will also be guiding the web-site development and management. UBB will cooperate with all other workpackages: data gathering, module development, implementation & dissemination

Partner 5 ASFA Association St-François d'Assise

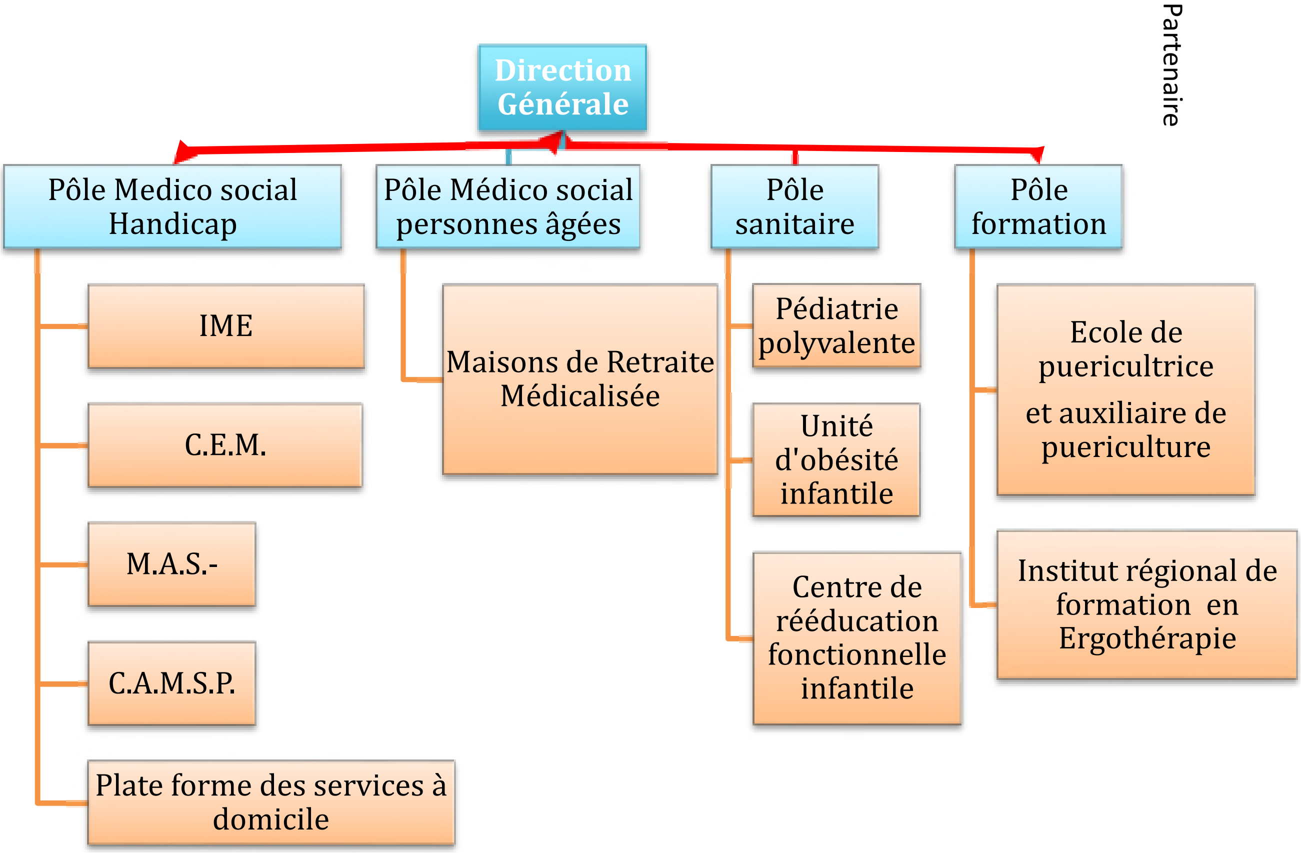
P5 FR

Association St-François d'Assise, Isle de la Réunion , Pôle Handicap
60, rue Bertin - BP 840 97476 Saint-Denis Cedex –
Tél. 0262.90.87.00 – Fax 0262.20.02.21
Directeur, Contact person : Elisabeth Houot diradj.cem.pfs@asfa.re

The Saint François d' Assise association or Asfa was created on June 6th, 1918 in Saint-Denis (Reunion island). Till the end of the 80's the Association developed simultaneously in parallel its hospital activity and its activity aimed at the elderly.

It is only from the 90's that the association started to invest in the medical and social field by reconverting a part of its health care activity and by creating and/or by starting again under its responsibility, a number of institutions and services intended to accompany children and adults in a situation of disability. It is the most important activity area of the A.S.F.A today. Finally, in 2000, a Training Deparment has been created to complete and to diversify the activity of the association.

The objectives of ASFA are to provide care and support to: elderly in difficulties and/or dependent, children and teenagers affected by chronic pathologies; children, teenagers and adults with a disability. ASFA manages a dozen establishments and services distributed in three competence domains: a health care department; a medical-social department and a training department.



The medical- social department consists of :

1. A Medical educational institute (IME)(80 places) and a SESSAD [Home Care & Support Service] (30 places). 30 people can be residential here; there are 50 places for a vocational training and 30 in a home support service.
2. A Center of Early Medical and Social Intervention (CAMSP) (100 places), created in 1995, has for mission the screening and the early support regarding disability, rehabilitation and social integration of children in their environment. Two “satellite” centres of the CAMSP have been installed, to work as closely as possible to the needs of the populations, one in Saint Benoît and the other one in Saint-Paul. An extension is planned to strengthen our presence on the West and the East of the Island by a doubling of the capacity.
3. A Physical Rehabilitation Center (CEM) (100 places) and a SESSAD (36 places).
   All these services for children and adolescents with cerebral palsy and PIMD (profound intellectual and multiple disabilities) are grouped in Sainte-Suzanne. The project allows to improve the quality of care, for the children and the teenagers, with the implementation of a quality approach (identification of the missions, the service provided, the users and their family). It takes into account the evolution of the needs of the population, in a methodological approach of an individualized project, centered around the triangle “education, learning and care”

The Training Department consists of :

1. An Institute of Training of Child Care Assistants (IFAP): the Institute trains every year 35 students. Their role is part of a global approach of the child, including supporting parenthood, with the aim of protecting and restoring its health and its autonomy, and favouring the social integration of the child in situation of disability, achieves of chronic disease or in situation of risk of exclusion

2. Pediatric Nurses' school: it was the first School of Pediatric Nursing which opened in the “ultra-peripheral” areas of France (the so-called “DOM”, departments d’outre-mer, literally “Department situated beyond the oceans”).
   it is approved for accomodate 17 students during 3 years. It forms since 2004, 17 professionals who want to specialize in the health of the child of the birth in the adolescence.

3. A Regional Institute of Training in Occupational therapy (IRFE). The IRFE is approved for accommodation facilities of 20 students, in partnership with the University of Réunion.

THE ASFA created a theater company “Ti pas Ti pas "(step by step). In 2012 the group knew an enormous success about the famous festival of Avignon with its show “La vie c’est comme ça (that’s life) ". This troop consists of 15 young people in situation of disability who are taken care within the Centres and medical-social services of SAINT - SUZANNE'S ASFA. Through dance and theater workshops in particular, the artists have worked hard to set up this musical comey, which tells the love story of “pépé Paul et mamie Rosie”.

Look at this site to watch their performance: http://www.asfa.re/accueil.php?centre=asfa&m=10&sm=1

The role of ASFA in the Enablin + project :

- The contribution of data on the needs for the multi-handicapped children, and the needs for staff training (nursus and education staff), the organization of the continuous support
- Share the experiences of the theater group with children / teenagers, as example of best practice
- Participation in 5 partners' meetings
- Collaboration with the creation of the modules of in-service training for the educational and supporting staff looking after multi-handicapped children
- Participation in the implementation of the modules of in-service training, and a project of activation and integration of multi-handicapped children
- disseminate the results of the project by organizing a colloquium / seminary

Partner 6 Karin Dom Foundation

P6 BG Karin Dom Foundation, Varna
contact person Apostol Apostolov aapostolov@karindom.org

Karin Dom was founded in 1996 with the mission to support the social inclusion of children with special needs and their families through professional services, advocacy, and raising public awareness. Over the years Karin Dom has become recognised as a ‘centre of excellence’ for providing services for children with special needs and their families. The team of Karin Dom consist of 50 staff, 35 of them are specialists working with children with background in physiotherapy, psychology, speech language therapy, special education pedagogy, social work. Every year, at least 10 people from Bulgaria and abroad volunteer at Karin Dom. The team of specialists participates regularly in national and international trainings for upgrading their qualification.

1. Karin Dom is a Centre for Rehabilitation and Social Integration of Children with Special Needs and Their Families. Our multidisciplinary team works with children with physical and intellectual disabilities, autism, learning difficulties, multiple disabilities. Professional services are offered to 35 children a day. We work with 180-220 children per year from the region and the country. For every child is made multidisciplinary assessment and ellaborated an individual service plan. The services include early intervention for children

aged 0-3, physiotherapy, occupational therapy, Montessory sessions, counselling, play-group therapy, parent support groups, therapy for children with autistic spectrum disorder, pre-school learning, basic life-skills programme, sensory room therapy.

2. Karin Dom is a Training and Resource Centre, licensed as a Vocational Training Centre

Our services include - on-site assessment of the needs of the trainees, sharing the goals of the training and the expectations of the trainees, developing training programs tailored to the trainees' specific needs, on-site seminars – lectures and demonstrations, seminars at Karin Dom – lectures, case studies, discussions, work in small groups, demonstrations of practical sessions with children, preparation and presentation of training materials, distribution of informational leaflets for parents, practical training and consultations to students, volunteers, parents, work meetings, conferences. The Centre offers a combination of theoretical and practical trainings for specialists working with children with special needs, mass teachers, assistants and parents. We are a Training and Resource Centre since the year 2001 and were encouraged by the European Commission to disseminate our experience to professionals in the country (this was a two year project awarded Grand Prix of the Delegation of the European Commission in Bulgaria). Throughout all the years we have invited foreign trainers – professionals having experience with children with special needs. Lots of our methods and practices are advanced for the country and they are not thought in Bulgarian universities. We are recognized as having expertise among professionals on a national level and provide trainings on a regular basis.

3. Karin Dom's Early Intervention Program – home-based service

This is the newest service that started in September 2010. Karin Dom's program serves children 0 to 4 who are at risk of or have a developmental delay or a disability. It follows the family-centered approach, working with parents and other family members to learn how to support their children in a natural environment. The program seeks to prevent the abandonment of children in institutions, thus contributing to the de-institutionalization process in Bulgaria.

The role of Karin Dom in the project is to host a partners meeting and to support the project's activities - needs assessment; research of good practices, make video samples of good practices, test training module, participate in international training, publication and dissemination.

Partner 7 Fondazione Don Carlo Gnocchi

P7 IT Fondazione Don Carlo Gnocchi, Milano, Centro di Riabilitazione Vismara (= service provider and vocational training organisation).
Contact person: Dr. Marina Rodocanachi marinarodocanachi@gmail.com

Don Carlo Gnocchi Foundation is a non-profit Institution founded by Don Carlo Gnocchi, a priest from Milan who became known as "the father of the crippled" and beatified on 25 October 2009. After the Second World War Father Gnocchi took shape in 1945 for orphans and children with disabilites victims of war. In 1952 this activity became the Pro Juventute Foundation. Once the emergency for the disabled children during the war was over, the charitable goal of the Foundation was addressed to a more serious problem for children in those years: poliomyelitis. In 1955 Father Carlo started his last and greatest challenge, a pilot Centre representing the synthesis of his rehabilitation methodology.

The Institution during the years passed through different reorganizations and transformations:

- **NON-PROFIT CHARITY FOUNDATION** (1952)

- **IRCCS** (Scientific Institute for Research, Hospitalization and Care - 1991)
- **ONLUS** (Non- Profit Social utility Organization - 1998)
- **NGO** (Non-Governmental Organization - 2001)

Today the Don Carlo Gnocchi Foundation continues to take care of disabled children, who have acquired and inherited complex pathologies; of patients of all ages who need neuromotor, cardio-respiratory and oncology rehabilitation; persons with multiple sclerosis, amyotrophic lateral sclerosis, Parkinson's disease, Alzheimer's disease or other crippling pathologies; of the not self-sufficient elderly, terminal cancer patients, patients with serious brain damage acquired or in a prolonged vegetative state.

Beside the social, medical, educational and health activities, the Foundation is active in scientific research, technological innovation, training at various levels and international cooperation. Credited as an Institution of Hospitalization and Scientific Care (IRCCS), particularly for the Centers of Milan and Florence, today the Don Carlo Gnocchi Foundation has more than 5700 operators amongst the personnel and professional collaborators, for whom there are constantly available training and updating programs. The services are provided through an accreditation with the National Health Service in about thirty Centers, grouped together in eight territorial Areas in nine Regions.

The participation of Don Gnocchi Foundation to the Enablin + project will involve the UNIT OF CHILD NEUROLOGY, PSYCHIATRY AND REHABILITATION who deals with 7 centres and 5 ambulatory services for child rehabilitation and education, with one of these five centres: VISMARA INSTITUTE in Milan.

Partner 8 Universidade de Evora

P8 PT

UNIVERSIDADE DE ÉVORA

Universidade de Evora. Centre for Research in Education and Psychology from the University of Évora (CIEP-UE)
Contact person Prof. Adelinda Candeias aac@uevora.pt
Colégio Pedro da Fonseca | Apartado 94 | 7002-554 Évora
ciep@uevora.pt | tel: +351 266 768 052

The University of Évora was the second university to be established in Portugal. After the founding of the University of Coimbra in 1537, it has been felt the need for another university to serve the South. The University of Évora is one of the universities in the Portuguese public higher education system and therefore aims:

- The production of knowledge through scientific and artistic research, experimentation and technological and humanistic development;
- The socialization of knowledge, providing to the traditional student population and the working population, the academic qualification at bachelor's, master's and doctorate, ad hoc training courses and informal training throughout life;
- The transmission of knowledge to the community in order to innovation and business competitiveness as well as the modernization of public services and social and cultural development of the community as a whole;

ciep|ue
Centro de Investigação em
Educação e Psicologia da Universidade de Évora

The Centre for Research in Education and Psychology from the University of Évora (CIEP-UE) started activity in 2007 and was created by researchers from the Departments of Education and Psychology, from the University of Évora, and develops R & D activities in this areas.

The CIEP's research team coordinates several research projects with external funding, whose results have been published nationally and internationally at various events and scientific publications.

Having as main concerns the investigation in the field of Education and Psychology and respective interfaces, the following research groups, as defined in 2013, reflect the organizational structure of his scientific activity:

- Group A: Educational Policies, Institutions and Territories
- Group B: Development, Learning, Inclusion and Well-being
    - B1 Line Learning, Teaching and Assessment
    - B2 Line Development, Risk and Inclusion
    - B3 line Welfare, Psychopathology and Development

The B3 Line was created in 2014 to respond to the investigation that has been achieved in the context of the factors responsible for the welfare and the psychopathology throughout the development. The CIEP-UE publishes the journal Education: Issues and Problems since 2005 and regularly organizes colloquia and conferences in order to strive for scientific debate concerning the major issues that the current organization and social project lay in the fields of education and psychology.

The UE/CIEP train bachelor & masters & PhD and organize post graduate studies (totalling 2000 students) in the field of Education, Psychology, Special Education and Psychomotor rehabilitation. 40% of the income comes from projects. Within the NUFOR (we also provide continuing education in the domain of disability with rehabilitation professions, special and regular teacher training, educators & other support staff, project development in the domain of social inclusion and inclusive education. The UE participates in international programmes within Erasmus (mobility of students and teaching staff), European research funding and other international research funding, Life Long Learning projects, Health and Social Affairs.

Past & present activities of CIEP and NUFOR include:

- Training:
    - since 2002 Professional post-graduate training in Special Education and Psychomotor Rehabilitation.
    - In-service training of teachers, educators & rehabilitation staff of children, adolescents and adults with learning difficulties and/or disabilities in the area of: Dynamic assessment; Inclusive education, Portfolios, ICF. Workshops have been given in Brazil, Spain, Italy, Belgium, Swiss, United States of America.
    - Coaching with parents from children and adults with disabilities (enabling parents to enabling children), in association with the national association ‘network of parents’.

- Development of didactic materials for teaching learning prerequisites; of trajectories for training educators of children, adolescents and adults with learning difficulties & training manuals
- Intervention: Pilotproject inclusive education for children with developmental difficulties in mainstream schools; Coaching schools in transforming towards an inclusive, living and learning organisation
- Research in Dynamic assessment of learning processes, the implementation of ICF in Portugal, the use of Portfolio to improve more inclusive assessment and education.
- Networking: Internationally we participate in International Association for Cognitive Education & Psychology IACEP; and DAFFODIL Group - www.daffodilproject.org. National: we are partners in a national network – Oficinas de Pais – that works in coaching to enabling parents of children with disabilities.

University of Evora/CIEP as a partner collaborates to all work packages: needs assessment; research of good practices, competence definition, module development, pilot trainings, international training, publication and dissemination. The Portuguese team is constituted by professionals and parents. Professionals come from institutions/associations (University of Evora, APPACDM and CERCI) that represent special needs support centre working with severely affected children and parents' organisation (Dar Resposta: www.darresposta.com).

Associated partners

Each partner collaborates in its own region with a local/regional/national network, which consists of vocational training providers (in continuous learning system); service providers and parents' organisations

The Enablin+ Consortium works together with all experts dealing with the target group of children with CISN, e.g. the Special Interest Group of the IASSID (International Association for the Scientific Study of Intellectual Disabilities) for Profound and multiple disabilities; specialists in alternative communication members of ISAAC; expert-centres for children with CISN such as Multiplus (University of Leuven); SUSA (Université de Liège, de Mons); parents associations in various countries; Inclusion International; Réseau Lucioles in France, etc.

How and why this partnership?

- To be multidisciplinary (education, school, medicine, rehabilitation)
- To have parents as well as professionals as a source of knowledge
- To have training institutions, who can easily organize in-service training modules
- To have research institutions with students doing master theses to do the research
- To have service providers who can apply the modular training and report experiences

Appendix 1 Needs analysis questionnaire

Questionnaire for professionals on the needs of children with intense and complex support needs

ENABLIN+ project is an initiative of 8 partners belonging to different workplaces and fields – universities, in-service training providers, service providers, expert centres, coming from 8 different European countries. It is intended to strengthen social inclusion of children and young people (aged 0-21) having intense and complex support needs, facilitating also their formal and informal caregivers, enhancing school integration, home-based assistance, tailored to their needs, with sufficient services in order to respond to needs for assistance regarding health, education and social participation. Within this context, the goal is to develop a system of interdisciplinary in-service training, involving both parents and professionals, so as to improve quality of life of children and youngsters.

In order to better identify the contents of this training, as well as the required skills for an excellent support service, we would like to have some more information about the children's needs, as well as the needs of their caregivers and supporting people.

This survey is divided in 3 parts:

I. Who are the children having intense and complex support needs?
II. Examples of good practices of care & support
III. Personnel's and families' training needs

You are kindly requested to send back this document sticking to the following deadlines:

- Part 1 before 30 June 2014
- Part 2 and 3 before 1 September 2014

To: ……………………………….

Thank you for your collaboration. Best regards

The Scientific Committee: Dr. AM Boutin (Cesap, Paris), Prof. Adelinda Candeias (Univ. Evora), Dr. Marina Rodocanacchi & Anna Dal Brun (Don Gnocchi, Milan), Prof. Dr. Jo Lebeer (University of Antwerp), Dr. Reka Orban (Babes Bolyai University Cluj-Napoca), Marc Bénédetti (ASFA, St Denis)

This survey was filled out by:

	Medical doctor
	Psychologist
	Special needs educator
	Daily life personal assistant
	Social worker

	Teacher	
	Educational psychologist	
	Speech therapist	
	Physiotherapist	
	Occupational therapist	
	Other, please clarify	

Your age :	
Your country :	
Your education:	
Your profession :	

You work for :	
Special school	
Institution for children with disability	
Mainstream school	
Home-based support service	
Other support service	
Rehabilitation service	
University	
Vocational Training Organisation	
Other, please specify	

I. Who are the children having intense and complex support needs[10]?

1. Situation of children/youngsters you work with

Age		number
0-5		
6 - 12		
13 - 21		
	Yes	Please specify
Young people having a combination of severe limitations		
Especially in the cognitive area		
In the motor functions		
In the sensory field (audio-visual)		
Other health problems. Please specify :		
Severe problems in language and communication		
Severe learning difficulties		
Severe mobility problems		
Severe difficulties in personal autonomy		
Severe participation problems		
Which are the most frequent environmental barriers? They are the result of a lack of (many possible answers)		
	If yes	Please specify
Technical supports		
Money/financial support		

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[10] These children are often identified with the term « polyhandicapés » in French, « PMID » in English, « EMB » in The Netherlands. The aim of the project is to focus on needs. We would like to use the definition of Saramago et al, 2004, based on the ICF (International Classification of Functioning) created by the WHO.

Access to buildings		
Proper attitudes		
Personal assistance in daily life		
Professionals' support		
Access to mainstream schools		
Opportunity of being included in leisure activities		
Families' support		
Other, please specify		
Where are they? (more than one possible answer)	If yes	Please clarify
Special school		
Included within mainstream school		
Staying with their family		
In special institutions for people with disability		

If you wish, you can add any comments

2. *EVALUATION MODELS/ NEEDS ASSESSMENT of people with intense and complex support needs*

2.1 Which are the evaluation models that you use?					
2.2 Which assessment tools do you use?					
Name, designation	authors		references		
Do you use any tool that you made by yourself?			How did you build this tool		
Are you satisfied with the tools that you use?	Very much	sufficient	So so	A bit	no

Which are the strong and weak points	Strong points	Weak points

3 Bibliography:

Please write down the 10 main bibliographic references, both national and international, that you consider interesting about these themes:

- The concept of « need » in general
- Intense and complex support needs
- The needs that need to be responded to in order to assure access to a good quality of inclusive life

	Authors (year), Title, (title magazine or book), vol., pages (publication site : publisher)
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	

Please send back this part before 30/6/2014 to …………………………………

II. Examples of good practices

Do you know any example of good practice within the following domains?

Domain	**Project title**	**Place**	**Country**	**Contact (e-mail, telephone)**	**Web-site**	**Any video available?**
1. Continuity of care						
1.1 Early intervention						
1.2 Medical follow-up						
1.3 Global treatment follow-up						
1.4 Other						

2. Inclusion						
School inclusion						
Social inclusion						
3. Management of behaviour						
4. Communication						
5. Family care						

Why do you think it represents a good practice?

III.Training needs

Which kind of needs do you think professionals or parents may have, in the following domains:

Domain	Particular issues	For whom?							
		Everybody	Physicians	Therapists	Educators/ Personal assistants	Teachers	Parents	Social workers	Others
Knowledge of profound & multiple disability									
Continuity of follow-up									
School inclusion									
Social inclusion									
Management of behaviour									
Communication									
Physical care									
Health									
Family care									
Learning process									
Cognitive modifiability									
Quality of life									
Support techniques in daily life									

Pain and physical suffering									
Ethics									
Affective & sexual life									
Body and sensory approaches									
Others, please specify :									

Please send back part II and III before 31/8/2014 to ….

THANK YOU FOR YOUR COLLABORATION

Appendix 2 –*Polyhandicap- Report of French Working group*

Translation of French text published by CÉRÉ (CESAP Council for Studies, Research and Evaluation)working group: -

Author: C. Plivard, G.Taussig, Ph. Rosset, Dr A.M. Boutin.
Edited by: Prof. G. Ponsot, Dr. F.A. Svendsen, Ph. Camberlein – 2009
Published in 2009, in 2014 part of this text is still current

The idea of polyhandicap/multiple disability appeared in the 60s and was used to characterise a population who found no place in the structures for people suffering from motor disabilities (Cerebral Palsy in particular, for which Pr. Tardieu has already shown the differences in terms of the cognitive abilities they retain) and people with mental disabilities whose motor skills are not affected. From the beginning, this was a **categorisation based on exclusion**, involving people with disabilities who could not find a place in the specific support methods offered at this time. These people were gathered together using the term ***polyhandicap.*** This produced a **typology for people with multiple disability**: serious disability combined with motor deficiencies and severe or profound intellectual deficiencies +/- other serous deficiencies. The specific focus on people with multiple disability made it possible to understand better their problems and their skills, and above all to develop methods of support that were better adapted to their specific needs.

In parallel, other categories of "exclusion" were being better understood, particularly people suffering from PDD (Pervasive Developmental Disorder, autism, psychosis with or without mental deficit), who benefit from support that was more appropriate for their specific needs.

In the 80s, the work of the CTNERHI defined the different fields of "combined disabilities" and gathered them together in the term ***multihandicap*s**:

1. ***Plurihandicap*:**
Circumstantial combination of 2 or more deficiencies without mental deficiency (exc. deaf/blind)

2. ***Surhandicap*:**
Secondary disability as the result of the initial disability, idea reserved above all for psychological overburdening in people presenting another deficiency (motor, sensory, intellectual…)

3. ***Polyhandicap*:**
Serious disability combining severe mental deficiency with motor +/- other deficiencies. NB that at the time (**before the work of Wood**) the term "handicap" was used more for deficiency.

C**urrently,** the term polyhandicap and the ideas it covers are progressively being challenged and as a result replaced by ***handicap complexe et de grande dépendance*** (disability with complex needs and major dependency)

There is also a trend towards grouping different types of deficiency and incapacity together as a result of their **situation of high dependency.** This transversal approach poses the risk of eliminating the specific features of multiple disability, which must be noted and taken into account as an essential element for providing suitable support.

The idea even of "dependency" must be clearly defined according to whether it is at the level of:

- **Physical dependency** (above all motor). It is better to be precise and,in this case, discuss **(independence)**
- **Psychological dependency**, decision making dependency, which comes under **autonomy**

These two categories of dependence have very different impacts at the level of personal characteristics, their needs, and the level of representation

A person with multiple disability is in a situation of physical dependency and a lack of decision-making autonomy. But this characteristic of "dependency", even though it is a major issue for the position of a person with multiple disability, does not provide the specificities that must be taken into account to provide adapted support.

These specificities are:

1. In terms of the lesional damage, whether it is early damage to the immature Central Nervous System, which could be genetic, as is the case for numerous rare diseases or those linked to pregnancy or child birth, as for *IMC* or Cerebral Palsy, or the consequence of cranial trauma and early infection, or other factors, whether identified or not.
2. This lesion may be:
   - Fixed or progressive
   - Isolated or combined with other damage (sensory, somatic, peripheral SN or other…).
3. This lesion produces deficiencies causing major functional consequences: **severe intellectual, motor, and -other deficiencies (sensory/somatic/metabolic, etc.), altered psychological development, often epilepsy.**
4. These functional consequences are themselves the source of often serious disability:
   - **Somatic, visceral (respiratory, digestive)**
   - **Orthopaedic deformity**
   - **Behavioural problems**
   - **Worsening of the cognitive deficit by the accumulation of multiple deficiencies**

   These disabilities may be at different levels but are always severe:

   - Are always progressive (whether the initial lesion itself is fixed or progressive)
   - Produce a condition of serious disability,
   - Severely limit motor independence and psychological autonomy
   - Affect communication/activity/participation
   - Influence the quality of life
5. This situation can be worsened or improved by the environment: which can provide the features that facilitate or, on the contrary, that limit activity and participation, and so affect the quality of life of a person with multiple disability. These three levels determine:

   At level 1, **the lesion. The medical approach** presents the possibility that etiological research may find preventive or curative measures (anti-epileptics for example).

   At level 2, **the deficiencies and their functional consequences.** Suitable **education and rehabilitation measures,** material and human **compensation** have been devised aimed at developing remaining skills to compensate for deficiencies and their functional consequences.

   At Level 3, ***Surhandicap/multiple disability***. In the last few years this is the main area where advances have been made in **therapeutic measures and support** aimed at eliminating or, rather, limiting surhandicaps/multiple disability.

   At level 4, **the environment**

To eliminate the factors exerting a negative impact on the quality of life and encourage those that improve it, improving the material environment in terms of architecture, accessibility, organisation, routine, are all proposed, as well as measures involving the human, familial and professional environments, which must be supported, informed and taught.

A consensus now exists on the fact that **support must be personalised.** All that is needed now is to collect the problems, on the basis of the polyhandicap/multiple disability typology.

In fact, although the **etiologies of the lesions are different, the grouping is based on a certain homogeneity in their functional results and the multiple disability most frequently encountered make it possible to develop more suitable support methods on a therapeutic, educational, rehabilitation level and in terms of human, material, financial and organisational compensation. It is in this sense that the polyhandicap typology should be retained, to specify and define so that it is possible to pursue the proposed approaches to adaption and support.**

Among the numerous definitions suggested for polyhandicap, that of the GPF seems to us the most applicable to the realities it covers. **Polyhandicap is** defined as “the specific life situation of someone presenting a brain malfunction, early or in the course of development, with serious consequences with multiple progressive manifestations for motor function, perception, cognition, and building relationships with the physical and human environment. It is a progressive situation of extreme physical, psychological and social vulnerability, in the course of which, some people may present passing or long-term signs on the autistic spectrum.

The complex situation of a person with polyhandicaps makes it necessary to use specialist techniques for his/her education and life plan. These include medical monitoring, learning, relationships and communication, to waken sensory-motor and intellectual abilities, with the aim of making it possible to exercise optimum autonomy.”

Preserving the specific nature of polyhandicap, for the above reasons**, does not exclude the question of people with different disabilities “living together”, to:**

- Avoid over segregation
- Encourage pleasant interaction between different people
- To open up different fields of support action

However, there is a risk that this could respond less well to the specific needs of people with **polyhandicaps**: on an architectural level, an organisation, routine, and less suitable quantitative and qualitative human services.

There is also the question of disabilities acquired later in life. If, as a rule, these do not respond to the criteria of early appearance of the cerebral lesion, in certain cases, it seems that their needs could be covered by the support structures for people with polyhandicaps, with however, provisions in the case of acquired disabilities:

- Functional damage and surhandicaps cannot be superimposed and require slightly different rehabilitation and therapeutic approaches.
- The family and professional support are different and this has a major impact that should be taken into account
- Finally, doesn’t the family environment (partners, children) deserve consideration when it comes to organising care?

Finally, links remain to be established with organisation for people suffering from related **disabilities**:

- IMC, (cerebral palsy),
- Rare diseases
- Cranial trauma,
- Rare disabilities/plurihandicaps,
- PDD
- epilepsy

Who, each in their own fields, increase the etiological dimensions, the functional results individual to each of these entities and develops support methods that could be used with benefit by people with polyhandicaps.

In conclusion:

It appears important to preserve polyhandicap typology and to specify and define it so that it is possible to pursue the proposed approach to adapted support.

However, preserving the special features of polyhandicap does not exclude the question of people with different disabilities “living together” and the question of acquired disabilities.

People should be housed so that it provides the best possible response to their needs and taking into account their individual situation.

Links should be made with people suffering from related disabilities so that all are in a position to benefit from each other.

enablin+

Enabling & Including Young People
with Complex & Intense Support Needs

University of Antwerp INCENA- Inclusion & Enablement	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	Association St-François d'Assise – Pôle Handicap	Karin Dom Foundation – Varna Centre for Children with Special Needs	Rehabilitation Centre Vismara - Milan	Centre for the study of Psychology & Education - Evora
Belgium	The Netherlands	France	Romania	Isle de la Réunion-FR	Bulgaria	Italie	Portugal

Education and Culture DG
Lifelong Learning Programme

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