



## Workpackage 2 – Deliverable 4a

# Report

# Continuous Support Systems and Good Practices towards Inclusion, Activation and Participation of young people with complex and intense support needs

Jo Lebeer & Heleen Neerinckx (Editors )  
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## Colophon

Continuous Support Systems and Good Practices towards Inclusion, Activation and Participation of young people with complex and intense support needs

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# Introduction

Although it is beyond any doubt that people with very severe disabilities, who are dependent on support for almost everything (eating, moving, communicating, learning, bodily care, relating, playing, etc.), have a need for continuous support and teamwork, it is less clear what kind of support is needed, and for what purpose. This generates controversy, in the scientific world, as well as in daily practice. According to the UN Convention on the Rights of People with a Disability, children with intensive and complex support needs – as we prefer to designate them by their needs rather than by their deficiencies – have a right to “participation” and “personal development. But many questions remain: what kind of participation, with whom? What for? What kind of activities can be done together with “typically developing” children? What kind of activities can be done *tout court*? Is there any possibility of learning and developing, or is it all fixed after a certain time? What kind of support is needed to allow this “universal right” to become realizable? Should efforts be oriented to passive participation or active participation? To trying to increase the repertoire of activities, or to just “happiness”? How much support and what kind of support is needed?

The answers to these questions depend on the conceptual framework one has. In recent years, there are here and there initiatives which try to implement the UN convention, in the sense of facilitating more participation, rather than separate caring systems, and promoting activity, even for children with the most severe impairments. Sometimes the “barriers against participation” originate not in the child, but rather in the environment. Barriers can be of bodily nature (e.g. an impossibility to generate words, or understand spoken language) but can also lie in the environment (e.g. the absence of a centre which looks in to alternative communication possibilities, of people who take the time to invest in alternative communication, hence a barrier in attitudes and belief systems). This has been conceptualized in the International Classification of Functioning, Disability and Health (ICF), as has been described in the Needs Assessment Report (WP1).

In this report, we would like to explore systems of continuous support and methods facilitating activity and participation. We start with an analysis of the existing systems of support in the different partner countries, focussing in particular on children with CISON. We wonder how far the “official” support systems of the countries are with the organisation of support of the most in need, because this is what they signed when ratifying the UN Convention. This will be *Part I* of this report. We also would like to analyze the underlying resistances against deinstitutionalisation and inclusion, as well as belief systems regarding activation and inclusion.

*Part II* describes a selection of “*examples of good practice*” in the various partner countries, combining adequate support as well as initiatives in activation and participation in education and other domains of society, which comply, fully or at least partly, with the principles of “quality of life” as defined by Schalock & Verdugo. First we will define the criteria of selection, and how the process of selecting criteria was made. This section will just give a selection. It does not pretend to be complete. As the nature of this project is a structural growth process, undergoing permanent changes, if anyone thinks that a certain project offers such an innovative quality, the reader is invited to nominate a candidature. Part II will therefore focus on concrete projects or centres.

*Part III*, on the other hand, will focus more on methods and ways of application. The idea is to present a panorama of approaches, which facilitate main domains, such as: learning, communication, health and self-care, participation, movement and mobility, arts and play, communication. Equally, this part does not pretend completeness, but it wants to be a “site under construction”.

Case reports will be presented, which are illustrative of examples of good systems of support, as methods of activation and participation.

Part I Description of systems of support.

On the basis of enquiries sent to partners in 8 EU countries or regions

- What financial allowances are given to children (0-21) with very severe multiple disabilities and complex needs?
- What services exist for this group? How are they financed (public – private)
- Are there any data on evaluation of services by end users (families)?

Part II In search of examples of good practice of innovations which try to improve quality of life, in particular: activation (development and learning) and participation (inclusion)

- What are examples of good practice: How the process of arriving at quality criteria was done
- Examples are described on the basis of nomination by the Enablin+ partners in 8 EU countries, who each had to make enquiries in their own national networks

Part III Approaches and methods in supporting care & education

A selection was made on the basis of methods and approaches of integrated support to children with CISN, which are not in the first place innovative – some of them may exist already for years – but which each in their own way aim at improving quality of life, in the domains as defined by Schalock & Verdugo.

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# **Part I Current support systems in seven European countries for children with complex and intense support needs**

# Current support systems in Belgium

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## Intro

The Belgian Federal state has four regions, each having their own regional government: Flanders, Brussels, Wallonia, and German-speaking Belgium. The Federal Government has different powers than the Regional Governments. The Federal Government has the power to allocate allowances and governs medical care and health insurance aspects. The Regional Governments govern aspects of support (people, technical and institutional) and education. Regional Governments operate in quite an autonomous way. This means that education and support systems vary quite a bit between Flanders and Wallonia.

## Financial allowances

Children with a disability are entitled to a financial allowance until the age of 21 from the Federal Government (Ministry of Social Affairs), regardless of the parents' income. The allowance is proportional to the degree of disability. This is determined to the largest degree by a list of medical conditions (pillar I), partly on the degree of restrictions in functioning and activities (pillar II) and partly on difficulties regarding external factors such as distance to centres, need for technology etc. (pillar III). There are thus some ideas of the ICF incorporated in the determination of the need of financial support. The child is evaluated briefly by a medical team of the Federal Government, whose doctors decide on the basis of existing medico-psychological and other objective reports made by others, on interviewing the parents and filling out a checklist. Appeal is possible.

As from the age of 21, those individuals with a disability who are not able to gain an income in a regular employment, are entitled to a life-long financial allowance. This is enough to survive, but it lies below the national minimum salary, so it is not enough to survive in an autonomous way.

Persons with pronounced or severe disability (defined as > 66% potential income loss, and to be assessed by the Federal Ministry of Health medical service officials) benefit from fiscal facilities: greater tax exemption on income from wages, a reduction on taxes on buildings and land, on vehicles (cars and motor-cycles), exemption of traffic tax. Also people with severe disability are entitled to a reduced tariff on electricity, gas and telephone services.

## The organisation of support for people with a disability

In each of the 4 regions of Belgium, there is one central funding Agency for the Disabled. In Flanders it is called the VAPH ([www.vaph.be/vlafo/view/nl/204713-en.html](http://www.vaph.be/vlafo/view/nl/204713-en.html)), in Brussels the "PHARE" (Personne Handicapée Autonomie Recherche), in Wallonia the AVIQ (Agence pour une Vie de Qualité - [www.aviq.be/handicap](http://www.aviq.be/handicap)) and in German-speaking part the "Dienststelle für Personen mit Behinderung" ([www.dpb.be](http://www.dpb.be))

The VAPH aims to promote participation, integration and equal opportunities for people with disability in all areas of social life. The ultimate goal is to help people with disability lead a better and more independent life. The VAPH does this by subsidising facilities and services for people with disabilities:

### *Equipment and modifications*

To better organise his or her daily life a person with a disability is entitled to a benefit to cover the cost of a piece of equipment or modification to his or her home or car (e.g. adapted bathrooms, lifting equipment, adapted car, equipment for the blind).

### *Current services and facilities*

The VAPH subsidises services and facilities which provide care for persons with disability through daytime or residential facilities, care or guidance:

1. early intervention & family guidance services: they give advice to parents at home, 1 per 2 weeks of 1 per month. This is considered largely insufficient because they don't have the opportunity to work daily with children.
2. Functional assessment centres (C.O.S. or Centres for Developmental Disabilities): these centres offer a comprehensive functional diagnosis, of various aspects of development. They work with a multidisciplinary team (MDT), which is mainly classifying and in function of orienting the child to a type of service or school, or determining the degree of functional impairments. They give advice how to stimulate the child's functioning or participation.
3. Multi-functional centres offering occupational therapy, speech therapy, physiotherapy, non-school education. In many cases, these centres are located on the same campus as special schools
4. Centres for children who are not going to school: offer day-long activities and therapies. They mostly have children with profound intellectual and multiple disabilities (PIMD). They now also belong to the "multifunctional centres
5. Residential facilities
6. from age 18 : day-care centres, nursing centres, assisted living centres (small scale housing with assistance)

### *Perspective 2020: a giant reform of disability services*

Currently, the Flemish Agency for Persons with Disability is carrying out a big reform, which should be finished by 2020. It is called "Perspective 2020"<sup>1</sup>. The support should be looked for as much as possible in the "regular" service sector, and only when no help is available in the regular sector, can help be sought in a disability-specific sector, according to the scheme of concentric circles (figure) .

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<sup>1</sup> <http://www.vaph.be/vlafo/view/nl/5146351-Perspectief+2020.html> (in Dutch)



*figure 1: The support circles, principle at the basis of the Ministerial Reform “Perspective 2020” in Belgium*

This model is reflected in the organisation of the access to support services. All services for children-in-need have been grouped together in the service “Integral Youth Help (IJH)”, whether they have a disability or a functional problem due to whatever cause.

An important distinction is made between directly-accessible and indirectly accessible forms of support. Parents who experience a problem with their child can go directly to service centres, via school guidance centres (CLB), or General Welfare Centres (CAW); Youth Advisory Centres (JAC), Mental Health Care Centers (CGZ) or Services for Support Plans (DOP) when there is a presumed disability. When these cannot find adequate or insufficient support within the regular sector, these centres can refer the child to an “intersectoral access gate” (which functions like the French MDPH) to make a comprehensive assessment and search for more long-term and specialized disability-specific support.

The specialized centres dealing with children with disability (whether residential, semi-residential, or ambulatory), have become more flexible and “open their doors” to reach out in the community. They are now called “multi-functional centres”. They are invited to create “mobile teams”, which is a directly accessible way of support. Their staff is from now on allowed to do assistance work e.g. at schools. This opens the door to giving the necessary assistance (e.g. speech therapists, physiotherapists, daily caregivers,...) in inclusive situations. The whole idea behind it, is that the person with disability (or in the case of children, the family) decides best what to do; they become the captain of the ship, whereas before, the whole care system was more expert-oriented.

Another reform is that the centres which care for children who are not going to school – therefore usually the centres caring for children with complex and intense support needs (CISN) - are no longer called “centres for non-schooled children”, because that is not compatible with the UN Convention of the Right of People with Disability, i.c. the right to inclusive education. They have to provide some form of education, and have either to become a school, or ally with a school, and also become “multi-functional”; in principle they can also become a resource centre.

#### *Personal assistance budget*

People with a disability can apply for a personal assistance budget. This budget can enable them to employ personal assistants without having to recur to existing services. They can decide to “hire” the services offered by existing institutions.

Who is entitled to benefit from the services of the VAPH? The VAPH is dedicated to people with a disability. The VAPH uses the following definition: *“any long-term and significant participation problem experienced by a person and attributable to a combination of functional disorders of a mental, psychic, physical or sensory nature, limitations in the performance of activities, and personal and external factors”*.

This definition allows for an individual approach to every person who calls on the services of the VAPH. However, there are several other conditions governing access to the services offered by the VAPH: Age requirement (0-65 years); and a residence requirement: the disabled person lives and resides in Flanders. This means the person must be listed on the population register or immigration register and have lived in Belgium for 5 years prior to registration (or 10 years in the course of his or her life). The condition of 5 or 10 years does not apply for the citizens of the European Union.

The budget of the VAPH is not unlimited. That means that people do not have a right to support; it depends on the budget. The consequence is a long waiting list and thousands of people waiting on the list to receive a kind of support. At present 4000 people have requested a personal assistance budget, and some of them are already waiting 10 years.

In the Minister of Welfare’s reform plan “Perspective 2020”, by 2020 every person with a disability should receive at least a minimal form of support. Some will receive an “basic support budget” of about 300 euro, on top of the national, federal allowance. The others will receive support in terms of people, facilities, personal assistance. The new principle is that governance of the support will be no longer managed by the service providers, but by the people with a disability themselves.

All people will be re-evaluated. The guiding principle will be the ICF, and the degree of assistance needed to allow maximal participation. People can then choose where to use this budget, either with a service provider, or just as a personal assistance budget, with total freedom how to organize support.

This is a huge transformation process that is taking place.

Now, most children, and a fortiori adults, with CISM, are used to residential or semi-residential forms of care, in institutions which historically have been founded by caritative organisations. Often they are situated far from the integrated life.

From now on, people will be able to choose more, and theoretically at least, there will be more opportunity to lead a more integrated, or inclusive life.

### *Rehabilitation centers*

Next to disability-related services, there are also rehabilitation centres, which have been operating in the health care sector up till now. They have rehabilitation doctors, speech therapists, physiotherapists, psychologists and occupational therapists and social workers. They offer multidisciplinary therapy to children with a variety of developmental disabilities or learning disabilities, but tend to limit themselves to the more “higher functioning” children. They have long waiting lists and operate a limited number of years.

Children can also receive rehabilitative services with reimbursement by the health sector in private sector. The problem here is that there is no register of who is doing what, in what areas they are competent. Parents have to find out themselves.

## Organisation of inclusive education

Belgium has a very strong and intense network of special schools. The majority of children with disability are in a special school. Belgium is, according to the European Agency for Development of special Needs Education, one of the most “separating countries” as regards school education in Europe. Up till recently, services for children with disability (diagnostic services, functional diagnosis centres, Child Guidance Centres, Child Rehabilitation Centres) tended to refer to special schools, which is considered “normal”. Also children with mild problems, borderline intelligence, learning difficulties who are not able to follow the speed of the regular academic programme, are referred to special schools, of which there are now 9 types.

Integration of children with a physical or sensorial impairment who are able to follow the regular school programme is already taking place since 1979. They are entitled to 2 to 4 hours per week of support teacher or therapist in a regular school. But this is a minority.

During the past 10-15 years there has been a “movement”, led by parents of children with intellectual disability” to opt for inclusive schooling. This is still a small minority.

Since 15 years, children with an intellectual disability have a possibility to be in a regular primary and secondary school with max. 5.5 h/week support of a special needs teacher. Until recently this was limited to a pilot group of 100 children. Now in principle there is no limit.

Following the UN Convention of the Rights of People with a Disability, the Ministry of Education has been forced to change the law. As from September 2015, children with disability are encouraged to stay in a regular school. Regular schools will be discouraged to refer children with mild learning difficulties, without registered intellectual disability, to special classes. Also children with intellectual disability can stay, but schools are still allowed to find a way to say they do not have the capacity to take care, let alone give a proper education, to a child with an intellectual disability. There remains a big resistance from regular as well as special schools, who have a different financing system (Van De Putte & De Schauwer, 2013).

There are strong parents’ advocates, such as the Parents for Inclusion organisation, and “GRIP”, an Association for Equal Rights of People with Disability, but they are a minority. These parents and children act from a different perspective. They claim inclusive education as a right (Mortier e. a., 2009). At present about 100 children with moderate to severe intellectual disability (out of 5000) are in regular classes. The conditions for successful inclusion are now well known, as are the barriers (Lebeer, 2012).

It is even more rare to integrate a child with multiple disability in a regular environment. Perhaps there 2-3 in the whole of Belgium.

Many children with PIMD are not even in a school. Up till now they received an official statement of “freedom of compulsory education”. They are in day-care centres of residential centres for children with PIMD.

Although the “care” is generally considered as good, children with PIMD have a chronic and substantial lack of activity and participation (Maes, 2014). The Government, however, wants to put an end to this practice, following the UN Convention of the Rights of People with a Disability, which states that all



children with a disability have a right to inclusive education. A Governmental Commission has been installed, presided by prof. Bea Maes of Leuven University, and of which Enablin+ is part of the Committee. A report has been published on behalf of the Minister of Education. The report recommends that all children, even the most severely cognitively disabled (1) are able to learn and (2) have a right to have an educator from a school, to a properly needs-adapted individual education programme, to be educated in a school, even in a regular school environment. The report also makes recommendations regarding attitudes, equipment, support and necessary conditions.

Very recently, the Specialized Care Centres for the Disabled, are now called “multifunctional centres” and they are allowed to support a child in a regular environment.

In any case, the support system for inclusive education is still very rudimentary in Belgium:

- There are not enough support teachers
- The numbers of supporting hours is insufficient
- Children with borderline intelligence and mild intellectual disability (= the majority) receive few supporting hours
- lack of training of training of support teachers as well as regular teachers in inclusive education. The Government has been funding projects, and now, in view of the change of law, there are some initiatives opening up possibilities for a change
- there is still an intolerance for difference, especially difference in learning performance
- a tradition to “think special”: “children are better off in a special school because there are all the facilities, all the support people, all the experts, children can receive therapy, meals, transport to school, protection...”
- the diagnostic centres, child guidance centres, often keep referring to special schools, rather than proposing an inclusive trajectory.
- often parents pay extra for more supporting hours. Only a few “happy few” parents who have a personal assistance budget can have full time support in regular schools.

There are pioneering parents, who find their way anyway: they find “willing schools”, who are open to inclusion, and see it as a challenge and a right. They find welcoming teachers, who are willing to flexibilize and make a mind-shift. Support can be given by students doing internships, therapists willing to come to school, volunteers, family members, retired teachers, etc. In this way, inclusion is best learnt by doing it. An example of such a good practice is given in part II of this report. Slowly, the impetus is growing.

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# Current support systems in the Netherlands

Rianne Kleine Koerkamp, Inge Kroes & Mia Nijland

## Introduction

The Netherlands has 12 provinces; each province consists of a number of municipalities with own municipal councils (390 municipalities). The national government has a different executive power than the municipal government. The province councils supervise the municipalities. The municipalities, replacing the county/ national authorities, are since January 2015 responsible for youth care, employment and income, and care for chronically ill and elderly people (including children and young people with CISON, children with intensive and complex support needs). Some of these tasks they had originally, other parts are taken over from the central government. The idea is that local authorities are closest to the community and can therefore provide care and social work more effectively, less red tape and less expensive. The Netherlands has a sound health care system in which the majority of the people with needs for care are being treated and cared for. Implementing organizations are responsible for the access and financing of care, and several social institutions provide the necessary care and support. Typically, health care is traditionally divided sectoral and by target group; elderly, mental health, disability (divided into physical, mental and sensory disability) and home care (source: Projectvoorstel ondersteuning Passend Zorgaanbod July 1, 2016).

The above can contribute to adequate or tailored care. In daily practice, many people feel that it is not smoothly translated into practice, and they experience many problems. The Netherlands has introduced 'Suitable Education' in 2014, and the 'Transition Youth Social Work' took place in 2015. These operations are implemented side by side. However, several years of evaluations show that the integration has not been given sufficient stature (*EJAVIK, één juiste aanpak voor ieder kind*).

## Goals Suitable Education

All students should be given a place at a school that suits their abilities and their potential. This is called suitable, or tailored, fitted education. This form of education is to ensure that every child lives up to their own potential. Schools therefore provide additional assistance to students who need it, such as children with learning or behavioural difficulties.

With suitable education the government wants to achieve that:

- All children have an adequate place in education;
- a child can go to a regular school instead of special school if possible;
- a child goes to a school for special education if intensive guidance is needed;
- schools have the potential to customize student support;
- not the restrictions but the possibilities and educational needs of the child are decisive;
- children are not staying prolonged at home.
- Parents have the freedom to choose for mainstream or special education

### Appropriate place for students because of 'care obligation'

Schools have the obligation of care. That means that the school is responsible for providing an adequate education situation. This requirement will help to achieve the goals of suitable education.

Some numbers from the Netherlands:

- 100,000 children attend special education. This is 4% of all school-aged children (LECSO)
- 13,000 children do not attend school. Day care - KDC - day treatment (NSGK) of which 8,000 children with autism (VWS)
- 18,000 children with severe communication limitations (MILO Foundation)
- 113,000 children with a (combination of) disabilities (VGN)
- 55,000 with a mild intellectual disability (kenniscentrum LVB)
- 60,000 with a severe intellectual disability (Dr. J. Beernink-Wissink)
- 15,000 with very severe multiple disabilities (RUG - Platform EMG)

### Not all care demands fit the system

A relatively large proportion of people with care needs, do not "fit in" the way health care is organized. This happens, for example, when the demand for care exceeds the limits of the sectors, and roles and responsibilities are complicated. This problem is not new. Currently, almost one and a half years after the transition from long-term care, there are signs that more people struggle to find adequate care. They feel sent 'from pillar to post' or the care they need proves to be hard to find or unavailable. Unfamiliarity with the new regulations is partly to blame for this. At the same time, it is striking because the new health care laws provide more room to organize and to finance tailored care. This does not seem sufficiently well-known and used. It requires that professionals listen carefully to what a child and its parents' needs, but also knowledge of the opportunities offered by the law, the courage to realize creative solutions, and good cooperation between health care providers and sometimes financiers.

## Financial allowances

### Laws in health care and welfare

The Netherlands has differing laws and regulations that make social work and welfare possible. These include the Exceptional Medical Expenses Act (Awbz) (until January 2015), Social Support Act (WMO), Health Insurance Act (Zwv) and youth law.

**The Long-term Care Act (WLZ)** is the successor to the Exceptional Medical Expenses Act and is for people who require intensive care or close-by supervision throughout the day. For example, elderly people with advanced dementia or people with severe mental, physical or sensory impairment.

**The Social Support Act (WMO)** provides people with disabilities the services, help and support they need. You can request WMO assistance at the municipality.

**The Health Insurance Act (ZVW);** Everyone who lives and works in the Netherlands is required to take out health insurance to cover the cost of medically necessary care. For care that is not covered, you can take out a supplementary insurance.

**The youth law;** Since January 1, 2015, municipalities are responsible for the youth social work. They can organize care closer to the community, but also simpler and cheaper. The new organization of the youth social work is enshrined in the youth law.

With a Personal budget (PGB) people can buy their own care and assistance. The PGB is a sum which one - with a diagnose and 'indicator' - may arrange care by itself. There are two types of PGB's. The PGB AWBZ (care, nursing, guidance or short stay) and the PGB WMO (for help at home). Read more on : <http://www.zorghulpAtlas.nl/zorgatlas/wet-en-regelgeving-zorg-en-welzijn/>

### **Funding for students with severe multiple disabilities**

After consultation with the House of Representatives, a specific funding for students with Complex Intensive Support Needs, or CISN (Source: [www.enablinplus.eu](http://www.enablinplus.eu)) was introduced before the summer of 2015. Based on this regulation, special schools can request different funding for CISN students who need more care than can be provided with only the General Education funding. With this national regulation, (secondary) Special Education schools no longer have to submit an application to a large number of partnerships per pupil for additional funding. The funds come from the budget of the partnerships Suitable Education. In addition, where necessary, additional care (funding) can be used utilizing the Long-term Care Act, juvenile law/WMO and/or the Health Insurance Act. In practice, this proves to be difficult to achieve.

Children who fall within the Long-term Care Act can have education; the number of hours used from the Long-term Care Act-fund remains the same. The care provider and the school agree on how care at school is organized.

### **Financial uncertainty**

Due to the decentralizations educational organizations should create new financial agreements for their education care arrangements. Interviews show that this leads to financial uncertainty in some cases. The uncertainty has several causes:

- Continuity of care has been agreed upon for 2015. In 2016, halfway throughout the school year, however, was not clear which students would be covered by the Long-term Care Act or by youth law. Because of this, into the school year (2015-2016) there was no certainty about the mode of funding of educational care arrangements.
- This includes educational care arrangements that receive funds from the municipality (youth law) and/or the partnership. These parties have sometimes pledged funding for one year, but would not make any assumptions on possible continuation of financing. When funds disappear in the near future, for example funding coming from the municipality, it may be that education care arrangements cannot be continued any longer, which can lead to serious ramifications. (Source: LESCO)

Money is directive and determines the organization of care and/or education. The schools have to deal with different municipalities with different arrangements. There is a school in the Netherlands who has to deal with as many as 21 municipalities, all with different requirements, accountants etc. Which

makes the organization of the education of these students almost impossible. The organization is extremely complex and it is not to resolve as money continues to direct. This is the result of "non-integral" work.

## The organisation of support for people with a disability

### Policy, education and care

#### Fragmentary approach

People with CISN need daily and intensive care from their (home) environment. Compared to their peers, they have "extra support questions" and they (permanently and often non-stop) rely on help from others. In all cases there is a disorder and/or intellectual disability (from very mild to very severe). People with severe multiple disabilities (EMB), belong to this group as well. The international partnership Enablin + uses the umbrella term CISN, for all -in the Netherlands existing- subgroups within the (disabled) care. CISN emphasizes on the demands of people instead of their limitations or disability. If the definition of the target audience is so different already, how can it be organized unambiguously?

Children and adolescents with complex intensive support needs (CISN) have just as much right to education as children without such obstacles. As well as the right to receive education at a mainstream school. Now it is true that special education in particular, is designed to offer -specific- education. Nevertheless, these children often don't have or have partial education, for various reasons. For example, from a very young age they have (standard) education exemption and then they'll go (willingly or unwillingly) to a KDC or ODC until the age of 20, and from there on to another form of day care for the disabled. In response to this they initiated 'To School Together' classes for children with EMB, which is currently increasingly implemented.

Truants and parents get stuck in the procedural side. At this moment an investigation is being held on behalf of the ministry into an evaluation framework regarding the coverage of children. Currently, children are covered by the WLZ. Children under the age of five are covered by youth care and CISN children from five years and above by WLZ. Intensive child care is covered by the Health Insurance Act. The problem is an improper classification of areas when it comes to funding. Children are divided into education and health care. Demands are divided, while there is a comprehensive demand and therefore requires a comprehensive approach. You don't fit in anywhere as a child with CISN. At this time a fragmented organization is looking into improvement, as well as it's gaining national attention (Project proposal: Min VWS Elke de Bruin).

## Organisation of inclusive education

The Netherlands is transforming from 'no inclusion' to 'almost inclusion' to 'inclusion'.

There are steps made to provide more children the appropriate educational support and care. In many regions, a movement has emerged, which lead to more successfully offering children an adequate place. More and more this happens at a regular school. Practice shows that many collaborations manage to realize a suitable education within the current framework. (Government)

## Registration and (health)care obligation

All children are entitled to a suitable place in education. Finding a suitable place starts with a written notification by parents at the school of their choice. When they expect their child needs extra support, they indicate that at registration. The notification activates the duty of care. That means the school must make a suitable offer for the child. It is therefore imperative that parents register their child in writing.

The majority of the children find an appropriate school without problems, but unfortunately it is not always possible to achieve a fitting place quickly. This can happen if the school and the parents do not come to a consensus or because extra care is needed. In such cases, support is available to still come to an agreement regarding schooling of the child.

## National development, quality agenda's and point of attention for children with CISN:

### National Organisation: The EMG Platform

**National movements: municipalities and organizations find their way and strive for quality.**

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Tol, G. v. EJAVIK, één juiste aanpak voor ieder kind. Een richtlijn voor het opstellen en uitvoeren van één en het beste welzijnsplan voor ieder kind.

# Current support systems in France

Eric Zolla, Christine Plivard & A.M. Boutin

## The education of disabled students in France

Extract [http://www.education.gouv.fr/cid84379/l-ecole-inclusive-une\\_dynamic-who-is\\_growing-in-favor-of-students-and-students-in-situation-in-handicap.html](http://www.education.gouv.fr/cid84379/l-ecole-inclusive-une_dynamic-who-is_growing-in-favor-of-students-and-students-in-situation-in-handicap.html)

In France, the law of 11 February 2005 on equal rights and opportunities, participation and citizenship of people with disabilities reinforces the actions in favor of the education of disabled students. It affirms the right of everyone to mainstream schooling closer to his home in a continuous and adapted schooling.

Parents are more closely associated with the policy decision of their child and the definition of his personal schooling project (PPS).

The right to education for all children, regardless of their disability, is a fundamental right. Sick or disabled students have long been supported by specialized institutions. The law of 11 February 2005 on equal rights and opportunities, participation and citizenship of people with disabilities has strengthened action for the education of students with disabilities situations. With the orientation and programming law for the overhaul of the School of the Republic of 8 July 2013 now appears, from Article 1 of the Education Code, the principle of inclusive education for all children without any distinction.

Now more and more students with disabilities are enrolled in regular schools.

### *School systems in France*

From the age of 2 years, if their families so request, disabled children can attend school in kindergarten. Each school is intended to accommodate children within its catchment area. To meet the special needs of disabled students made schooling project (PPS) is organizing the school the student, together with the accompanying measures decided by the Committee on rights and autonomy of people with disabilities (CDAPH). Schooling can be individual or collective, in mainstream schools or nursing home.

## Individual school

The conditions of individual educating a disabled student in an elementary school or a school in the second degree depend on the nature and severity of the disability.

Depending on the situation, schooling may take place either:

- without any special help,
- subject to adjustments when the student needs require

Recourse to the accompaniment of a school carer for -individuelle help (AVS-I) or a school carer for help pooled (AVS-M) and suitable teaching materials combine to make possible completion of schooling.

## Collective enrollment

Primary education level classes for inclusive education (CLIS)



In elementary schools, classes for inclusive education (CLIS) allow pupils with disabilities to benefit from education in ordinary schools. Students receive an adapted education within the CLIS and share some activities with other students without disabilities. The majority of students of the CLIS are also participating parttime in other classes in the school.

### **In middle and high school: units located for inclusive education (ULIS)**

In the secondary, where the requirements of individual schooling are not compatible with their disabilities, students with disabilities may be enrolled in a localized unit for inclusive education (ULIS). Supervised by a specialist teacher, they receive an appropriate education which implements the objectives set by the personalized schooling project. Students are enrolled in their reference class

In autumn 2013, there were 2,808 Ulis. The installation of these units located for inclusive education is organized so as to leave no area out of reach of students, taking into account the reasonable transport constraints. This movement continues particularly in vocational schools. Les Ulis are encouraged to operate on a network, especially to meet the needs of professional training for students with disabilities.

Both Clis and Ulis classes may have an educational assistant (AVS-co), responsible to provide support to teachers and to enable appropriate care to each child of the class.

### **Nursing home schooling**

*Children in situations of multiple disabilities (PIMD) .*

In all cases where the circumstances of the child or young person requires is referral to a nursing home that is the solution to offer an outlet in the school office, suitable educational and therapeutic .

The training courses of a young disabled within these institutions can

- take place in full-time or part-time in the teaching unit
- include various possible schooling arrangements

They are always in the context of personal schooling project (PPS) of the student. They are implemented through the presence of a teaching unit responding with flexibility and adaptability to the specific needs of each child or young person with disabilities. The medico-social institutions under the Ministry of Social Affairs and Health. The Ministry of National Education, Higher Education and Research ensures educational continuity by assigning teachers in teaching units (EU).

# Current support systems in Romania<sup>2</sup>

Reka Orban, Eniko Batiz & István Szamosközi

## Intro

In Romania the rights and obligations of the persons of the disabled are described by the Law No. 448 of 2006, modified and republished in 2014. The main goal of these rights and obligations stated by the law is the inclusion of these individuals into the society.

According to the above mentioned law, “persons with disability” are considered those whom the social environment - which is maladjusted to their physical, sensorial, psychical, mental and/or associated deficiencies – deter or limit the access with equal chances to the life of the society, thus requiring protective measures to support integration and social inclusion.

As we can observe, even though the law states that the goal is inclusion, the terminology used within the law still remains derogatory.

## Financial allowances

The protection of the persons with special education needs (SEN) is carried out by the following financial resources: a) local town budgets; b) local budget of the county, respectively of the districts of Bucuresti (Romania’s capital); c) state budget; d) monthly contribution of subsistence for the handicapped persons who benefit of the services of the social services and within the centers; e) donations, sponsorships and other sources, according to the law. These resources will be managed by the Ministry of Labor, Family and Social Protection, throughout the field agencies.

Persons with pronounced or severe disability benefit from fiscal facilities: tax exemption on income from wages, on buildings and land, on vehicles, moto-cycles, and moto-tri-cycles adapted to the persons special need, from taxes for the release of authorization of functioning for the economic activities and exempt from the annual visa for these activities, as well as hotel fees.

According to the mentioned legislation, adults with severe disability are entitled a monthly allowance (approx. 40 €), regardless of income and a complementary monthly personal budget (approx. 18 €), regardless of their income. In order to create a proper image we have to consider, that the life costs in the country are similar to those in Western Europe. Usually these persons have an illness pension and/or survivorship pension too. Thus their income can reach 220 up to 290 € per month, which represents the minimum wage in the country.

The financing of a child with disability is possible up to his full schooling age (18 years). After this age people are considered as an adult and they are granted a final certificate of disability.

Children with a disability are entitled to a financial allowance regardless of the parents’ income. The allowance is proportional to the degree of disability. This is determined by the child’s medical condition. The child is evaluated by a team of professionals, which include doctors, physiologists, psychologists, special therapists. The team, based on the existing medical, psychological and other objective reports, interviews with the parents and filled checklists will make a proper decision

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regarding the child's condition. Based on the decision taken, the team will issue a certificate which comprises not only the condition of the child, but also suggests the steps to be taken. But the ultimate decision belongs to the parents.

There are special conditions to finish school for children with disability: they ought to finish in regular time up to the age of adulthood (18 years of age). In special education settlements the regular time can be prolonged with four more years (up to the age of 22). In the case of people with very severe disability who are home schooled, the ultimate age of getting educational support is 30 years.

So, if a person with disability – after becoming legally adult, but at later until the age of 30 - is unable to gain - by himself - a monthly income as a regular employee, he will be entitled to a life-long financial support.

## **The organisation of support for people with a disability**

The law aims to promote participation, integration and equal opportunities for people with disability in all areas of social life. The ultimate goal is to help people with disability to have a better and more independent life. The law ensures this by subsidising facilities and services for people with disabilities:

### **Equipment and its modifications**

To better organise his or her daily life a person with a disability is entitled to a benefit to cover the cost of a piece of equipment or modifications of equipment to his or her home or car (e.g. adapted bathrooms, lifting equipment, adapted car, equipment for the blind).

### **Services and facilities**

In order to protect the physical and mental health of people with SEN, the authorities are obliged to take specific measures. The first legally ensured obligation is to include the needs of persons with SEN and their families in all the local, regional and county policies of development strategies and programs. Their needs have to be included in national health protection strategies also. In order to increase and/or maintain the quality of life, proper conditions have to be created for availability of transportation, infra-structure, communication, medical and socio/medical services.

In order to meet specific requirements of people with disabilities, the responsible authorities have to establish and sustain rehabilitation centers specialized on the types of disabilities. Within these centers assistive technologies and specific access have to be granted for the persons in need.

The policy makers have to acknowledge and create programs to prevent the occurrence of disabilities. If occurred, they have to support the person's access to treatment and recovery programs and facilities. Within these treatment methods they have to include and recognize the importance of sports, physical and movement therapy methods. Specific movement and sport supportive methods have to be developed to meet and fulfill their specific needs and conditions.

The persons with disability, their families or their legal representatives are entitled by the law to all the information regarding the medical diagnosis, the therapy, the recovery and/or rehabilitation plan, to the available support services and programs in all their medical conditions and stages. They are also entitled to all the rights, benefits in the field of therapy, support and rehabilitation.

The life of persons with disability is not limited to proper diagnosis and treatment, they have to be included in the society. Thus special labor opportunities and employment have to be created to meet the requirements of their specific conditions. The SEN persons can be employed on the free labor market, they can benefit of home employment or protective forms of employment can be developed. Protective employment forms are either job-protected work places or authorized protected units. However for most people with multiple disabilities, this will be too far-fetched.

The law urges the establishment of services and facilities which provide care for persons with disability through daytime, or home facilities, care and/or guidance. These centers are providing early intervention programs and family guidance. Parents can benefit twice or more (but not on daily basis) a week from advice, guidance and support. Even if they attend the programs offered by the center several times a week, these programs can be different each day (e.g. one day they attend physio-therapy, one day speech therapy and one day psychological counselling). This is by far insufficient, because they don't have the opportunity to work daily with children, they do not have enough time to deepen the knowledge they are presented, there is not enough time to familiarize with presented techniques. There is no or not enough time for the parents to benefit from the individual counselling for their state of wellbeing and their own mental health (law of education).

The early intervention centers are mostly non-governmental organizations, created by foundations or they are completely private institutions. Some of them are in partnership with the Ministry of Education, but rarely they have a connection with the Ministry of Health. They are often on subordinate not equal partnership level with the state institutions. It was a big step forward that the Law on education (2011) included early intervention in the legal frame.

Another form of structural support is the complex diagnosis center. These establishments are offering comprehensive functional diagnosis on the various aspects of development. They work with a multidisciplinary team covering the physical, psychological, medical and social aspects. Their attributions are mainly in classifying and orienting the child to a type of service or school, or to determine the degree of functional impairment. They are offering guidance in stimulating the child's functioning or participation. The evaluations are carried out in these centers are compulsory every year until adulthood. When the person becomes an adult a final decision is taken and a certificate is issued.

The inclusive education centers are offering occupational therapy, speech therapy, physio-therapy, non-school education. In many cases these centers are former special schools, but today they are responsible also for the children with SEN included in mainstream schools.

The centers for the persons with disabilities— as nominated by the law — are established to fulfill the specific needs of these persons. According to the law, they are entitled to social services carried out in different types of daycare centers and residential centers. These centers can be public, public – private or private ones. The daycare or residential centers are defined as locations where the social services are given by qualified personnel. These professionals are mostly social workers. These locations are provided with adequate infrastructure in order to be able to provide these services. The residential centers are locations where the SEN persons are lodged at least for 24 hours. The law defines the types of residential centers as:

- Centers for assistance and care
- Center for recovery and rehabilitation
- Centers for integration throughout occupational therapy
- Centers for training for independent life
- Respiro and/or crisis centers
- Centers for community services and training
- Protected houses
- Other centers.

The **centers for children with severe SEN, motor or health problems** are hosting children who are not going to school. They offer day-long activities and therapies. The centers are hosting mostly children with PIMD. They now also are considered as “multifunctional centers”.

The residential facilities are dedicated to adults from age 18. These are day-care centres, nursing centres, assisted living centres (small scale housing with assistance) mostly they are private facilities.

The specialized centers dealing with children with disabilities (either residential, semi-residential, or ambulatory) have become more flexible and “opened their doors” to reach out in the community. They are now called “inclusive centers”.

In the national frame of social assistance, every county (there are 41 counties in Romania) has a **County Center of Resources and Educational Assistance (CCREA)**. In the nomenclature of these centers itinerant teachers and psychologists are employed to assist the school teachers. The itinerant teacher is employed by the special school or resource centre. This support staff is giving the necessary specialized assistance (e.g. speech therapy, physiotherapy, daily caregiving, educational support) in inclusive situations. Even though this support personnel and the services the CCREA provides are available, the final decision belongs to the disabled person. IF the person is a child, it belongs to the family or to the legal guardian.

Another novelty stated by the law is that the centres for children who are not going to school due to their severe impairment are no longer called “centres for non-schooled children”, because that is incompatible with the UN Convention on the Rights of People with Disability (the children’s right to inclusive education). These schools have to provide some form of education, so they have to either to become an inclusive school, or have to partner with a school and become “multi-functional”. Ultimately they can also become a resource centre.

The severe SEN children have also the possibility and opportunity to become home schooled (regulation on SIE).

## Personal assistance budget

Persons with very severe disabilities are entitled, based on a socio-psycho-medical evaluation, to a personal assistant.

The children or adults with severe disabilities and their personal assistant are entitled to free access to shows, cultural events, museums, artistic and sport events.

According to the legislation, children with complex and intense support needs have the right to be housed in residential or semi-residential forms of care, in institutions which historically have been

founded by caritative organisations, but most of them are in home care, often being excluded from an integrated life. Theoretically, people have the right to choose from various possibilities and they have now more opportunities to lead a more integrated or inclusive life, but practically they have only one or two possibilities, due financial or other constraints.

Besides the disability-related services, there are also rehabilitation centres, which have been functioning in the health care sector up till now. These centres are also operating with rehabilitation doctors, speech therapists, physiotherapists, psychologists and occupational therapists and social workers. They are offering multidisciplinary therapy to children with a variety of developmental or learning disabilities, but tend to limit themselves to the “higher functioning” children. The specialists from these health-care related centres usually have long waiting lists and they provide services only for a limited period of time (no life-long support service available here).

Children can also receive rehabilitative services in the private sector. These services can be reimbursed by national health services. The problem here is that there is no register of who is doing what, in what areas they are competent. Parents have to find out themselves.

## Organisation of inclusive education

Children with SEN have free and equal access to any form of education, regardless of age, according to the type and level of their impairment and their educational needs. They are granted with permanent education and life-long professional training. The person in need, his family or legal representative is entitled to decide the type and form of schooling and the educational institution. The education of persons with SEN and continuous and intensive support needs is part of the national education system, which is co-ordinated by the Ministry of Education. This education is carried out by:

- special education institutions
- individual integration in mainstream education units, including the minority schools (teaching language is the mother language of the children, besides the official language of the country, e.g. Hungarian, German, so on)
- special compact groups or classes integrated into mainstream pre-school and school institutions
- education services provided by itinerant and support teachers
- home schooling up to graduation from high-school, but no later than age 26, provided by the Ministry of Education
- “hospital schooling” during the prolonged hospital treatment
- other educational alternatives.

All education forms are also provided in the languages of minorities.

Most disabled children are in special schools or they receive home training offered by special educators. Services for disabled children are offered mostly by school centres for inclusive education. The integration of children with SEN who are able to follow the regular school programme is already ongoing. They are entitled to 1 hour per week of assistance from a support teacher or therapist in a regular school (Borca, 2010).

The children with intellectual disability - if they can face the adapted curricula with 1-2 hours of support from a special educator – can choose inclusive schooling. But still too few opt for this option, because only few of them – even with intensive parental support - can manage to get to the final exams.

Regular schools are not allowed to reject any child, excepting the case if in the class already are two SEN children. The first step chosen for every child is to try out the mainstream school. If he doesn't worth up the expectations, the second option is the special school. Unfortunately the schools still have the back door to find an excuse in order to reject the SEN children, mostly arguing that they have no human and/or infrastructural means to handle a disabled child. There is still a huge resistance both from the regular and from the special schools, due to their different financial system.

Although major changes have been undergoing in the legislation and in fact in the country in the last decade, the support system for inclusive education is still very scanty.

There are not enough support teachers working in the system. Education being underfinanced, the school budgets allocated by the state permit to employ a (de)finite number of teaching staff. There is no restriction in hiring support teachers or the number of the needed support staff, but one must fit the total number of staff allowed. So there is the dilemma: hire support staff and fire the math teacher, or vice versa?

There is one support hour/week allocated for SEN children in kindergarten and secondary school, and no support hour for high-school children. One hour per week is far insufficient even for the kindergarten children.

In the curricula of the teaching module for master student there is one class on the teaching method for pre-school up to secondary school SEN persons. This course includes topics on inclusion, integration. These is by far insufficient. But there is no course dedicated to the teaching methodology of high-school SEN children. This state of fact leads to the insufficient knowledge on SEN, inclusion and integration of these people the teachers are complaining about, and it also leads to the persistence of reluctance, intolerance and indifference toward children with SEN, especially considering difference in learning performance. The mentality still persists to consider these children so "special" that they would perform better in a special class or special school. In most cases the parents themselves think about their child as described above.

One can find groups of parents and specialists who are dedicated to fight for the disabled children's rights. They are committed to organize special infrastructure, settlements, equipment, human resources to build special care-giving units, but they are still a minority. These parents and children act from a different perspective. They claim inclusive education as a right, they are entitled to an equal quality of everyday life for the SEN persons too. Often parents are willing to pay extra for more support hours, but in most cases they have low social-economic status (LSES) and they cannot afford to pay even if they want to.

There are even more rare cases to integrate a multiple disabled child in a regular environment. Perhaps there 2-3 cases in the country with a population over 20 million inhabitants. Many children with PIMD are not even in a school. They are either at home, or in day-care of residential centres. A major resistance from the teachers themselves still exists, claiming that educating a SEN child included into a mainstream class requires supplementary effort, training and time they do not possess due to the rigid curricula and performance centred education system (Orbán, 2008).

There is an imperative need for a paradigm-, mind-shift and an intensive information campaign - starting with the school curricula - to awaken the society and make it receptive to disabled people's

needs and rights to a prosperous, worthy and dignified life. Cringing steps were taken by including internships into the student's curricula, and rewarding extra-curricular activities - such as volunteering in special education settings described above – with scholarships from private companies. There is also an imperative need of mind-shift in the parents' thinking: in many cases parents are feeling contempt for their child's needs, feeling sorry for themselves instead of reconsidering their point of view regarding the abilities and worth of their child.

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Regulation on organization and functioning of special and inclusive education



## Current support systems in Bulgaria

Apostol Apostolov

In Bulgaria, it is important to know that many services are still institutionalised. Alternative services (in the community) for children with disabilities are developed but put for the small children (0-3), their situation appears to be most in need of change.

The law for integration of people with disabilities states the right for medical and social rehabilitation for people with disabilities in Bulgaria. The existing services for children 0–3 with disabilities can be categorized into two types, according to the institutions that regulate their provision—social services and medical rehabilitation services.

The social services are regulated by the Bulgarian Law for Social Support and the Regulation for Implementing the Law for Social Support (Council of Ministers 1998).<sup>3</sup> These services could be provided either by municipal structures or other providers, including NGOs. The national government provides the financing for these services to the municipalities, which can, at their discretion, delegate these services to other providers. According to local needs and opportunities, municipal authorities can also set up additional services and provide funding for them from municipal budgets. In most cases, public funds are not sufficient to finance these services and cover the needs of all children with disabilities across the country. Thus, although all of the above services should be available, when funding is limited, some services rarely prioritize children 0–3 as their target group, with the exception of the Mother and Baby Unit service, which supports pregnant women and mothers with newborn babies in crisis situations.

There are two types of services—services in the community, and services provided by specialized institutions. The specialized institutions provide residential-type services, while the community services can be provided in the home or in various types of nonresidential centers. The following community-based services can directly support child development and family capacity:

**Personal assistant:** a service for a disabled person who needs constant care. The service is provided as a support mechanism for the family.

**Social assistant:** a service to help meet the daily needs and organize the free time of people with disabilities, including activities for their social inclusion.

**Center for Social Rehabilitation and Integration:** provides a package of social services that include rehabilitation, social and legal consultations, educational and professional training and counseling, and individual programs for social inclusion.

**Mother and Baby Unit:** shelter and support are provided for single mothers and pregnant women. This is a package of services, aimed at the prevention of abandonment, involving the extended family.

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<sup>3</sup> The Regulation for Implementing the Law on Social Support was passed by the Council of Ministers on November 5, 1998, and published in the *State Gazette* on November 11, 1998. It has been amended several times since.

Community Support Center: provides a package of social services for children and families at risk. These include family consultation, family planning, prevention of school dropouts, supporting victims of violence, and individual work with children with disabilities.

In addition to social services, children 0–3 with disabilities have access to medical rehabilitation services, which are also meant to support their development. These services are under the Law for Medical Establishments and the Health Insurance Act and should be available to all people with disabilities. The services include physical therapy, occupational therapy, kinesitherapy, speech and visual therapy, psychotherapy, supportive medicine therapy, and provision of supportive aids and other medical supplies.

These services could be provided by medical centers, specialized institutions (DMSGDs), or private providers specializing in such kind of medical support. They are paid for by the National Health Insurance Fund or the Ministry of Health, but there is a lack of priority policies and funding for these services, meaning parents often have to pay for the services privately.

DMSGD provides specialized support for children with disabilities through day center services. These include diagnostics, treatment, rehabilitation, psychotherapy, speech therapy, and educational and social support. The beneficiaries are children with disabilities from the community.

The social and medical rehabilitation services together provide a good basis for supporting children with disabilities and their families. These are community-based services and target the needs of either a child with disability or the whole family. However, children 0–3 are often referred to medical rehabilitation services that mainly focus on the physical health of the child, do not focus on the other developmental areas, and pay less attention to the child-parent interaction.

There are only three types of services that provide real opportunities for involving both the child and the family and thus follow a comprehensive approach to meeting the needs of the whole family. These are the Center for Social Rehabilitation and Integration, the Community Support Center, and the day center, operated by the DMSGD. Although all social services are in theory available for children 0–3 with disabilities, in practice many of these services are not developed by their providers to support early childhood needs, or only support children and families in crisis situations. In reality, this deprives the 0–3 children with disabilities and their families from receiving appropriate services. In many places in Bulgaria, there are no services at all for children with disabilities. Similarly, personnel qualified for working with children with disabilities 0–3 are also lacking in many municipalities.

Often as soon as a child with a disability is born in maternity hospitals, medical personnel still direct the attention of parents to the disability and the deficits their child will have in later life. This is the first precondition for many parents to want to abandon their children to institutional care. In addition, the fact that children 0–3 are primarily referred to medical rehabilitation services where the focus of intervention is also on the disability of the child, the risk of child abandonment on the grounds of disability is heightened. This clearly highlights the need for services that support the whole family by developing the family's capacity to address the needs of their children, rather than abandon them. Early childhood intervention services build on existing social and medical services in Bulgaria but provide a sharper focus on the strengths of the child and on child-parent interaction.

**Early intervention** services are piloted by Karin Dom Foundation in Varna. The core element of the service is the home visit. The Bulgarian Government is introducing a service called “centre for early intervention of disabilities”, which are getting started in over 40 municipalities. Karin Dom Foundation is training the staff in all these centres.

# Current support systems in Italy

Marina Rodocanachi & Anna Maria Dal Brun

## Intro

The support system for children with disabilities (0 to 18 years old) in Italy is regulated by several national laws with specific allowances. Though the laws recognize the same right to people with disabilities, financial support for children has a specific regulation. When a person with disability reaches 18 years of age, the request for allowances has to be repeated and new rules are applied.

## Financial allowances and support management for people with a disability

Italian regulations concerning disabilities state several principles of intervention and economical support. Three major Laws regulate this intervention:

1. Attendance allowance (Law 11/2/1980) is a financial support given to the families every month for severe disabilities regardless of age and income. The evaluation is based on forensic criteria. Every year the request must be repeated. In case the severity of the condition is not recognized, which means there is a condition of disability but the child doesn't need continuous assistance and support, a "frequency" allowance is recognized for the period in which the child attends school or a rehabilitation service centre (usually ten months a year).
2. Law N° 104/1992 is the most important law that promotes assistance, social integration and disabled people's rights. The law is addressed to people with a disability and their families. The assumption is that social integration and independence in life are possible if there is a financial support given to people with disability and their families. There are different kinds of support : psychological , technical aids, services and facilities, financial. To receive the benefits of Law 104 a medical commission must ascertain the handicapped child's conditions, i.e. the conditions that cause social exclusion. It is different from the recognition of "incapacity", i.e. the difficulty in performing daily-life activities. This assessment is based on medical-legal criteria.

Several of the most important articles of this law are:

Art 5:

States the general principles about disabled people's rights; activity and participation barriers have to be removed through:

- Scientific research and development
- Support prevention as well as medical and social intervention as soon as possible
- Help the family to understand better the handicapped patient's condition
- The family's and the disabled person's involvement in the choice and implementation of the medical and social intervention
- Guarantee of psychological care, education, technical aids and financial support
- Promotion of social inclusion

Art. 6:

States the prevention and early diagnosis

Art. 7:

States the right to have rehabilitation and free specific health services. The National Health Service guarantees early rehabilitation and early therapies in hospitals, rehabilitation centres, at home, in day-care centres or residential institutions, as well as free technical aids and assistive technologies.

The law also states benefits regarding parents' jobs : 3 days / month of paid leave; two years of working dismissal; tax reduction.

Regional governments have to apply the law through services and financial support.

3. Regional Law (decree 14/11/2014) states a monthly financial support to the patient, regardless of his income. It is given to severely disabled people who are heavily dependent on technical and human aids for daily life. This new law, is mainly meant for adults having Amyotrophic Lateral Sclerosis and traumatic brain injury with a vegetative persistent condition. It is also applied to very severe dependency conditions in childhood and in terminal living situations.

Other financial allowances are supported by the local government for sensorial disabilities (deafness or blindness).

## Inclusive Education Management in Italy

### A brief history of the process of inclusive education

Inclusive education was introduced in Italy between 1971 and 1977 thanks to several important law bills, that were approved by the Italian Parliament stating the rights of disabled children to have an inclusive education.

**1971, Law 118 approved by the Italian Parliament: «A handicapped person's education must be carried on in normal classes, within the public national school system»**

**1975, Falcucci's Document outlines the philosophy and principles of integration**

**1977, Law 517: mainstreaming is spread to different school levels**

From 1977 to 1992, special schools began to close down and mainstreaming education became a reality in the public school system. All disabled children from this moment on have the right to have a support teacher. All disabled children are, therefore, guaranteed a support teacher from Kindergarten to University.

**1982, Law 270: establishes and regulates the role of the support teacher for children with disabilities attending normal classes**

**1992, Law 104 establishes the rights of disabled people.**

**1994, Legislative decree: this establishes and regulates the competences of health districts; a functional evaluation and diagnosis is made for disabled children in relation to their inclusion into normal classes**

The basic principles included in these legislations are that mainstreaming is a determining factor for disabled children to overcome marginalization and that learning and socialization in normal schools are complex processes. Many barriers still have to be removed.

According to the Italian school system, for each disabled child a support teacher is nominated. The disabled child is included in normal classes and has a certain amount of hours assigned to him, depending on what is stated in the functional diagnosis elaborated by the medical team.

### **Evaluation towards inclusion: the Italian model**

The process of evaluating disabled children to include them in normal schools, involves various participants and has a complex system, helping to develop various instruments that are then shared among the school, the health system and the family. This helps to choose the best teaching methods and to plan the learning objectives in the different functional areas.

The main participants that cooperate together are:

1. The health system (the specialized medical multidisciplinary reference team that is responsible for the disabled child's evaluation and that maintains contact with the school and the family during the disabled child's schooling; the public health commission that is responsible for the certification of the request to have a support teacher);
2. The public administration (in other words, the regional bureau and the local administration) which is responsible for the economic fees of inclusion;
4. The school along with the support teacher, the board of teachers for disabled children attending the school and the teaching staff;
5. The family that has the right to ask for inclusion and to share and approve the educational individualized plan;

The instruments for inclusion are:

- **The certificate** (which includes a clinical diagnosis and a **functional medical profile** of the child) drawn up from the health rehabilitation team that knows the child.
- **The proceedings from the local Public Health Commission**, that state the right to have an individual teacher, the level of severity of the disability and the validity period of the proceedings.
- **The functional diagnosis (DF)** redacted from the rehabilitation team describing the characteristics of the child in terms of functional areas (Cognitive – Emotional - Behavior - Speech – Language and Communication – Sensory - Gross and fine Motor control – Neuropsychological – Self- help - Social relationship) and stating the number of hours with the support teachers, caregivers, health assistance and the aids and technical supports the school must have to include the child in the school.
- **The Functional Dynamic Profile (PDF)** written after a first period of observation at school. It's

a cooperation among the teachers, the family and the rehabilitation team. It includes the expectations of the disabled child's development, his difficulties, his resources and his 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, short and medium term objectives, the modality of intervention and the modalities of evaluation, as well as the outcome/final results.

## Critical aspects and good practices

Several critical aspects in Italy are the collection of data regarding disabled children with intense and complex support needs. This data is lacking in Italian statistics and, therefore, doesn't recognize these children as an entity.

Furthermore, financial resources (that should be granted to schools, so they can give disabled children more hours with their support teachers, as well as health assistance) are often lacking. Regular teachers are not always cooperative with the support teachers to include the disabled children among the other classmates.

Another Italian problem is the lack of training that teachers and professionals receive, as well as the need for new models of training necessary to take care of children having different kinds of severe disabilities. Parent empowerment is yet another necessity.

Although inclusion in mainstreaming education has been widely diffused and applied here in Italy for many years, there are still problems for inclusion of children with severe disabilities into regular schools, with cases of bad practices. Since the few special schools still existing nowadays accept the most severely disabled children, there is a real risk to marginalize these children within a kind of "well functioning ghetto". There is an on-going debate in Italy regarding the possibility of going back to special schools, seeing as the inclusion of a child with intense support needs into regular schools often fails.

Nevertheless, the Italian school system has obtained a lot of experience concerning inclusion during these past years, in other words, since Falcucci's 1975 "Document on Philosophy and Principles of Integration" and Law 517 (introduced in 1977). Experimental models and pilot experiences of inclusion in regular schools for severe cases of disability do exist, though not all over the country. Several pilot models are still being tested/tried out in some Italian districts. In these models interaction between normal and disabled children is strengthened with the presence of experimental laboratories. Furthermore, teachers are specialized to teach severely disabled children through experimental methodologies and individualized educational plans. The individual project for each child is a network that includes families, the health district and social services.

Parents' networks and associations are very active in Italy. The cooperation between schools and health systems towards inclusive education is regulated by the law. However, there is a need to expand and consolidate the good practices, to train and support specialized teachers, professionals and caregivers, as well as to work on parent empowerment. Going back from inclusion to special schools does not 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 as not to lose it.

# Current support systems in Portugal

Vitor Franco, Maria-José Saragoça, Merca, & Nuno Costa

## Pre-school support systems

Concerning pre-school support systems in Portugal, there is the National System of Early Intervention (SNIPI), being in the front line of children care with developmental issues in Portugal. It is a community-based model and covers the entire territory. The aim is to respond to children's needs, up to 6 years of age, with developmental disorders (disability or developmental delay) or living high-risk situations (Franco, 2017).

The operation of this early intervention system is accompanied by a very important conceptual and professional change (Franco & Apolónio, 2008). The concept of Early Intervention has undergone changes over time in accordance with the actual paradigms related to childcare and disability. The contributions from the bioecological (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) and systemic perspectives that emphasize the importance of life contexts in development are central. So, the support provided should reinforce the context (specially family) abilities as to promote development, autonomy, and social inclusion of the child (Guralnick, 2008, 2011) (Franco, 2017).

Besides that, contributions from neurosciences and the advances of the knowledge on the functioning of the brain and on the cerebral plasticity are valued. This knowledge points to a timely intervention. It is also valued everything that is known about child development and gives a special importance to the mother-baby relationship and to attachment as the basis for the child to explore the world and acquire competences. Field studies show that the early capacities of children to establish relationships and transactions that are fundamental to their development. All this is on the base of the family-centered perspective, as family is the more important context in child's life and the main promoter of development (Franco, 2017).

According to the current legislation (Decreto-Lei nº 281/2009) SNIPI is defined as an "integrated support measure, centered on the child and the family, promoting actions of an enabling and preventive nature in children aged between 0 and 6 years of age, who present or are in risk of developing difficulties in terms of education, health and social solidarity". Considering one of the areas (Alentejo), 60% of the children supported by the SNIPI present developmental delay (without known etiology), 18% disability or some specific and diagnosed condition, and 22% live in family or social high-risk situation (SCRIPA, 2015) (Franco, 2017).

The implementation of this early intervention network was made through the creation of local intervention team's (LIT) in all municipalities, who receive and follow the children and families. These



teams work in articulation with other health, educational and social support, other structures and services. Currently, the first great and innovative quality of this service is that it does not depend on a ministry policy, but it is resultant from a legislation involving three sectors: health, education and social affairs (Franco, 2017).

Detection of situations and children who may benefit from SNIPI can be done by pediatricians, general practitioners, or kindergarten teachers. The family can as well do it itself or by any person or service making referral to the LIT (Franco, 2017).

The local teams are multidisciplinary and they often are composed of psychologists, teachers, therapists (physiotherapists, speech therapists, occupational therapists) social workers, and sometimes doctors, nurses or other health professionals. The LIT works in close collaboration with local partners, within working groups that, in each municipality: local authorities, municipalities, police, health units, schools, fire services, employment services). This interinstitutional cooperation is critical to the success of the program. It allows to promote an integrated response to family's needs and to make a good use of local resources (Franco, 2017).

This current network is based on a hierarchical structure (composed of three different levels) that depends on Regional Coordination Committee that ensures the coordination and management of the resources needed to implement the system in each region, in accordance with a national plan of action and it depends on a National Coordination Commission (Franco, 2017).

The philosophy underlying the SNIPI emphasizes three fundamental principles:

- a) Family-centered services organization, considering the central role of the family to promote children's development, in a systemic understanding, and keeping away from a rehabilitative or stimulation perspective, that in the past was the mainstream approach to work with children with disabilities.
- b) An intervention on children's contexts and a perspective of care based in community resources. In our region, 14% of the children are exclusively supported at home, 37% receive support in the educational settings, 41% receive support in a mixed system (at home and kindergarten) and only 8% of the cases have support only in the health care services or specialized centers (SCRIPA, 2015).
- c) A teamwork that aims to be transdisciplinary. The composition of the LIT presupposes that the intervention is not done through the professional competences of only one of its members, but is based on a reflexive, cooperative and integrated process defined and implemented by the team itself, at all moments of the their work: case reception, evaluation and diagnosis, planning, intervention with families, direct work with children and intervention with the community (Franco, 2017).

Following this model of intervention, in the region of Alentejo, there is the Alentejo Early Intervention Program. This Program has been recognized as an example of good practices at the national and international level. In 2009, the Program won the 2nd Prize of Good Practices in Health in its participation in the "Good Practices Prize on Equity, Effectiveness and Efficiency in Health", awarded by APDH / HOPE & FIH, with the support of Novartis Oncology. In 2010 it was equally being bestowed by the WHO - World Health Organization with the United Arab Emirates Foundation for Health Award for his contribution to the development of health in Portugal (Franco, 2017).

This Early Intervention program is a valid response to the needs of children with CISE up to 6 years of age but when they get to school age, 6-18 years old, children are included within the education system in Portugal, which provides various kinds of support to children with special educational needs of permanent character. The number of students with disabilities in special education institutions has been decreasing over the last years and from a total of 79.203 students with SEN, 9567 are in private (regular) schools and only 1028 are in special schools (IGEC, 2016).

## Support for inclusive education

Every public school has special education teachers, with specialized training (post-graduate, masters, PhD) in fields related to diverse problematics. Across the country, there are around 6.500 special education teachers to support 68.608 children with Special Needs Education (IGEC, 2016).

Teacher's support to those students may be done in a direct or indirect way (working only with the student's teachers), in an individual way, in small group or in the mainstream class.

Besides the diverse educational measures to adapt the teaching and learning process, it exists in a few schools specific modalities of education that aim to address the students' problems such as: deafness, blindness or low vision, autism spectrum disorders or multiple disabilities.

The implementation of Decree Law nº3/2008, 7 of January (Diário da República, 2008), brought a major framework and adequacy of responses to students with Special Educational Needs of permanent character.

Therefore, where there is a concentration of students with deafness, reference schools arise to provide bilingual education to deaf students (inside mainstream schools). Here, in addition to special education teachers in the field of deafness, there are also Portuguese Sign Language (PSL) teachers, interpreters of PSL and Speech Therapists. There are 17 of these reference schools spread across different regions of the country.

Students with blindness or low vision also possess human and material resources suited to their handicaps. Among other goals, it is thus intended to ensure the teaching and learning of reading and writing in braille, orientation and mobility, development of daily living skills and the development of social skills. Throughout the country, there are 32 schools that ensure a more appropriate monitorization of these students.

In the case of students with autism spectrum disorder, the response is given through Structured Teaching Units that can be grouped with 3 to 6 children with that disorder, and they are organized according to TEACCH model (Treatment and Education of Autistic and related Communication handicapped Children). There are already, in Portugal, 337 units that support students with autism spectrum disorder. These units are not one more class from school, that is to say, students attending them have a reference class. The Units are specialized teaching resources that the school provides. The time that a child will spend in this Unit will depend on the level of his/her functionality.

When it comes to children with multiple disabilities or congenital deaf-blindness concentrated in one school, there may be created Specialized Support Units, with 378 of these units already in place. Promoting the participation of students with multiple disabilities in activities with peers from the class that they belong and ensure the adequate support in what concerns to therapies, psychology, orientation and mobility are just a few goals from those Units.

Another important aspect about the several specific modalities of education is to support and organize the transition process to life after-school. This is also one of the purposes from the special needs educational provision in the intervention with students 15 years of age (or older), who are provided with a specific individual curriculum, namely, with content highly differentiated from the mainstream curriculum, in accord with the functioning profile.

Schools may keep developing partnerships with one of the 92 Resources for Inclusion Centres that, through specialist technicians (Speech Therapists, Psychologists, Physiotherapists and other professionals), intervene with students in the school context or other specific contexts for their respective therapies (riding therapy or hydrotherapy).

At the groups of schools exists a Department of Psychology and Guidance whose Psychologist supports the intervention with students with SEN and articulates with teachers and carers.

Here in the country exists a network of 25 ITC Resource Centres for Special Education, which goals are to evaluate the students with special needs education to adapt the support technologies to their specific needs, to inform and train teachers, professionals, school support staff and families about issues related to different areas of disability or impairment (IGEC, 2016).

The International Classification of Functioning, Disability and Health was the chosen document to guide all the referencing, assessment, and intervention process with children with SEN. Since it addresses a biopsychosocial approach of the individual, it is considered appropriate to identify the functioning profile of the student and, consequently, to define strategies and intervention resources (Saragoça, Candeias & Rosário, 2013).

An example of good practice will be described in part II.

## **After-school inclusive support measures**

Leaving school constitutes an issue for every student and naturally it is an even bigger issue for students with any kind of disability. What future and life project awaits this young people? (Merca, 2017)

Many young people with a disability or an impairment don't meet the conditions to proceed their studies and when compulsory schooling is completed, in an articulation between the School (Team from CRI and teachers), family and themselves, they can be referred to the different responses that are suited to their needs, interests, and expectations, in a way that, together, they can outline his life project (Merca, 2017).

Several approaches have been proposed in literature to a person-centred planning, with a strategy outlining to value active engagement from youth on decision making about the future and in exploring its competences and participation opportunities (Afonso, 2005; Halpern, 1994; Crockett & Hardman, 2010) (Merca, 2017).

There are many possible ways given the potentialities from youth with a disability: Occupational Activities Centres (OAC), Resource Centres for Employment (RCE), where we find measures such as IAOQE (Information, Assessment and Orientation for Qualification and Employment), SP (Support for Placement) and VT (Vocational Training) (Merca, 2017).

-Occupational Activities Centres (Decree Law nº 18/1989) – It is a response from Rehabilitation Entities where activities Strictly Occupational are develop, on fields such as autonomy, adaptive behaviour, recreational therapeutic process, and Socially Useful activities, enabling for a progressive autonomy and personal and familial self-worth, developing socio-professional skills and behaviours in several fields. Also, activities as OAC Business are developed, representing an alternative way to socio-professional integration for people with disabilities or impairments (Merca, 2017).

-Resource Centres for Employment (decree nº9251/2016) – It is a supportive framework for the Institute of Employment and Professional Training (IEPF), presenting two measures as after-school response (Merca, 2017).

-IAOQE (Information, Assessment and Orientation for Qualification and Employment) notifies young people of possible professional paths considering their work capacity, their potentialities, and impairments in participating in activities, providing them some job experience that reinforce their life course decision making (Merca, 2017).

- SA (Support for Placement) allows young people to experience different working activities in entities or businesses, enhancing their employability skills, culminating with a process of mediation to integrate professionally on the job market (Merca, 2017).

Vocational Training (Decree Law nº 290/2009) developed by training institutions on the context of the Operational Programs of Funding by the European Social Fund, aiming to qualify and include on the job market the youth with diverse impairments, namely, intellectual disability, motor and hearing impairment, mental illness, among other things (Merca, 2017).

The vocational paths are flexible and individualized, adapting to the learning ability of young people and their needs, improving their employability skills beside the acquisition/strengthening of personal and social skills.

One of the components of the training course, the practical training in work context, allows the acquisition and/or consolidation of the acquired skills, potentiating the development of a work practice and sense of responsibility, key factors for professional inclusion. The key factor of this process is finding the right worker for the right place, a work place where the impairments are not constraining and where the professional performance can be the highest (Merca, 2017).

Rehabilitation Entities dispose of a Specialized Team (transversal to all the responses), with specialized training, in different fields namely: psychology, social work, occupational therapy, physiotherapy, physical education, and mediation for professional inclusion (Merca, 2017).

Professionals are challenged to value the individual as a whole, with its talents, possibilities and working to build a life plan, where his skills can be shared with others (Mount, 1992).

For people with disability and impairment that reach IEPF services, 10% (in an universe of 11.857 on a national level) are accompanied in Alentejo region, given that 39% of those people are accompanied by Resource Centres and related with job market measures (IEFP, 2016).

The inclusion of people with disabilities or impairments on the job market is a decisive factor for social inclusion, financial autonomy, and consequent self-worth and self-fulfilment (Merca, 2017).

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## **Part II**

### **Examples of innovation and good practices regarding activation and participation**

## Introduction: Criteria of good practices of supporting inclusion and activation

Research on good practices is always risky. First, it needs to be defined what are good practices. Second, the odds are that centres which rather work “in the shadow” and do not make publicity, will not be found. Third, the risk is that those which are thought to be “good practices” will be subject to fluctuations.

On the other hand, when the aim is to highlight innovative practices in a domain which tends to be in the shadow, i.e. the support for children with particularly complex and intensive support needs, it is important to show the pioneers, who are trying to innovate. As became clear in the first Work Package of Project Enablin+ , the “Needs assessment Research, the sector of supporting children with multiple disabilities, who have intensive and complex needs of continuing support, is in need of innovation, because children are too passive, many of them are not even schooled, let alone invited to participate in various domains society (school, leisure time, normal family life). Assistive technology is innovating rapidly, but it remains to be seen if these innovations reach out to children with CISON.

Therefore, one of the aims of the Enablin+ project was to search for examples of good practices which try to improve the quality of life of children with intensive and complex support needs.

### Working methods

First we did a kind of Delphi method to set up a list of criteria of “good practices” of continuous support systems in integrated care and education. As a first round we organized an interprofessional expert meeting in September 2014 in Varna (Bulgaria). 31 people participated: 9 educational psychologists, 4 medical doctors, 5 speech therapists, 3 physiotherapists, 4 teachers, 2 sociologists, 2 social workers and 2 directors. We asked the question to list criteria of good practices based on the quality of life paradigm. We worked until consensus was reached. The first round ended with a provisional list of 12 criteria. We then asked each project partner to send out a questionnaire to nominate examples of good practice in their own country, asking for a brief motivation why these are considered good practices, and to what degree they correspond to the 12 criteria. In a second round, during the next partner meeting in March 2015 in The Netherlands, we refined the criteria and let the “good practices” present themselves in a public seminar. The seminar was attended by professionals and parents. The partners were again asked to nominate examples of good practice. A third round was done during a partner meeting in Cluj-Napoca, Romania, in September 2015, to which again a public parent-professional meeting was added. The process was concluded in a four.th meeting during the train-the-trainers course in Milan, organized by the Don Gnocchi Foundation, where some new examples were shown.



## Results

The list of criteria which resulted from the discussions ended up like this.

1. Good practices must reflect all 8 domains of Quality of Life (QoL) as defined by Schalock & Verdugo (see also Claes, in Report of Needs Assessment, Workpackage 1)
  - (1) emotional well-being – contentment, self-concept, lack of stress
  - (2) interpersonal relations – interactions, relationships, supports
  - (3) material well-being – financial status, employment, housing
  - (4) personal development – education, personal competence, performance
  - (5) physical well-being – health and health care, activities of daily living, leisure
  - (6) self-determination – autonomy / personal control, personal goals, choices
  - (7) social inclusion – community integration and participation, roles, supports
  - (8) rights – legal, human (respect, dignity, equality) relation to the UN Convention of the Rights of People with a disability
2. Good practices must offer a challenging learning environment. This criterion corresponds with n°4 of Schalock’s QOL, but it needs to be stressed separately
3. Quality of care should not block quality of life. This means that high quality care oriented at physical, emotional and social well-being, must not stand in the way of an inclusive life.
4. Good practices should focus on the family; they should organize work not because of staff commodity, but should be focused on the needs of the families
5. Good practices should be a place of teamwork
6. Good practices promote inclusion (participation) in school, leisure and society in general. This is N°7 of Schalock & Verdugo’s quality of life criteria, but it deserves particular attention; real inclusion creates a sense of belonging and togetherness. Inclusion must be adapted to age as well.
7. Good practices must put a belief in modifiability into practice: the belief that all children can learn, whatever their barriers, must lead to the organization of challenging activities with sufficient mediation to allow activities. Time, patience and mediating skills of supporting staff are key
8. Good practices use as “regular” things as possible (learning materials, assistive technical aids, toys, furniture, etc.) , based on the concept of “universal design” and “universal design for learning (UDL)
9. Good practices must show that inclusion is enriching for all, that children with CISEN have a positive role in society, and be not just a burden
10. Good practices must have a flexible and innovative rule system
11. They must be evaluable
12. They must be accessible to people with less resources. This has a political aspect, because it will require political action

In composing a shortlist, there is always a risk that some centres who also offer good quality care will perhaps feel offended for not being mentioned.

A distinction must be made:

- What are examples of continuous support systems which stress the aspect of inclusion in education and daily life, and activity?
- What are examples of good comprehensive care?

# Innovation towards inclusion, participation and educational activation in Belgium

## Villa Clementina, an inclusive nursery

Kathleen Ballon<sup>4</sup>, Mieke Destrooper<sup>5</sup> & Katia Verhaeren<sup>6</sup>



*Villa Clementina is a daycare centre for young children with and without special needs, which opened in January 2013. Its dream is to develop an innovative model of care and support.*



## Achievements

Villa Clementina has been running now since 2 years. In this timeframe it succeeded to set up and operationalize the most inclusive child day care center in Flanders. It attracted the government's attention, who invited them to be a part of a brain trust concerning child day care, education and inclusion.

Villa Clementina could not exist without the cooperation of social profit, non-social profit and politics. As in other child day care centers there are a lot of didactic materials but no specific technical aids. There is also an active collaboration with home guiding services, regular and special needs schools.

## Work and activities

Villa Clementina has 7 places daily for 11 children with special needs, and 15 places daily for children with a "typical" development. They work with pre-school aged children: typically developing children normally start at school at age 2y6m. Children with special care needs have the possibility to stay until the age of 6 years.

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<sup>5</sup> Special needs psychologist, Centre for Developmental Disabilities, University of Leuven

<sup>6</sup> Director & founder

The children play in vertical groups (all ages/with or without special needs). The typically developing children enjoy the stimulating environment and multidisciplinary team and learn that there is diversity in our society. The children with special needs have an individual program with speech therapy and physiotherapy. This program is at their own rhythm, in the peaceful space of Villa Clementina. They often have therapy together with their typically developing peers. The therapists share their knowledge (e.g. advice concerning feeding difficulties, alternative speech, positioning in orthoses,...) with the rest of the staff, that consists of 5 full time equivalents of educators, a nurse, a pediatrician, a remedial educationalist, physiotherapists, a speech therapist and 16 volunteers. They organize weekly theme classes like speech classes, hippotherapy, creativity class,...

Next, Villa Clementina works together in a network of regular schools and a school for special needs, which sends 1 teacher, to help in customizing school programmes for all. This cooperation should be seen within their framework of 'the goal of education'. Very innovative is also their 'inclusive school project': they strongly believe in the strength of and the right on education, even for children with severe disabilities. Four days a week a teacher from a school for special education comes and stimulates our special needs children aged >2y6m by an individual and goal-directed program, in cooperation with the speech therapist. This project receives some subsidies from the government, which are, however, largely insufficient to cover all costs. Therefore it is dependent on a lot of fundraising events.

## Principles and goals

### Principles:

- respect for diversity
- learning to live and respect each other at a young age
- giving time to get to know the qualities of each child
- giving time for acceptance
- offering a stimulating environment
- working together in a network
- giving parents the chance to go to work, to study, ...



### Goals

- to give parents of very young children time to get to know their children, to continue as much as possible their 'normal' lives in a 'normal' environment.
- to give children time to develop in a stimulating environment and postpone the need for long travelling distances to specialized schools or day care centers.
- to stimulate special needs children intensively but at their own rhythm, in a green and safe environment.
- to stimulate typically developing children by a multidisciplinary team e.g. every child can enjoy hippotherapy, theme classes, music therapy...
- our goal is to prove that typically developing children (and their parents) will notice that there is diversity in our society and so have another point of view upon persons with disabilities
- for our young adults with a disability (but also for the other members and volunteers of our staff) we work with 'talentmanagement'
- by organizing inclusive events we hope to create an ideal space where everyone has his own talents and gifts.

## Sustainability and multiplication

60% is financed by the government (Child and Family Services), the other 40% are gathered by fundraising on inclusive events and donations. Organizing inclusive fundraising events will always be part of the job. There is also an intensive collaboration with profit organisations.

The staff also started an outreach, guiding different trajectories of inclusion in other organizations (kindergartens, schools etc).

## Conclusions and recommendations

In the beginning, the biggest problem was to convince the government to “think flexibly”. At first, neither the ‘Department for Child and Family’ and neither the ‘Department for persons with disabilities’ wanted to release any subsidy, the inclusive approach did not fit into their current administrative rules. From november 2013, the Government decided to subsidize , in an experimental way, some inclusive child day care centers. However, not enough to cover the working costs. Next, another big problem was to convince the professional field: e.g. the Centers for developmental disabilities also at first opposed the idea. Luckily skepticism has turned to enthusiasm!

Through and despite these resistances , the belief has grown stronger in the value of inclusion for very young children. Every day one can see a developmental progression of all the children, but definitely for the children with special needs, a lot of progression that even never was expected!



### More information:

[www.villaclementina.be](http://www.villaclementina.be) (in Dutch)

A videoclip is available in Dutch & English, on the accompanying DVD.

## Pioneering teamwork for inclusive education for children with CISN

Jo Lebeer<sup>7</sup>, Beno Schraepen<sup>8</sup>, Inge Wagemakers<sup>9</sup> & Luk Dewulf<sup>10</sup> (Antwerp University, Belgium)

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

One of these pioneers is the school “**Het Hinkelpad**” [“The hopping path”] in Antwerp<sup>11</sup>, a regular primary school which includes many different children, coming from different cultures and backgrounds; having a wide variety of abilities, some have been diagnosed with a developmental disability; one of the children has multiple disabilities and will be the focus of the present presentation and article.

K. is a boy of 5 years. He is sociable, loves to play with other children, loves action. His favourite games are football, hide and seek, playing with building blocks ... What he likes the most is sliding down the slide. He is a fan of Captain Winokio (a children’s music project), the children’s programme on the Radio, St Nicholas songs and songs from school ... and he loves to dance.

This sounds almost like a normal toddler, and that is what he is. Therefore, K. goes to a regular school. What is different is that K. has CP (Cerebral Palsy) and multiple disabilities. He has severe difficulties in language expression (he understands, he speaks a few words and uses gestures to make himself clear), in mobility (he cannot walk alone; he is able to sit and stand with support; he has severe difficulties in hand coordination so that drawing, eating, playing are difficult); he is dependent for all daily activities and needs permanent support.

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

His parents constructed an extensive network around K. The teacher works closely with the internal care team of the school, such as the S.E.N. coordinator and the principal. In addition, many external partners are brought to the classroom. Those counsellors or ‘special teachers’ regularly come along to support the teacher in the classroom. There are co-teachers such as “a mobile assistant teacher” (employed by the multifunctional service

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<sup>9</sup> PhD in Development Studies, researcher and expert equal education opportunities, investigative journalist for broadcast media

<sup>10</sup> Investigative journalist and director for broadcast media and print

<sup>11</sup> [www.hethinkelpad.be/Hinkelpad/index.php](http://www.hethinkelpad.be/Hinkelpad/index.php)

centre) who regularly comes to support K for group activities. Students in special needs pedagogy help the teacher several times a week and serve as co-teacher. They are working with the teacher so that K. can participate as much as possible with the other children. Then there are also two external support professionals from the Special Education Needs support centre. One focuses on the visual capabilities of K. and encourages him to focus, the other counsellor looks at the movement functions. A private physiotherapist visits the school four times a week, one of which is during gym class. He helps the teacher and other support staff to move in a good way with K., to help him to walk and perform actions. The speech therapist visits once a week and works on communication and eating, which is an important link. The speech therapist provides input to the teacher and other support staff. During team meetings, K's learning objectives are being discussed and agreed so that everyone is working towards the same goals.

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

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

A DVD has been made<sup>12</sup> of the first three years of kindergarten, showing various situations in the class (welcoming, play, mealtimes, gym lesson, staff meetings, and a day at the seaside). It is very useful for training purposes, for all professions, accompanied by a series of guiding questions. It illustrates the following topics: learning together (how to differentiate tasks, how to ensure full participation), playing together, how to give support in the classroom (with subcategories according to the persons giving support e.g. peers, co-teacher, educator, speech therapist, physiotherapist, students; and according to the goal of giving support: to enable mobility, communication, eating, peer interaction, participation), support by an external multifunctional team; integrating care & education; how to set up teamwork.



*Figure 2 Children are fascinated by experiments; the child with several impairments actively participates.*

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<sup>12</sup> Production: Luk Dewulf & Inge Wagemakers (production house De Seizoenen), Antwerp, Belgium



### More information:

<http://www.hethinkelpad.be/Hinkelpad/index.php>

## Professionalizing staff in Multiplus



Multiplus is a centre of expertise on support for people with profound intellectual and multiple disabilities (PIMD), a spin-off of the University of Leuven (BE). Multiplus' mission is to improve the quality of life and the quality of support for people with PIMD by spreading and stimulating knowledge and expertise of practitioners and parents.

Multiplus has four core functions:

- Spreading and exchanging information e.g. website, newsletter, publications, work- and intervention groups,
- Initiating practice-oriented research e.g. inventory of schools and services for persons with PIMD in Flanders, multi-sensory storytelling, communication passports,
- Giving training & advice to professionals e.g. programs for direct support workers and staff members, by request or initiated by Multiplus
- Sensitizing society and policy e.g. right to education

Partnership: Multiplus collaborates with other expert centres: AP3 (Belgium), Platform EMG (Netherlands), PAMIS (Scotland), Leben Pur (Germany).... There is also close collaboration with clients, parents, practitioners and scientific researchers, as well as with research centres represented in the Special Interest Research Group PIMD of IASSIDD, University of Groningen, Cologne, Manchester, Dundee, Genève, Stockholm, Bangor,..., and worldwide

### More information:

[www.multiplus.be](http://www.multiplus.be)

## "Lus" connects people



LUS is a centre which organizes circles of support for community-based inclusive approach. It works with families to help them setting up networks around a person (child or adult) with a disability. The network functions like a think tank. "Lus" is a Dutch word meaning "loop": the symbol stands for creating loops in society, so that a person who has a need for support, is not left alone.

The basic inspiration comes from , among others, John O'Brien, with a philosophy and practice of inclusion. To be able to really participate in society, despite impairment, to be a full citizen, one must

not leave all initiative to the person with the impairment or his family, who is often isolated, but one must work at community building. One way to do this is to create a support network. The person who is in a need for support (Lus calls them consequently “the central person”, and does not want to speak about “the disabled person”) chooses his/her own supporting people, in principle. Those who have difficulty to expressing themselves, will have the help of the close circle around them, to choose people in slightly wider network. These can be people from the extended family, friends, neighbourhood. Care must be taken to choose people who have some influence to get things moved, to look for practical solutions.

#### More information

<http://lusvzw.be/>

### Looking for ways to communicate: Comalso



Comalso is a consultation centre for children and adults with aphasia and dysphasia, trying out the possibility of communication via augmentative and alternative routes than speaking, using computerized individually adapted solutions. Comalso is led by a speech therapist Anne Courtejoie, member of ISAAC. She evaluates and gives advice to children and adults. Comalso takes the necessary time to explore communicative solutions. For some people, especially children with multiple disabilities, this requires a lot of patience, inquisitiveness, endurance, to be attentive to small signs of reaction. Naturally, this is a process of many days and even months. The sessions are spread over time, e.g. once a week. Comalso also helps in choosing the right assistive device, and tries the highest possible mental level, which allows the individual to communicate in the richest way. Many devices are too restrictive, so it takes time to look for the best. Comalso also trains parents as well as professional staff in Belgium and France. Furthermore, there are many initiatives which developed interesting approaches in some partial aspects, which are worth disseminating.

Hardware systems are e.g. a Tellus or an unbreakable Panasonic portable computer. Examples of software are “Mind Express”, Kurzweil, Minspeak.

#### More information

[www.comalso.be](http://www.comalso.be)



# Innovation towards good practices regarding inclusion and educational activation in the Netherlands

Rianne Kleine Koerkamp<sup>13</sup>

## The Songbox

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Contact person	Mariëlle Jacobs <a href="mailto:mariellejacobs@visio.org">mariellejacobs@visio.org</a> Tel. ++31 885858209
Website	<a href="http://www.visio.org">www.visio.org</a>
Age of Target group	The Songbox can be used at any age, but fits a developmental age of 0 – 3 years
Kind of target group	Children with (severe) visual, motor and intellectual disabilities
Objectives of the project or initiative	<ul style="list-style-type: none"><li>- Encouraging communicative conditions which form the basis for good communication</li><li>- Observation instrument to determine the initial situation and to recognize and understand the communicative signals of the child.</li><li>- In addition to the conclusions of a standardized test, you can get additional information from the Songbox</li><li>- how to support communication</li><li>- stimulating the development of showing preference to learning to choose.</li></ul>
Main project activities	<ul style="list-style-type: none"><li>- With the Songbox an additional practical course has been developed to offer users a theoretical basis and to learn how to use the Songbox to get a good communicative basic attitude.</li><li>- The Songbox can be offered both individually and in group.</li><li>- The Songbox can be used by parents, teachers, assistants, supervisors, (speech) therapists.</li></ul>
Motive for nomination as “example of good practice”	The Songbox has been successfully used for many years at the school of Visio in Breda. The method is included in the education of children with (severe) visual, motor and intellectual disabilities. It is a method with concrete and attractive material. By adjusting the way of communication of the facilitator, communicative development can be triggered by using songs.
Further documents:	The box consists of 35 songs. Each song is linked to an object, photo and picture. The box also includes a booklet with CD and brief explanation.
Video document:	<a href="http://bit.ly/learningbymusic">http://bit.ly/learningbymusic</a>

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<sup>13</sup> Quality of Life Centre, Wijhe

## Together to School classes: A School Where Everyone Belongs



Joke Visser

*To School Together* ('Samen naar School') classrooms make it possible for children with severe disabilities to learn in a mainstream school with support specially tailored to their needs. *To School Together* is an initiative of the NSGK, the Dutch Association for Children with a Disability, and aims to stimulate the founding, professionalization and use of these classrooms. What began as a few scattered classes has turned into a national movement.

### Every Child Can Learn

An estimated 13,000 children with a disability in the Netherlands never see the inside of a school. Some sit at home all day, others go to day care centers. NSGK believes that every child, regardless of their disability, should be encouraged to develop to their maximum potential. Every child can learn, as long as education is tailored to a child's specific needs and abilities. Preferably in the company of peers without a disability. It is much more natural for people to live in an inclusive society when children with diverse abilities grow up learning together.

### Together Wherever Possible

That's why in 2015 NSGK kicked off the project *To School Together*. The foundation helps to set up *To School Together* classrooms around the country. These are classrooms where children enjoy education adapted to them, with the care and support they need. And where possible they join the regular activities of the school with other children, in the show-and-tell circle, music lessons, play time, eating and drink breaks, reading time; you quickly see that children can do a lot together.



### It Started in Alkmaar

*To School Together* was inspired by the 'Classroom on Wheels' in Alkmaar, where since 2011 children with and without disabilities have been attending mainstream school together. The instigator, Roeland Vollaard, wanted to do something about the societal barrier that all too often exists between children with and without a disability. 'At our school I see daily how much children with and without disabilities can learn from each other. Interaction is really important for both sides. Regular learners learn what it means to have a disability and how to work with it. And vice versa, children with a disability come out of their isolation. Not only are they more stimulated, they can also handle more stimulation. They grow before your eyes.'

## A Start for Life in an Inclusive Society

Not only are children learning from each other; by going to school together they are also laying the foundation for an inclusive society. Roeland Vollaard: 'Where children from a young age grow up together, they find it natural later on to live in the same communities. How can you possibly learn to live together if you never run into each other? Education should play a much bigger role in this. A school that teaches that everyone belongs, prepares us for a society where everyone counts.'

## Building on Success

Following the Classroom on Wheels concept, slowly but surely five other classrooms got set up, all with financial support by NSGK. But more was needed. More classrooms, more financial support, and also more coordination. The new classes had to constantly reinvent the wheel, negotiate with schools, municipal government, care insurers and other relevant parties. That's why NSGK initiated *To School Together*. With *To School Together* we provide financial support and give good advice for setting up more of these classrooms. There are now sixteen of them, already double the number of when we started. Our dream is to set up a *To School Together* class in every municipality. So that children with a severe disability all over the Netherlands can go to a school in their own neighborhood.

## From a Few Classes to a Movement

*To School Together* not only aims to expand the number of classrooms, the project also provides an umbrella organization for new and existing classes. Within *To School Together*, participants exchange knowledge and experience, combine their strengths, help newcomers and provide information to those interested in starting their own *To School Together* class. We see that people are starting to recognize *To School Together*; classrooms that were set up earlier are happy to call themselves *To School Together* classes. Various politicians have visited a *To School Together* classroom to see firsthand how we are giving form to inclusive education in the Netherlands.

## Scientific Research

It's clear to the parents of children attending *To School Together* classrooms: they experience that their children are more alert during the daytime and sleep better at night. They see their children making developmental leaps as they learn from their non-disabled peers. The Department of Special Needs Education and Youth Care of the University of Groningen is now doing research into the effects of *To School Together* on the development of children with severe multiple disabilities and the factors that contribute to these effects. The research will continue to 2020.

## More information

Address	NSGK Wibautstraat 1091 GS Amsterdam Tel ++31 6-15007919	212-214
Contact person	Joke Visser, NSGK	
Website	<a href="http://www.nsgk.nl/samennaarschool">http://www.nsgk.nl/samennaarschool</a> (in Dutch)	
Age of Target group	4-21	
Kind of target group	Children with (severe) visual, motor and intellectual disabilities	
video	<a href="https://vimeo.com/13852891">https://vimeo.com/13852891</a> Bram Foundation: kindergarten & primary school (Dutch spoken with English subtitles): on accompanying USB-card <a href="https://www.nsgk.nl/wat-doet-nsgk/projecten/samen-naar-school">https://www.nsgk.nl/wat-doet-nsgk/projecten/samen-naar-school</a>	

## In one school

### A better world starts at school

In1school is committed to the right to inclusive education. Education where children with and without limitation can learn, collaborate and play. The right to inclusive education is stipulated in the UN Convention on the Rights of Persons with Disabilities (IVRPH) and the UN Convention on the Rights of the Child (CRC). In1school makes unequal treatment of children in education visible and fight violations of this law to the courts. This is how a fundamental and irreversible change towards inclusive education is launched.

## The EMG Knowledge Network for Parents and Professionals

The EMG platform is a carrier of the new developments in the Netherlands:

### What does Platform EMG do?

Platform EMG is a network of knowledge and information for everyone who is professionally or personally involved with people with severe multiple disabilities.

Platform EMG aims to:

- collect and disseminate knowledge, information and experiences
- contact professionals, parents and others involved with people with severe multiple disabilities
- promote knowledge

Platform EMG focuses on parents, relatives, volunteers and professionals involved with persons with severe and multiple disabilities.

### Exchange of knowledge and contentual depth

Platform EMG provides opportunities for the exchange of information, experience, knowledge and in-depth content:

- Network Workgroups
- Knowledge Networks
- Workshop
- The monthly digital newsletter (free of charge)
- Projects
- Theme meetings
- Annual EMB congress

## Vision

Platform EMG operates from the belief that people with severe multiple disabilities are entitled to a fulfilling life in society, and this often requires creative solutions.

A good quality of life for people with severe multiple disabilities and their close family and friends.



[www.platformemg.nl](http://www.platformemg.nl)

## Quality of Life centre

The Quality of Life Centre (Wijhe) can be considered a spin-off of networking in the Enablin+ project in the Netherlands. It is a start-up to coach institutions, schools, families and service centres to develop inclusive projects for children and adults with complex and intensive support needs

Life is far from easy for people with complex intensive support questions (CISN). Their quality of life, in the year 2016, yet leaves room for desire. Not only because of their impairment, disability and handicap, but also by the influences of the medical-social domain, starring a variety of professionals. A force to which they rely upon, their whole lives, day in and day out. We need an inclusive society where everyone matters and can participate. But how do you transcend your diagnosis, and how to become more than the sum of its parts? Fragmented care is a daily reoccurring issue. The mutual cooperation between the people involved is often not ideal. In particular, the collaboration between parents, health care and education must improve.

Health Care and education for people with CISN often leads to impoverishment of their lives instead of enrichment. The leanness affects not only the target group itself, but the people around them as well. The 'system world' and the 'human world' are laying farther apart than ever, and despite relentless commitment of many people, they often miss their goal. This leads to loss in social and economic terms. Recent legislative changes, transitions and cuts, provide as of yet no solution.

The image of people with CISN has changed significantly over the past 15-20 years. From dependents with disabilities who just require good nursing and care, they became people with a voice, with capabilities and with a right to quality of life (QoL). How to shape this, is still a problem. These last years,

knowledge for and about this group has increased. Including evidence-based knowledge (scientifically), empirical (parents) and practice-based knowledge (professionals). The wide availability of this knowledge should be beneficiary for QoI, but unfortunately it doesn't reach the target group sufficiently. The knowledge is either not, or shredded applied. And although the state of scientific knowledge is clear and this knowledge is honoured, the appreciation of experience and practice-based knowledge is less explicit. Its use is often organizational and person dependent. This is, among other things, attest to the fact that this sector, unlike other sectors, still lacks proper guidelines, a working standard and a unified work system. Knowledge is therefore not optimally utilized. So it's time for standardization of knowledge on target group level, which provides the opportunity for individual customization. Given the new roles and responsibilities of municipalities, this is an urgent matter. Implementation of this new direction translates into a 'transcendent' process of innovation, which should also be transcendently facilitated with people and resources.

We represent and advocate the importance of a good life for people with CISN. A life in which they can thrive and learn, with a lifestyle that suits individual support questions and concerns. We explicate and represent that what our own management and quality experience induces. We use the knowledge of all parties involved and encourage the use of that knowledge in daily practice. The Quality of Life Centre operates independently. Through partnership a lot of room is offered for influence, involvement and cooperation.

#### **Collaboration Quality of Life Centre and Expertise Centre EMB**

The Quality of Life Centre and the Expertise Centre EMB have joined hands in favour of the quality of support for people with severe multiple disabilities (EMB). In recent years, knowledge for and about this target group has increased. Including evidence-based knowledge (scientifically), empirical (parents) and practice-based knowledge (professionals). The wide availability of this knowledge should be beneficiary for QoI, but unfortunately it doesn't reach the target group sufficiently. The Quality of Life Centre wants to give more direction to the quality of life for people with complex intensive support needs (CISN) by using good practices, by making experience and practice-based knowledge available. The Expertise Centre EMB concentrates on the availability and applicability of scientific knowledge for people with severe multiple disabilities. Through the collaboration between the Quality of Life Centre and the Expertise Centre EMB, we want to ensure standardization of practical knowledge and scientific knowledge on target group level. That way we can better meet the individual needs of children and adults with EMB. Read more about '**het landschap Kennis en Expertise**'.

<http://www.qolcentre.eu/wp-content/uploads/2016/09/Landschap-Kennis-Expertise-voor-CISN-Web.pdf>

'One stop support system' explanation of QoI. (infographic) <http://www.qolcentre.eu/wp-content/uploads/2016/07/Quality-of-Life-Centre-Totaaloverzicht-aanbod.pdf>

[www.qolcentre.eu](http://www.qolcentre.eu)

# Examples of Innovative good practices in France

Eric Zolla, CESAP, Paris

## Initiative of inclusive education: Adapei de la Corrèze

Florence Bergamasco & Lauratie Krouit



Age of Target group	6 to 16 years
Kind of target group	Children with multiple disability ("People with severe mental impairment associated with multiple disabilities in particular motor (PIMD - Profound intellectual and multiple disability and / or Cerebral Palsy)
Objectives	Install main actions of the teaching unit project in a mainstream school of Education
Contact	ADAPEI de la Corrèze, 3, Allée des Châtaigniers, 19360 MALEMORT Gérard RESTOUX (Directeur Général) g.restoux@adapeicorreze.fr Tél. : 05 55 17 75 90 <a href="http://adapei-19.fr/">http://adapei-19.fr/</a>

ADAPEI de la Corrèze <sup>14</sup> has inclusiveness at the forefront of its thinking in everything it does. And that means not denying difference, but recognising it, so as to be able to understand it and enable every individual to live their life, with their difference, in society. For us, that is the whole point of the **outsourced teaching units**: being able to live one's difference, whilst having access to the same facilities as other people, only adapted appropriately. Accessibility is one of the pillars of an inclusive society; that should be everyone's rights: accessibility to schools, leisure centres, care services in town. Only if it is impossible to leave the institute, the services should be made available inside the Institute. .

### The initial project

The multiple disabilities outsourced unit at the Medical-Educational Institute of Puymaret is a project that has existed since the start of the school year in 2013. This class is one of 4 outsourced units. It is the result of a partnership that has seen a great deal of debate, between the Regional Health Agency of Limousin, the Ministry of Education and the Association of Parents of persons with Intellectual Disability (ADAPEI) of the Département of Corrèze. The project started from the needs of 5 pupils with multiple disabilities, for whom no adequate schooling and support was available in the existing integration projects (CLIS) or home care centres. The Medical-Educational Institute of Puymaret has an expert team in place and is capable of providing adequate accompanying services.

In terms of its design and its logistics, on the human and the material resources side, this measure makes it possible to go beyond ordinary school learning for children with multiple disabilities. It is a kind of

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<sup>14</sup> Association Départementale de Parents et Amis de Personnes handicapées mentales = Association of Parents & Friends of People with Intellectual Disability. Each French department has one. Corrèze is one of the departments south of Paris.

learning that could not have happened elsewhere, such as in a residential care facility where conditions for assistance and care are more favourable, but where learning opportunities are lacking. in favourable conditions, within the Medical-Educational Institute itself.

## The school context

The teaching unit is delivered in Brive, in the Louis Pons elementary school. It is at the heart of the school, and this is something that our pupils take great pride in. Access to the playground is direct, like all the other classes in the school. They use the same canteen, have the same menus, and follow the same rules as everyone else.

In the first 2 school years, we welcomed 8 pupils aged between ten and twelve with multiple disabilities, each having intense, specific needs, but also real potential for learning and becoming more sociable. The school routine is adapted to suit the needs of each person: some come into class for 6 hours (2 half-days), others for up to 15 hours (5 half-days).

The evolution of the initial project, three years after its creation, is, in essence, linked to the evolution of the people that it welcomes.

## The team inside the classroom

- a special needs teacher
- a reference classroom teacher
- a teaching assistant made available by the mayor's office of Brive
- teaching and care staff employed by the Medical-Educational Institute of Puymaret
- a team of paramedics (a nurse, a psychomotor nurse, etc.) who intervene depending on the needs within the school itself.

It is important to point out that the whole of the teaching team at the elementary school is an integral part of this project, via the implementation of shared teaching projects, via a welcome into school-life by the whole school; and via constant work with the children (and sometimes with the parents) following ordinary school curricula, focused on understanding and accepting difference.

## Material resources and logistical constraints

Material resources, we have at our disposal:

- 2 large rooms, specially furnished and adapted, a classroom and an education room.
- Specially adapted furniture and school materials.
- A dedicated space with accessible toilets and showers designed to meet the needs of the various disabled children.

The premises are made available by the mayor's office, for the benefit of Adapei de la Corrèze.

The Medical-Educational Institute is responsible for providing transport for children, and given that each pupil has a rhythm of school education that is entirely personal to him or her, the main difficulty faced is often a logistical one:

- Transport in the mornings and evenings
- But also, and above all, during the daytime for children who, for reasons related to tiredness,



are not able to complete a full school day.

## Work in the classroom

The special needs teacher is responsible for design, development, implementation and assessment of the individualized teaching plan for each child. For each school year, they define the class project.

The teaching assistant's role is to facilitate access to these learning courses.

The teaching and care team are present to encourage the child's well-being, allow him or her to have some breaks, provide care, and aim to achieve greater autonomy.

## Three years later...

The implementation of this project was clearly not all plain sailing, with a good deal of pain and resistance along the way. Today, though, there is not a single person - even among those most resistant to it, and we could name certain doctors from the establishment here – who would cast doubt on the validity of this method of providing schooling.

For the professionals and for the parents, inclusive schooling changes the way they look at this issue. The child is no longer seen as a child with disabilities, who is the object of care; he is, above all, a child, a pupil, a citizen subject, a subject with plans, desires, and duties. The arrival of these young people at the Louis Pons School also brought in a dynamic of inclusion with the other sections of the Medical-Educational Institute.

For young people, attending school is part of the process of restoring one's self-esteem, encouraging them to become sociable and develop social relations with young people of the same age. They are proud to be able to go to an establishment that everyone is entitled to attend.

For some, this translates into an additional incentive for wanting to invest in learning at school.

For them, the opportunity to learn at school opens up new possibilities. It is something which they or their caregivers perhaps never had imagined; that learning at school has become a target, both learning in class, and social learning, by being included in a regular group of young people.

Moreover, they have, just like their peers, a school programme - one that is adapted, of course, but that is on a par with the official curricula and the shared basis of knowledge, skills and culture.

They have a schoolbook, a plan for their school learning with inclusive education objectives, considered collectively with the CLIS<sup>15</sup> of Louis Pons and individually for some.

Personalization is often evoked in this document: personalization of plans, personalization of the school routine, of care, and of transport. To this end, the school also allows the children to be part of a group, the class group, and to function as part of a collective - something that is so rare that it is worth emphasizing.

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<sup>15</sup> CLIS Classe d'intégration scolaire, is a special education class within a mainstream environment, with activities in common with "typically developing children part of the time.

In the same way, for a young person attending school in the teaching unit, the relationship with others changes as a result, too: Medical-Educational Institutes are still, all too often, 'behind closed doors' establishments, where the child's peers are different too. In our universe, where difference is the norm, it is the others, the other children who grow up in an ordinary setting, who become strangers.

The simple fact of seeing a child with multiple disabilities evolve in a playground, that noisy, teeming place, a space that is a little bit frightening and yet so enticing, is, in and of itself, indescribable.

Another surprising effect was that inclusive school learning distracted the children from aches and pains resulting from things such as orthopaedic operations. They had less pain. Apparently the change of context, took the focus away from their pain.

The outsourced teaching unit is not a place where all is sweetness and light, however. In fact, from an organisational point of view, it means subjecting the child's comfort zone to a permanent state of danger. The medical-social team has to agree to work outside the Medical-Educational Institute, and thus to adapt to a different context, something that is far from straightforward.

The ideal of putting in place a fully-fledged therapeutic team of experts at the school was at odds with the chronic shortage of professionals in our area. But the absence of a therapeutic platform ultimately also represented an opportunity for the children: for care remains within the Medical-Educational Institute, and does not enter into their world as schoolchildren.

Regarding the teaching staff at the school, they had to adapt to working together with a team of non-teaching professionals. Sharing one's normal surroundings is not always as easy as one might think, especially given that school is a place that has always been considered as sacred. Each team has to meet the other one halfway, so that outsourcing can enable the kind of inclusion one would want to occur. This is one of the missions of the special needs teacher: to create and maintain links between the teams.

Ever since this initiative started, the children, whether they had disabilities or not, have shown us every single day that they can live and work together. We nonetheless observed that an outsourced class for children with multiple disabilities was, in the end, just as stigmatising as what we wanted to fight against. Since the start of the 2015/2016 school year, the project at Louis Pons is no longer exclusively aimed at children with multiple disabilities but has also opened up to other young people at the Medical-Educational Institute, with teaching of modules no longer divided up based on the type of disability, but based on needs, particularly in terms of learning.


Age of Target group:	6 years - 16 years
Kind of target group:	Children in multiple disability ("People with severe mental impairment associated with multiple disabilities in particular motor (PIMD - Profound intellectual and multiple disability and / or Cerebral Palsy )
Objectives	<p>This action involved in children and young people with multiple disabilities the right to a real educational management. It is part of the need to develop programs tailored to the potential of children implemented as part of the educational units. Eventually the expected results, are constitutive of a good practice:</p> <ul style="list-style-type: none"> <li>- Develop a more fine learning needs and cognitive processes underlying young people with multiple disabilities;</li> <li>- Better defining the conditions of access to learning and education for children with multiple disabilities and adolescents;</li> <li>- Enhance the training of multi-professional teams involved in the education of these young people (developing training content) and professionals involved in the process of training through research.</li> </ul>
Contact	<p>CESAP Formation, 62 rue de la Glacière, 75013 paris  Contact person: Christine Plivard  cplivard@cesap.asso.fr  Tel ++33 1 53 20 68 58  <a href="http://www.cesap.asso.fr/cesap-formation-documentation-ressources/actuformation">www.cesap.asso.fr/cesap-formation-documentation-ressources/actuformation</a></p>

## Home support centre Service d' Education Speciale et de Soins à Domicile (SESSAD)



Age of Target group:	0 to 20 years
Kind of target group:	Children in multiple disability ("People with severe mental impairment associated with multiple disabilities in particular motor (PIMD - Profound intellectual and multiple disabilities and / or Cerebral Palsy )
Objectives	<p>SESSAD professionals (social workers, allied health professionals) move to the homes of children in the school or the device or is regularly the child concerned (as a nursery or nursery) to implement accompanying projects adapted or care, or help families for these projects.</p> <p>Services Education, Care and Domestic Help (SESSAD) are existing devices for many years to CESAP. This form of service has a legal recognition in France (in their current form since 1989). The CESAP manages 9 SESAD - They are called more often in France "SESSAD" (Special Education Services and Home Care) - CESAP does not use the word "special".</p>
Main project activities:	<p>The missions of these services are set out in French law:</p> <p>"early care for children from birth to 6 years, with the advice and support of families and familiar surroundings of the child, deepening the diagnosis, using the initial psychomotor development child and preparation for future collective orientation</p> <p>"support the integration or acquisition of autonomy with medical means, paramedical, psychosocial, educational and teaching adapted</p>
Contact	<p>CESAP,  62 rue de la Glacière  75013 Paris  Eric Zolla  ezolla@cesap.asso.fr  ++33 1 42 85 08 04  www.cesap.asso.fr</p>

## Time for a toilet: Prevention and management of pain in toileting and handling of child care and young adults with multiple disabilities (film)

Age of Target group	Children and young adults
Kind of target group	Children in multiple disability ("People with severe mental impairment associated with multiple disabilities in particular motor (PIMD - Profound intellectual and multiple disabilities and / or Cerebral Palsy )
Objectives 	<p>"Time for a toilet" is a training film on the prevention and management of pain during bathing of children and young adults with multiple disabilities. The approach to pain in the multiple disabilities were well covered. In addition to its evaluation, no document focuses on the child's pain when performing the toilet and gestures around him. Yet this time can be extremely painful for some children with multiple disabilities due to their health condition and the large number of manipulations and transfers it requires. Indeed, in the person with multiple disabilities, the toilet can cause discomfort, fear, anxiety or severe pain because of the care itself, the necessary mobilization of the child and any previous painful experiences.</p> <p>Through images and reviews, the team wanted to emphasize the philosophy that underpins the achievement of the care center Vendin Viel "pay special attention to this special time of the toilet." Indeed, it is, for many children, one of the longest of the day talk time with adults. The film also illustrates the need to multidisciplinary care for children with multiple disabilities and the need to implement means not drug (mobilization, utilization of the patient lift, massages, speech.) or medication (analgesics from different levels) to do, what time of the toilet and mobilizations it generates a care free of pain, a fun time and communication between the child and the caregiver. This 21 minutes film is the ideal medium for training and a basis for discussion in hospital services, centers for children with multiple disabilities and home to drive a process of change.</p>
Further documents	Accompanying booklet
Video available	Available on request
Contact	<p>CNRD - Centre National de Ressources de lutte contre la Douleur (National Center for fight against Pain Resources)</p> <p>Unité Douleur, Hôpital d'enfants Armand Trousseau</p> <p>26, av du Dr Arnold Netter - 75012 Paris</p> <p>secretariat.cnr@trs.aphp.fr</p> <p>Tel: 01.44.73.54.21</p> <p><a href="http://www.cnr.fr">www.cnr.fr</a></p>

## Musical workshop for children in a community center

Age of Target group	6-12 years
Kind of target group	Children in multiple disability ("People with severe mental impairment associated with multiple disabilities in particular motor (PIMD - Profound intellectual and multiple disabilities and / or Cerebral Palsy )
Main project activities	<p>This musical activity establishes a relationship with children with multiple disabilities who receive many signals: balance, tension (muscle or other), posture, temperature, vibration, skin contact and body, rhythm, tempo, duration, pitch, tone, resonance, sound etc. who can get in touch with others in the context of the proposed activity that perform this activity closer to the ordinary world.</p> <p>The place where the activity takes place, the "Athena" is a center (community center type) that is located in the neighborhood or the facility is located, plays for adults and children, and association shows. The center, with an auditorium with 150 seats offers many arts education and a branch library dedicated to children</p> <p>Organization of a weekly music workshop in a selected part, outside of the institution for a group of children gathered to share an instrumented, sing, using polyphony, the gun, the instrument free sharing and rhythmic chants best intercultural.</p> <p>Accompanied by professionals (teachers, psychomotor / nes or physical therapists ...) and a music therapist</p>
Video available	Presentation of a video film by "TV Rueil"
Contact	<p>EME Les Cerisiers - CESAP</p> <p>29, rue du Docteur Guionis</p> <p>92500 Rueil Malmaison</p> <p>Nicolas Sempéré</p> <p>nsempere@cesap.asso.fr</p> <p>Tel ++33 1 55 17 37 10</p> <p>www.cesap.asso.fr</p>

## Team Network "Rare Disability" Ile-de-France

Karine Goust

### Kind of target group

Rare disability situations potentially affect all age categories (child, teen, adult, aging disabled person). Rare disability situations can be of birth, acquired, stable or progressive The target group is suffering from a rare disability persons having any of the configurations associated deficiencies or disorders whose prevalence rate is not higher than a case 10 000 inhabitants and under one of the following categories

1. The combination of a severe hearing impairment and a severe visual impairment
2. The combination of severe visual impairment and one or more other serious deficiencies
3. The combination of a severe hearing impairment and one or more other serious deficiencies;



4. A severe dysphasia with or without other disabilities;
5. The combination of one or more serious deficiencies and chronic disease, severe or progressive, such that :
  - a. Mitochondrial disease;
  - b. A condition of metabolism;
  - c. progressive disease of the nervous system;
  - d. A severe epilepsy.

## Objectives

- Organized in interregions, relay teams consist of many professionals. They are located at the interface between specialized resources and community resources. They advise missions and support professionals to develop a comprehensive intervention strategy adapted to the needs of the person and direct with his family to the right person and relevant resources
- They mobilize all stakeholders around the situations which they are aware. With resource center and GNCHR (National Association of rare disabilities cooperation), they provide support for the training of actors and the evolution of knowledge on rare disability situations
- Identification of needs and resources and network engineering in the territory

## Meeting the needs of children and adults in a situation of "rare Disability ". Example of a system set up in France

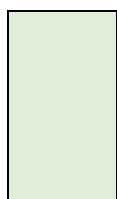
On cue, France, children and adults who are faced with complex and specific needs or whose disability is "rare". This notion of a rare reference to disability: the scarcity of public: a prevalence of 1 per 10 000, scarcity combinations deficiencies resulting in a complexity of the disabling consequences the scarcity of expertise required for diagnosis, functional assessment and the development of accompanying projects tailored for such people.

We have a piece of legislation (in the 'Code of Social Action and Family ") an article that states what we mean by " rare disability. " According to Article D312-194, "are suffering from a rare disability persons having any of the configurations associated deficiencies or disorders whose prevalence rate is not greater than one case per 10 000 inhabitants:

The following scheme can be presented. :

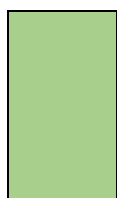
Technical accompaniment Location	simple	heavy	complex	Very complex
	simple	heavy	complex	Very complex
frequent	X	X		
rare	X	X	X	X

Exceptional			X	X



Regional and departmental organization

Rare disability



National Organization



National organization with international connections

## The French project in relation to this specific population

Among the various actions vis-à-vis persons with disabilities, the French State is implementing action plans called "national pattern of social organization and medico-social." One of them is the national scheme of social organization and medico-social for rare disabilities.

### ***1st national scheme from 2009 to 2013***

It was then observed that the assessment of needs and finding solutions for this population was not well known. Quantified. The idea was to develop knowledge of populations in limited numbers, of its very specific expertise needs, constructed response capacity; to organize, strengthen and network these highly specialized expertise that can not be present everywhere.

The objective of the first scheme for rare disabilities was to consolidate, develop and make available the rare multidisciplinary expertise required to assess and support people in this situation and their families in their daily lives, at home or in institutions.

The plan was part of the European guidelines on rare diseases, which recommend support for the networking of national reference centers and expertise as well as recognition of the roles of those involved and their caregivers.



## **The results of the 2009 action / 2013**

- 1) An in-depth inventory of interventions and dynamic players on rare situations handicaps interregional in France

This inventory, which was carried out, aimed at Know the available resources and identify potential gaps, Understand and promote the dynamic between the resources. We now have in France of a first information on the issue.

- 2) The creation of four national resource centers for specific topics: National Resource Center for Children and Adults Deaf Blind and Visually Impaired Deaf

- A national center for the visually impaired resources that have one or more associated disabilities
- A national resource center concerned by the situation of children, adolescents and adults with hearing loss associated with other disabilities or illnesses and children with a language disorder associated with complex disabilities or other pathology
- A national center concerned by the situation of children, adolescents and adults with rare disabilities with severe epilepsy.

- 3) the creation of the National Association of rare disabilities Resource Centres (GNCHR). The National Association rare disabilities cooperative has the following responsibilities:

- formalization of knowledge and contribution to research
- support to professionals and contribution to the development of networking;
- structuring, providing information and developing a communication plan to make it accessible to people, families, institutions and professionals;
- design, organization and implementation of training devices

- 4) Finally, in late 2014 and early 2015, were designated operators will implement "Relay Teams Rare Handicaps"

## **Missions Team Network “handicaps Rare”**

It is stated that the CESAP participating in ENABLIN + project will set up the team Ile de France relay. It is therefore, the objectives of the relay team are presented below. But other parts of France will also see the introduction of Relay Teams (other operators) with identical tasks. Five missions will be entrusted to the rare disabilities relay team Ile de France:

### **1. Identification of needs and resources and network engineering in the territory**

The main objective is to create a directory of land resources for rare disabilities. This tool will allow any player in a relevant way to direct a person device, request an appeal. It will be for the team relay power a national database from resources consolidated at regional level.

It will also be able to trace the needs relating to matters of the few disadvantages to refine the mechanisms put in place and the responses.

## **2. Identification of situations and shoring accompanying responses and supported the different situations of the territory**

The rare disabilities relay team of Ile de France:

- Will one be one of the entry points into the device for people experiencing rare disabilities and families who accompany them.
- Will be specifically placed to shape the person and his family to the right person.
- Will be a point of contact structures, professionals and families for a near shoring and will play an advisory role for the professional development of the comprehensive intervention strategy for the person
- Will have primarily addressed the requests that are submitted to the relevant local resources (when they exist!) Or to the National Resource Centres when this is not the case. Similarly, national centers for rare disability resources could send requests to the relay team, who will in turn forward the request to the most appropriate local resource.
- It will spot any shortcomings and difficulties in some situations

## **3. Estimated situations and support the development of individualized support project for people experiencing rare condition**

Relay team will seek to mobilize all stakeholders around the situations which it is aware and / or for which it is entered:

- It will be based on formal tools at the national level and she will promote the use.
- It will address other experts and will serve as an intermediary between families, professionals, MDPH
- It will be directly related to the MDPH, which will address it on rare disability situations.

## **4. Training**

The relay team must:

- develop the diagnosis of the training offer in the Ile de France
- participate in the training of local stakeholders and families,
- Participate in awareness professionals likely to experience situations of rare disability. It will also aim MDPH professionals to improve their knowledge of these rare situations disabilities
- supporting the training of GNCHR work.

## **5. Contribution to the funding of a high level of expertise in the organization of knowledge and knowledge acquired and their dissemination.**

The teams "on the ground" work with people with rare disability often have to develop methods and tools in each case it is necessary to capitalize, each experience can be replicated by others. It is therefore the mission entrusted to the team relay a double function:

1. Capitalization of knowledge: the team relay will be able to capitalize a significant amount of information, experience, empirical knowledge by leveraging the ingenuity and creativity of the

actors. The goal is to structure the capitalization of knowledge and expertise, to ensure the sharing and dissemination and feed the national level,

2. knowledge dissemination function: regular meetings (thematic reflection groups, practical analysis) will ensure the sharing of this information and postures; newsletters, cloud platform

## Contact

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## Réseau Lucioles: a parents-professionals knowledge network

Réseau-Lucioles has been founded by parents of a child with a severe intellectual disability. It is a parents-professionals cooperation network, based in the region of Burgundy and the East of France, with the objective to improve support and accompaniment of people with a serious intellectual disability.

One of the main concerns of Réseau-Lucioles is the lack of access to proper education of this group, the complexity of care, and many aspects of life still do not have good solutions: communication, problematic behaviour, mobility, regression, pain, affective and sexual life, etc.

What does Réseau Lucioles do?



Figure 3 Actions of Réseau Lucioles

In order to respond to the needs of families and professionals who are often searching for answers, Réseau Lucioles collects and disseminates knowledge and experience in the areas of their concern (Figure 3). It conducts research about problems which are usually scarcely researched. In every project, it cooperates with suitable experts.

They have an approach of “action research”: they look for initiatives in “the field” which they try to generalize and then share: Testimonials, tips and tricks, successful initiatives ...

#### *Products of Réseau Lucioles*

- Publications: about nutrition & feeding problems, sleep disturbance, problem behaviour (self-harm, self-stimulation,...)
- Films: they filmed in various care facilities, to give a picture of the real needs
- An app for tablet computers has been developed
- Newsletter
- Training & conferences

#### *Contact*

[www.reseau-lucioles.org](http://www.reseau-lucioles.org) (the website is only in French)

## Examples of good practices in Romania

Batiz Enikő, Orbán Réka, Szamosközi István<sup>16</sup>

Every child is a special human being, developing in a personal way and rhythm, for some children takes longer to reach their developmental milestones. In many cases these special children need special and continuous support help to achieve their potential.

### The « Reuven Feuerstein » institute at Babeş-Bolyai University of Cluj-Napoca

The « Reuven Feuerstein » Institute at the Babes-Bolyai University was founded in 2009, based on the agreement signed between the International Center for the Enhancement of Learning Potential (ICELP) in Jerusalem and the Babes-Bolyai University.

The Institute targeted the promotion of intervention programs developed by Reuven Feuerstein in formal educational environments (including universities), in the field of special education (recovery of people with socio-cultural handicap), in adult education (maintenance of adult mental capacity) and training (for professional qualification of staff in the field of production). The professionals working in the Feuerstein Institute are delivering the following **services**:

#### Individual assessment

A dynamic individual assessment of learning potential of children and young adults provided at the request of families, schools and other educational institutions.



#### Assessment Study group

This assessment is for enhancing the learning potential in a group format is provided at the request of schools and other educational institutions. Evaluation includes assessment of the dynamic of perception, memory, logical reasoning and problem solving for small groups.

#### Early Education

Dynamic evaluation focused on assessing cognitive and learning potential. Evaluations are conducted in a friendly atmosphere, using dynamic assessment tools.

#### Parental Training and small group counseling for parents of children with specific problems



The purpose of parental training and guidance is to increase awareness by parents on the importance of mediated learning-experience as an active and effective tool for improving their children's cognitive, social and emotional development.

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<sup>16</sup> Babes-Bolyai University, Department of Applied Psychology, Cluj-Napoca, Romania. Acknowledgements: the authors wish to thank their colleagues Kiss Szidónia, János Réka, Demeter Kármén, Szabó Kinga, Kálcsa-Jánosi Kinga, Pordea Anett, Maior Edit, Farcas Susana, for cooperation with research

## Cognitive rehabilitation programs for individuals with brain damage

The **aims** of the activities are also the:

- Spreading of scientific knowledge by organizing courses, trainings and workshops in the country and abroad
- Training of researchers in education, teachers and professionals, developing creativity in implementing educational methods,
- Promoting excellence in organizing of conferences, symposia, etc. in education and training
- Communication, information, self-evaluation and competition, promoting values, interdisciplinary and team work.
- Application practical skills training, competence and moral satisfaction by involving Masters and PhD students.



## The Gecse Dániel Foundation Educational and Rehabilitation Center at Târgu-Mureș



The “Gecse Dániel” Foundation was established in 1993 with the purpose of helping people with special needs and especially disabled children. The real work with the disabled children started in 1996, when the Educational and Rehabilitation Center was established. It all started with a group of 9 children. Until today 180 children have benefited from our services, out of whom many were integrated into other educational institutions.

The **aim** is to improve the quality of life for children with special needs and to support their families by

- ✓ providing adequate professional guidance in the development process, starting at an early age
- ✓ improving the general disposition of these children by decreasing the negative psychological effects caused by their disabilities
- ✓ acquiring and improving children’s self-care abilities so that they acquire the highest degree possible of independence
- ✓ helping children in acquiring communicative, cognitive and social skills
- ✓ assisting the process of their integration into school and society
- ✓ involving family members in the development strategy formulated for their children and supporting them in acquiring proper educational skills
- ✓ parents counseling and advising
- ✓ training of the staff

The **target group** of the Foundation services are:

- children and youngsters with various impairments and disabilities (physical, mental, visual, hearing, multiple, behavioral disorder and autism)
- toddlers aged between 0-3 with developmental delays
- preschool- and school-aged children from the general school system with different psychomotor deficiencies, severe speech disorder, learning disorder, visual and hearing impairment and behavioral disorders
- children with severe multiple disabilities who can't be integrated into any educational system

**Services provided** by the Educational and Rehabilitation Center:

❖ **Instructive and educative activities in preschool and school groups**

At the moment, 85 children and young people from Mureș County are benefiting from the services of our center. 30 children (divided into two preschool groups and two school groups) are taking part in the daily program. More than 55 children are included in the ambulatory program, and benefit weekly from specific individual therapies

❖ **Complex assessment and evaluation**

The evaluation of the children starts with data gathering and the identification of the problem areas. Special tests are run in order to define the level of psychomotor development



❖ **Occupational therapy**

The occupational therapy targets the children's mental development, and it is aimed to develop their individual autonomy and social skills with the purpose of integration.

❖ **Speech therapy**



The speech therapy targets the stimulation of the speaking abilities, the correction of the articulation disorders, the improvement of the vocabulary, spelling and grammar, and the prevention and therapy of learning disorders.

❖ **Physiotherapy**



Physiotherapy is a complex therapeutic means of physical rehabilitation that involves a set of physical exercises with preventive and therapeutic purposes

#### ❖ **Individual and group counseling for parents**

Parents receive both professional guidance and emotional support from specialists. We help them in their efforts to confront the problems arise out of their child's disorder.

#### ❖ **Special guidance for the parents of children integrated into general school system**

The center provides counseling for elementary and middle school personnel, in order to generate an efficient integration of the children with special learning needs.

#### ❖ **Transportation of children to and from home**

The **daily activities** carried out by the specialist are:

#### **Daily programs and care:**

- group activities – based on special syllabus
- special therapies – based on individual needs and development strategy
- inclusive social activities

#### **Ambulatory care:**

- special therapies – based on individual needs and development strategy

#### **Special therapies:**

- Occupational therapy aiming the neuro-psychical development of the children and the forming of individual autonomy and social skills with the purpose of integration.
- Speech therapy aiming the stimulation of speaking ability, correction of the articulation disorders, improvement of the vocabulary, spelling and grammar, prevention and therapy of learning disorders.
- Physiotherapy is a complex therapeutic means of rehabilitation involving a set of physical exercises with preventive and therapeutic aim.

#### **Individual and group counseling of the parents**

- Parents receive both professional guidance and emotional support from specialists to be able to confront the problems resulting from their child's disorder.

All programs in the center are based on teamwork involving project manager, physician, psychologist, speech therapist, physiotherapist, occupational therapist, social workers, teachers, special education and support teachers and additional person.



## Authelp Association - Miercurea Ciuc



social support centre.

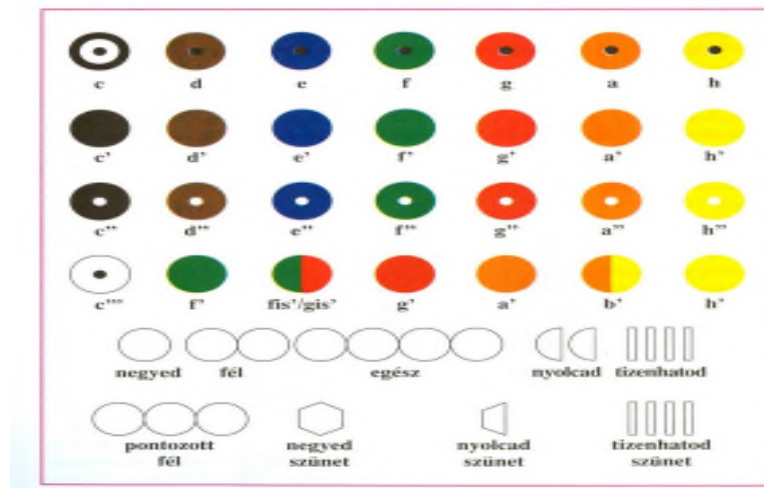
The “Authelp” Association operates in Csíkszereda (Miercurea Ciuc) with the goal to support the autistic children, youngsters and their families. It was established as an association of parents, but the civil organisation has become an accredited

social support centre. Its mission is to create proper conditions for children in need to develop their cognitive, communication and social abilities in a protected and adapted environment throughout personalised assistance.

To achieve this, the **Puzzle Educational Centre** was founded in cooperation with the “József Attila” Secondary School and the Harghita County Educational Authority (Inspectoratul Scolar Judetul Harghita) in September of 2009. There are three special educators employed by the state, but for the optimal functioning of the centre, special educators, music teachers, caretakers were employed to give the children specified exercises for their musical, pedagogical, social and physical skills. Besides this, the co-workers of the “Authelp” Association craft the tools needed for the activities.

In 2011, they started a **music therapy program** with the help of the Community Foundation and the Child-healing Program promoted by MOL. This program began with the aim to help our children identify and express their feeling throughout music while giving them an opportunity to enhance their communication skills.

The first step was to learn the method from “Parafónia” Music Band and the “A zene mindenkié” (Music belongs to everyone) Association. A method of colourful music sheets was developed by Heinrich Ullrich to aid the education of mentally disabled children. With the help of these colourful music sheets, mentally disabled people are able to play in an orchestra. This method was adapted to Hungarian by Anna Vető. This was the beginning of spreading the ULWILA (colourful music sheets) method in Hungary, as well as its usage, in 1991. The method of creating or reading the music sheets or the instruments don’t require a complex way of thinking or even knowing the names of the colours. It only requires two things from the children: to be able to identify a colour and the shapes which mark the rhythm.



The specialist from the Autehelp Association tried to adapt the method to the abilities of the autistic children and the tools at disposal. The special educators personalised the visual cues which helped the children foresee what would happen during a musical class. The flow of the musical therapy sessions formed slowly. Besides the presence of personal caretakers, the music sheets, the instruments and other tools created the structure of a safe and versatile session.

The first occasion for the children to perform in front of an audience was in the autumn of 2011, during an event held by the József Attila School called “Zenebona manócska módra” (Music the goblins’ way), then in December, when they performed during the Christmas market of the SEN children. The next one, entitled “Colourful music” took place with the help of the music teachers of the “Parafónia”, in July of 2012, where the visitors gain access to the musical therapy sessions in order to understand how they work.

In May 2013 the centre participated at the II<sup>nd</sup> Outsider Music Fest at Sepsiszentgyörgy (Sfantu Gheorghe). This event was organised by the Írisz House. This year the children performed in a show called “Music makes life colourful”. To the event several performers were invited, along with people who teach children with specific needs in education throughout music.

Autism lasts a lifetime so when the child becomes of age, their autism will linger on. These musical activities help the children develop skills that will help them even in adulthood. The music therapy also helps them to learn things that will enable them in structuring their days and to express their feelings, even to control and channel them.

Another main activity of the Association is to make aware what autism means, what SEN brings on. They aim is to help the parents whose children live with autism. It doesn’t matter whether the parent belongs to the association or their child was just recently diagnosed. They would like to ensure the parents that they exist and if they need help, they can rely on the AutHelp Association.

The representation of interests and validation of rights begins with informing. The association has organised conferences, courses and professional days every year:

- ❖ 2009, The Allday of Autism Conference
- ❖ 2010, On Autism. Comprehensibly and practicably for Educators
- ❖ 2010, Autism, Professional Forum

- ❖ 2011, Course for Parents
- ❖ 2012, Mentor-Parent Course in Transylvania
- ❖ 2013, a seminary entitled Autism and Puberty, for parents and professionals

#### **Permanent activities of the AuthHelp Association are:**

- Parent club, project writing
- Supporting the teachers' participation at conferences and courses
- Purchasing and lending textbooks
- Maintaining and developing connections
- Maintaining the connections with the media (newspapers, radio, TV)
- Visits to families, organizing integrating programs
- Collecting donations and accepting help from volunteers.

#### **The long-term goals include:**

- Sustenance of the Puzzle Educational Centre and maintaining the musical therapy sessions
- Getting an autism syllabus passed
- Organising the sustenance up to adulthood
- Maintaining the Transylvanian Mentor-Parent Network
- Validation of SEN children's' rights

### **Kozmutza Flóra" Special school for hearing- and language impaired children- Cluj-Napoca**

With its 125 years of experience, the "Komutza Flóra" Special School for the Deaf is the only school addressing the needs and rights of ethnic Hungarian deaf children living in Romania to study in their mother language. The students are coming from 18 Romanian counties. Besides children with hearing disabilities, the school accepts children with intellectual disabilities and having autistic spectrum disorders from Cluj County or from neighbouring counties.

The school's humble beginnings in 1888 meant a single classroom, but by 1893 a new, modern building - raised mostly with donations - hosted the deaf and hearing impaired children. The institution is currently housing the High-School for the Deaf.

The school received its present building in 1959, along with a two-hectare park initially shared with 20 families who were renting some of the adjacent buildings. It was at this new location that the school opened its first audiology lab in 1968. Similar to the current functioning, starting at this time classes were conducted in two shifts: morning and afternoon. The first kindergarten group started in 1979.

As a consequence of Babeş-Bolyai University suspending the training of special educators in 1977, in the following period the availability of specialized personnel decreased significantly.

After 1990 representatives of several Western-European foundations and humanitarian organizations visited the school. Donations have kick-started the construction of a new dormitory as well as the gradual rehabilitation and reconstruction of the school building, which is now equipped with modern amenities of Western-European standards. Since 2008, our school continuously changed on its exterior as well: thermic isolation, consolidation works and accessibility works took place courtesy to Cluj County Council.

Nowadays the School is able to host and teach children in modern classrooms equipped with computers, audio-visual tools and games. The focus is to ensure a specialized, differentiated and individualized educational approach to meet every child's needs by creating smaller student groups. For example, the efforts to facilitate speech development in primary school classes are aided by the small theatre-corners of their classrooms where therapy can rely on role-playing. To ensure individual attention, we have speech therapy and other individual rooms, too. The ceramics workshop and the drawing room offer a pleasant and well-equipped environment for teaching arts and other optional subjects.



The multimedia room has an interactive board, computers and tablets; these expand the students' opportunities for knowledge attainment. In our teaching kitchen (Life skills room) the children can learn how to cook and have the conditions to celebrate birthdays. Our recently remodelled gym provides the conditions for better physical education classes as well as the much needed kineto-therapy sessions.

## The Kindergarten

The kindergarten is hosting two groups of children: one group of deaf children and one of children with multiple disabilities. The services encompass individual work (psychological counselling, cognitive development, physical therapy, audiology, and speech therapy) and small group activities. The basis of our smaller group kindergarten activities is based on the common kindergarten curriculum (language and communication, sciences, aesthetics, moral education), adapted to the needs of the groups. In order to accomplish a differentiated education, the school organizes integrated activities for which they have the complex tools and means.

Besides the age-group of 3 to 8, the qualified professionals also receiving children with developmental delays and they organized early development activities, according to the needs.

The professionals are emphasizing the importance of our students maintaining strong bonds with their families, therefore families are involved in the educational process and receive counselling when needed. As for children not residing in Kolozsvár<sup>17</sup>, our educators provide a family-like atmosphere in the tastefully furnished and well equipped kindergarten dormitory.

*Special regards to the colleagues from the above described institutions for the contribution in writing this report:*

*Pokorny Emese (from Gecse) - special ed teacher*

*Vass Eva (from Authelp) - parent and manager*

*Kiss Csilla (from Kozmutza) - director, special ed teacher*

<sup>17</sup> Kolozsvár = the Hungarian name of Cluj-Napoca

## Art & culture: innovative inclusive practice on the Isle of Réunion

Nacer DJOUDI<sup>18</sup>, Elisabeth HOUOT<sup>19</sup>, Marika REITH<sup>20</sup>, ASSOCIATION SAINT-FRANÇOIS D'ASSISE (ASFA), Réunion



Age of the target group	from 3 to 20 year's old
Target group	Youngsters with disabilities hosted in the social medical disability hub of ASFA – mobility and intellectual disabilities / polyhandicap
Objectives	<p>Youngsters with disabilities :</p> <p>To enhance their artistic potential (creative abilities, memory...).</p> <p>To promote their aspirations and use art as a means of expression.</p> <p>To promote their personal accomplishments by valuing their differences</p> <p>To experience the demands of various arts.</p> <p>To promote social inclusion.</p> <p>Train the carers to help with inclusion through art and culture:</p> <p>Development of individual and collective competences with training and support</p> <p>Increase inclusion in cultural and artistic domains:</p> <p>Initiate and sustain partnerships with mainstream services.</p> <p>Create quality and innovative artistic projects, to demonstrate the creative and artistic capacities of the different people.</p>

<sup>18</sup> Director Social-Medical Disability Pole

<sup>19</sup> Deputy Centre d'Education Motrice ASFA

<sup>20</sup> Coordinator arts and culture ASFA and film director

	<p>These workshops and their public appearances are also for them an occasion to show their abilities in other art forms, another way of questioning our society on its values and the place it reserves for people with disabilities.</p> <p>This project has the ability to open doors, to welcome artists in our institutes, but also to expand workshops in a public setting (library, theatre...) and with different people (school pupils, students ...).</p>
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## Structuring the system of the socio-medical department

### System implementation for unveiling and training of artistic practice

To be able to give the project coherence, it is important to plan and develop the child's path. Thus, it is necessary to structure the organisation.

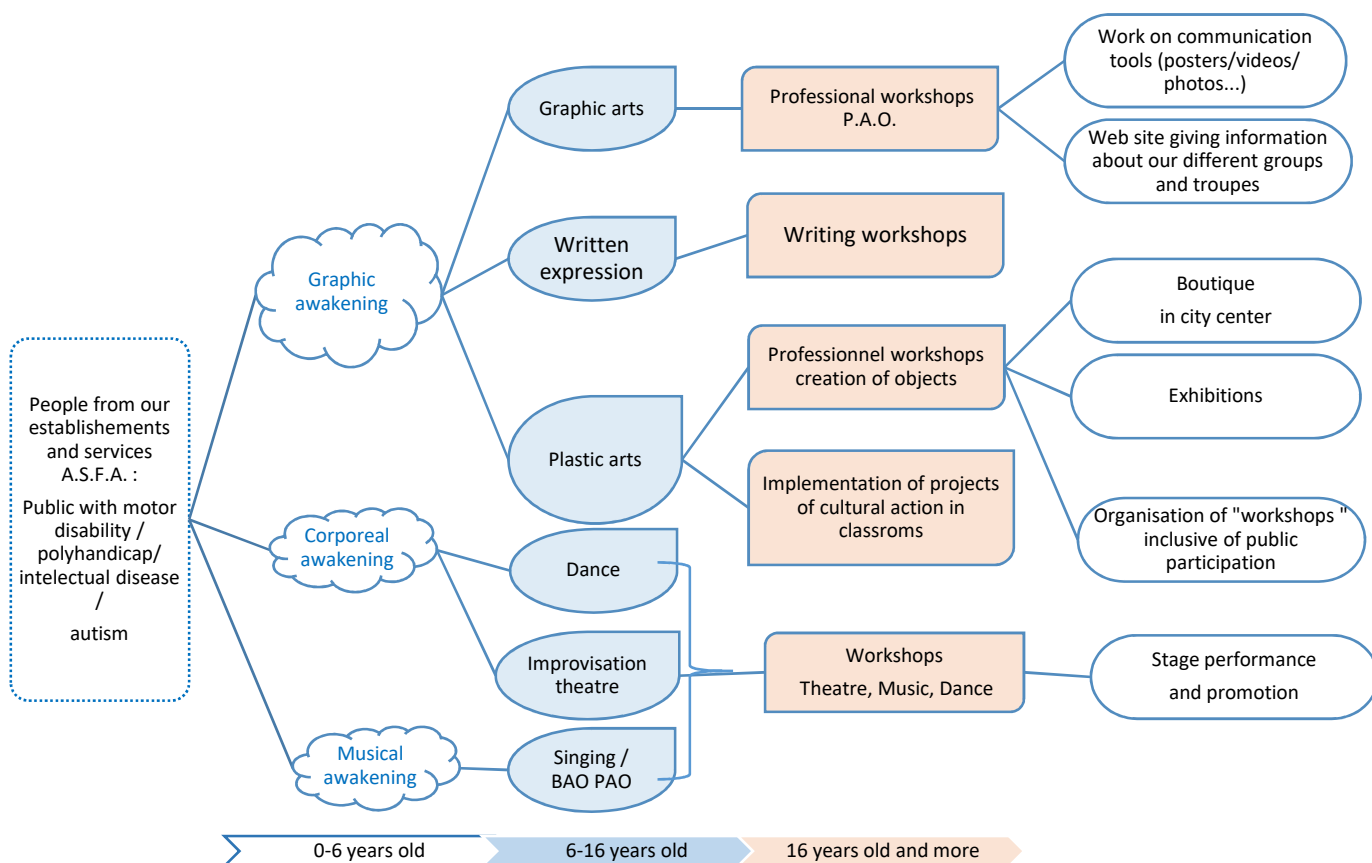


Figure 4 Process of inclusion through art and culture

## **Development and creation of artistic projects**

The realisation of a project requires a network of partners to facilitate, organise and promote. Thus, meetings and interviews are necessary to introduce the projects to the various role players who will eventually co-build the project.

Our wish is to sustain this partnership and to enhance our work to access cultural and leisure activities in the mainstream environment, this project needs to set up an aspect of awareness about disabilities aimed at:

- Artists / performers and cultural structures
- Extramural clubs and associations, parents associations
- Facilitators

## **Inclusive artistic projects**

### **From workshops to shows**

The work done in workshops can highlight the youngsters with the desire and the competence to integrate into a show project. The selection is based on casting, as it happens in classical shows. The show's creation is "fed" from different workshops (singing, music, dance, improvisation...). Then a group is formed who are going to work and rehearse for a period of time required to produce the show.

### **Promotion of the show**

Our aim is to perform in front of a large public, in famous venues, at festivals and other public events. The final step is to find venues, to promote the show and to sell tickets by decimating information through the creation of posters and press kits.

The project can also include a way of valuating its progress through a video documentary which can keep a track of the experience.

### **Videos available :**

- « Un fauteuil pour Avignon » - Marjorie Vigneau -2012
- « Regards d'ailleurs » - Tpk prod -2014
- « Musique en cité » – Fabien Rivière- 2015
- « Le petit Emir » - On en parle mercredi production - 2015



## Posters of the shows



## The project in pictures



Graphic art workshop



Dance work shop





*Music work shop*



### **More information**

**ASSOCIATION SAINT-FRANÇOIS D'ASSISE (ASFA)**

CS 81010 – 97404 Saint-Denis Cedex

Tél : 0262 90 29 86

Web site : [www.asfa.re](http://www.asfa.re) | Email : [directeur.msh@asfa.re](mailto:directeur.msh@asfa.re)

# Innovative practices in Bulgaria

## Early intervention service by Karin Dom Centre

*Apostol Apostolov*



Karin Dom's ECI program is offered on a voluntary basis for the families and is free of charge. The program allows easy access for parents and children. Enrolment is preceded by an assessment of the needs of the family and a screening of the child. The program is flexible and adapts to the needs of the families. The service is financed through the project Early Intervention for Prevention of Abandonment of Children with Disabilities, with funding from the

Open Society Foundation, Early Childhood Program–London, for the period September 2010 through August 2013. The total amount of the project is 299,624 USD. This includes financing of training, development of the early intervention services, promotion activities, implementation of the services, and their monitoring and evaluation. In the period April 2011–March 2012, additional funding of 41,594 USD was provided by the Open Society Foundation, Mental Health Institute–Budapest, for the development of the service parent-toddler playgroup.

The origins of ECI in Karin Dom Foundation date back to 1996, when it was founded to support children with disabilities and their families through providing therapy and counseling. At that time ECI in Karin Dom was primarily a center-based service, with occasional home visits. In 2009 Karin Dom officially launched its Children Ages 0–4, in partnership with the municipality of Varna, the local Child Protection Department, the maternity wards in two hospitals in Varna (MBAL St. Anna and SBAGAL Prof. Dr. D. Stamatov), and the Association Colourful Future. The program provides services to children who either have a disability, a delay in one or more of the developmental areas, or are at risk of developmental delay (e.g., when a child is born prematurely).

The program applies a family-centered approach and includes the following services: home visits, parent-toddler playgroups, family support network, and breastfeeding support. The multidisciplinary team of the program consists of a physiotherapist, a psychologist, a speech therapist, and a social worker. The team is led by a paediatrician. Training for the team was provided at Karin Dom Foundation by ECI specialists from Canada, the United States, and Russia. Members of the team also went on study visits to ECI service providers in Belgium, the United States, and Ireland.

The core service of the program is the home visit. The home is seen as the natural environment of the child. During the home visits the specialist works with the family on assessment of the child, setting of goals, and preparing an individual plan for a six-month period. Through a series of home visits, the specialist gives practical demonstrations to the parents on how to teach their child various skills through play or routine activities such as dressing, eating, having a bath, etc. The specialist considers the family's needs and beliefs and builds on their strengths, knowledge, and skills. In addition to home visits, the specialists can also make visits to other natural environments, such as nurseries, kindergartens, playgrounds, etc.

The second service is the parent-toddler playgroup. The playgroup offers an opportunity for parents and children to interact, learn through play, meet new people, make friends, and have fun together. Parents and specialists work together and teach children new skills and habits (cognitive, motor, speech, social). The playgroup sessions take place at an appointed hour in a specially equipped playgroup room in Karin Dom's building, with age-appropriate toys. The playgroups provide an opportunity for the children to socialize in a group environment and thus be better prepared for inclusion in a nursery or a kindergarten. In addition, the playgroups provide an opportunity for parents to practice new models of child-parent interaction.



The third service in the Karin Dom program is the Family Support Network. The role of this service is to empower parents to stand up for their rights and the rights of their children. The service provides information and psychological or material support. The Family Support Network includes a group of parents who have been trained to provide early support to families who have just found out about their child's disability. This group is called the "parent-on-call" group. Other components of the network are a resource library (containing toys, special aids, and books), and formal and informal parent support group meetings.

In addition, the program includes breastfeeding support, which is provided by Karin Dom's partner association, Colourful Future. Breastfeeding support is provided to mothers of newborn children in maternity hospitals, especially to women who are at risk of abandoning their children. Breastfeeding consultants are permanently based in the two maternity hospitals and assist the work of midwives. The service also includes regular group meetings of pregnant women and parents of infants. The meetings are facilitated by a breastfeeding consultant and provide an opportunity for the participants to share knowledge and skills about effective breastfeeding practices and challenges in the breastfeeding process. Breastfeeding is seen as a supportive mechanism for the prevention of abandonment of children. Through supporting the bonding process between mother and baby, the breastfeeding consultants significantly reduce the risk of the baby being abandoned. They also play a mediatory role between the personnel at the maternity hospitals and the home-visit service.

Karin Dom's Early Intervention Program is undergoing an ongoing external evaluation. The evaluation is in essence an impact study. One of the key instruments of the evaluation is gathering user satisfaction data and data from service providers (multidisciplinary team) and partner organizations involved in the implementation of the program. Data are gathered through semi-structured interviews and questionnaires, designed to reflect all services of Karin Dom's program. There are three main areas in which feedback from parents has been crucial for evaluation of the program and planning its development: child development, available services, and program impact.

One of the ways of evaluating the impact of the program is through parents' self-assessment of progress achieved with their child and satisfaction of the services. Parents saw progress in (a) the physical development of their children, (b) the development of communication skills, and (c) cognitive and social-emotional areas of development. Parents also thought that progress with their child was made because they were actively involved in all activities undertaken to improve the development of their child. Through being involved in the program, parents established a better understanding of their child's needs and became better equipped to respond to those needs. They became more confident

that they could cope with the challenges of raising their child. Parents particularly valued home visits, which enabled them to interact with ECI specialists in a natural environment and observe how the specialist engages the child in everyday activities, such as play. Providing advice to parents on how to interact with their child was also seen as beneficial.

The tables below shows the number of children and families served for the period 2011–2012, and the ratio of children according to age group at the time of entering the program.

*Table 1 Number of children and families supported by Karin Dom's Early Intervention Program, 2011–2012*

Beneficiaries of Early Intervention Program—Karin Dom	Number
Children enrolled in the home visits service	184
Children enrolled in the parent-toddler playgroups	64
Families in the Family Support Network services	110
Mothers receiving breastfeeding support	4,160

*Table 2 Ratio of children according to age group at the time of entering Karin Dom's Early Intervention Program, 2011–2012*

Age of the children at the time of enrolling in the Early Intervention Program—Karin Dom	Percentage
0 to 1	34%
1 to 2	19%
2 to 3	31%
3 to 4	16%

As of September 2014, the total number of children served by the ECI Programme is 400. The number of children currently receiving Early Intervention services is 80.

## Montessori School Svishtov

### Day Centre for Children with Disabilities

*Temenuzhka Todorova*

The Centre is located in the city of Svishtov. The centre is providing a social service to children with disabilities during the day. Depending on the needs of the clients, the services are provided during the whole day, half day or on an hourly basis. The activities in the Centre include rehabilitation, education, psychological support, speech therapy consultations, organization of free time, interpersonal contacts,

development of everyday and social skills in an environment close to the natural environment of the child. Children receive free food and have access to specialized transport.

The social service provided allows the parents of the children to overcome social isolation and become part of social life. Parents also receive professional support and help in raising their children.

The service is provided by a team of 10 specialists: 1 manager, 2 social workers, 2 psychologists, 1 speech therapist, 2 physiotherapists, 2 special teachers.

Currently the Centre is attended by 35 children with disabilities, aged 2 to 18. They are with different conditions: physical disabilities, learning difficulties, sensory issues, children with ASD, multiple disabilities, hyper-active children.

The service is provided in two buildings, owned by the Municipality of Svishtov. The children are grouped in 2 groups according to their age. For each group, there is Montessori room, physiotherapy, psychology and speech therapy rooms, a nature room, sensory room, a dining hall and sanitary facilities. The furniture and the equipment is tailored to the needs of the children. The working environment is structured; rehabilitation equipment and teaching materials are provided.

Everyday we organise individual, team and group activities for the development of children's potential. Children learn to follow the rules for working in a small group; they acquire academic knowledge and learn key skills, which they later on, if possible, transfer to a bigger group in kindergarten or school. At the same time, children acquire skills for self-help and care for the environment, which help them developing their self-sufficiency. The Centre is supported by Karin Dom, which ensures the quality of the work we do. Karin Dom supports the Centre through training, mentorship and supervision.

### **More information**

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# Innovative practices in Italy

Marina Rodocanachi

## 1. Preparing for a life project

In Italy mainstreaming education is mandatory by law and more than 90% of children, even with multiple handicaps and intensive support needs are in regular schools usually since 14/16 years of life. Health system supports them with an individualized rehabilitation plan which includes therapy sessions, health care, meetings with teachers and psychological support for parents. Nevertheless mainstreaming is becoming less efficient in this period of life as peers often marginalize young boys and girls with severe disabilities and resources in the territory to strengthen participation in social activities, sport and leisure are scarce and not so easy to be found. For that reason often families rely too much on rehabilitation services asking for rehabilitation sessions and health supports instead than ask for participation in social life.

### *The project:*

This project was held at Vismara Rehabilitation centre in Milan, Don Gnocchi Foundation in cooperation with public health service (ASL Milano Città –Local Sanitary Agency, town of Milan). The model is reproducible and can be considered an example of good practice.

### *Target group:*

Young people with multiple disabilities aged 14 – 21

### *Objectives of the project:*

To put a professional educator at the disposition of young children to work among family, rehabilitation team and school in order to build for each subject an individualized project and to find environmental resources.

### *Main project activities:*

Knowing the young and study his/her resources directly at home or at school, having meetings with the rehab team, with school teachers and with families, have contacts with environment in order to find resources in order to plan the best project of life for the future.

### *Results:*

In a short duration of time (6 to 8 months) 10 young persons with complex support needs were put in condition to be discharged from rehabilitation sessions, not anymore useful for them, and to find in their territory resources for inclusion and participation.

Parents didn't feel alone with decision making about the future and an occasion for continuity of care from childhood to adulthood was realized showing to parents that children can become adults integrated in social life.

The project also lowered the cost for sanitary assistance.

**Reference:** dr. Tiziana Lopez, psychopedagogue (tlopez@dongnocchi.it)

## 2. Integrated rehabilitative approach to improve quality of life in Rett Syndrome: inclusion and network care for Rett Syndrome in Italy, a project in cooperation with the families

### *The project*

Is an example of good practice to deal with a rare disease in cooperation with the families' association (AIRETT) and to afford the problem of a rare disease inclusion and participation.



### Target group

Girls with Rett Syndrome and their families from the whole national territory

Age 2 to 36 years

Girls with Rett Syndrome have intensive support needs in terms of general health, communication, mobility, autonomy.

### About Rett Syndrome

It is a rare disease, due to a mutation in the Xlinked MECP2 gene. Its prevalence is 1:10.000/15.000

About 350 females worldwide are affected.

It is a neurodevelopmental disorder due to a mutation in the Xlinked MECP2 gene.

There is a reduced dendritic complexity, spine and synaptic density and neural circuits defects

Girls have severe dysfunction in multiple area of development: motricity and hand use, with the presence of severe apraxia and ataxia, cognition, language and communication, autonomic system regulation with respiratory and gastrointestinal problems, a dysperceptive disorder with trouble in regulating and processing sensorial inputs, sleep disorder, problems in behaviour and emotional regulation, epilepsy, often very severe, metabolism and growth

Rett syndrome girls are at risk for health, for activity and participation.

In an "Enabling way of thinking" it is important to understand their needs.

## Objectives of the project

To give the opportunity to girls with this rare disease and to their families to spend one day with a dedicated team to afford the principal problems in term of rehabilitative and educational approach. A rehabilitative and educational «Day Hospital» for Rett syndrome girls was organized at Vismara rehabilitation centre to give to the girls and to their families the opportunity of an holistic evaluation at the presence of external team of professionals and teachers, parents and siblings. At the end of the evaluation day, with a standardized protocol, the expert team, the external team and the family had a discussion on the best way to deal with complexity of their daughters in terms of rehabilitation and school inclusion in order to improve quality of life and train the external professionals, the teachers and the parents.

Main proposal was to give to the individual girls, to the families and to the external team examples of good practices of intervention on motricity, posture, communication and learning, emotional regulation and to realize a repeatable model of intervention for complex rare diseases with multiple disabilities.

## Main project activities

### Clinical Protocol:

- CLINICAL EVALUATION: neurological and postural assessment
- ORTHOTICS EVALUATION
- CLINICAL ASSESSMENT IN WATER
- COMMUNICATION AND LEARNING ASSESSMENT
- MUSIC THERAPY ASSESSMENT
- PSYCHOLOGICAL SESSION
- REHABILITATION
- FINAL DISCUSSION with families and external professionals
- WRITTEN REPORT
- OBSERVATION AND COLLECTING DATA FOR FUTURE RESEARCH

### Measures & Data

- MOTOR ASSESSMENT: grid for clinical and anamnestic motor assessment: the therapist during the day care evaluation, the family with a written instruction at home in order to obtain a validated instrument to measure changes in motricity during time and as a consequence of rehabilitation (evidence based intervention, research in course)
- WALKING ASSESSMENT IN LABORATORY (for girls with independent walking)
- POSTURAL ASSESSMENT: muscular & skeletal abnormalities limbs and trunk – postural asymmetries (experimental grid)
- MODIFIED ASHWORTH SCALE
- HAND FUNCTION SCALE (Downs 2008)
- PARENTING STRESS INDEX (Abidin, 1990)
- RARS : RETT ASSESSMENT RATING SCALE (Fabio 2009)



- MEASURE OF PROCESS OF CARE 20 (King, S. M., King, G. A., & Rosenbaum, P. L. 2004)
- MUSIC THERAPY OBSERVATIONAL GRID (Colletti, Toshimori, 2015, not published)
- IDROTHERAPY OBSERVATIONAL GRID
- LEVEL OF SCHOOL INCLUSION



*Figure 5 Motricity assessment and intervention*



*Figure 6Modifiability of the walking pattern through some perceptive details during rehabilitation sessions*



*Figure 7 LEARNING TO WALK: In water through perceptive details*



*Figure 8 Interaction during a music therapy session*



*Figure 9 Interaction with peers through music.*

**Participation:**

Participating to the day care evaluation (2014-2017): 61 girls

54 Girls with Rett syndrome with classic form

7 Variant form (CDKL5 – FOXG1)

Age: mean 12 y 2 m

(Range: 3 y 4m – 34 y 10 m)

81% from Northern Italy – 10% from Centre Italy – 7% from South Italy – 3% from abroad

## Results

Data on motricity and walking abilities, in order to improve quality of rehabilitation intervention are under examination.

Clinical assessment of motricity with video registration made the team observe some peculiarities of the movement in Rett Syndrome that were used to improve quality of intervention. External professionals were trained for a better intervention on motricity.

When independent walking wasn't present, walking was observed and trained in the swimming pool and parents and therapist were instructed to do it.

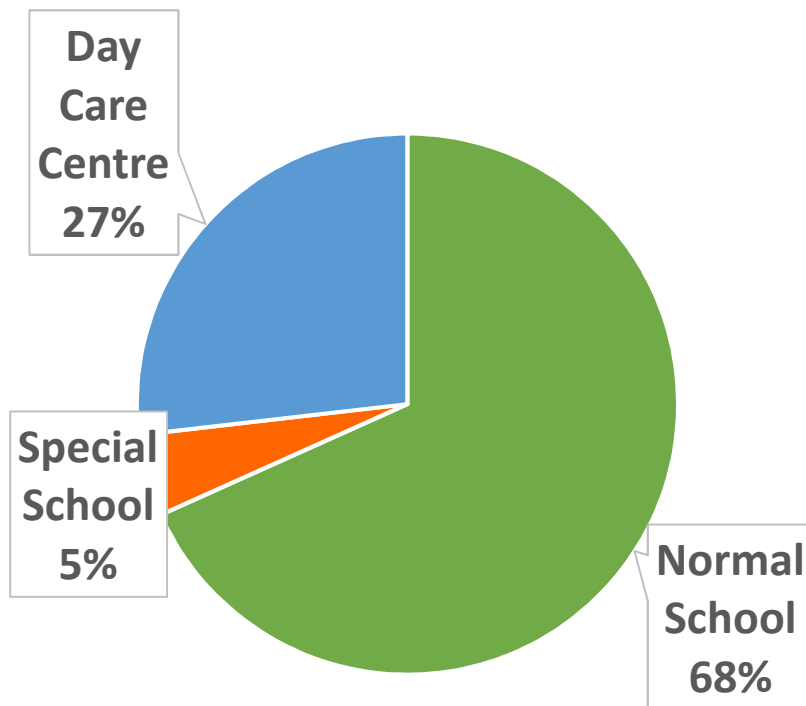
Music therapy is said in Rett syndrome to have benefit on behaviour regulation.

A qualitative grid of observation was elaborated. Videos are showing a better emotional regulation, and active participation. Hand stereotypies were reduced and quality of movement improved. (see video).

## School participation

Only older girl were in day care centre and very few of them in special schools.

The project had a strong impact on quality of inclusion as often teacher don't know how to deal in normal class with Rett Syndrome girls. Most of the girls were included in primary school though older than ten years of age.



### *Perception of care*

According to Enablin is important to better understand parents' needs in term of care.

We used for that the MPOC20 questionnaire (MPOC 20 - Measure of Processes of Care Questionnaire, Can Child, King S., King G., Rosenbaum P., 1994) a self report measure of parents perception of the extent to which the health services they and their children receive are family centred.

MPOC-20 is a 20 items questionnaire:

- 15 items referred to people dealing directly with the child in the reference service
- 5 items referred to the centre (all the people working in the service and providing general informations)

It is organized in 5 subscales and quoted in a 7-point scale:

1. Enabling and Partnership (EP) – 3 items
2. Providing General Information (GI) – 5 items
3. Providing Specific Information (SI) – 3 items
4. Coordinated and Comprehensive Care (CCC) – 4 items
5. Respectful and Supportive Care (RSC) – 5 items

To a very great extent	To a great extent	To a fairly great extent	To a moderate extent	To a small extent	To a very small extent	Not at all	Not applicable
7	6	5	4	3	2	1	0

Considerations emerging from 96 parents (54 families ), in charge to different teams of professionals in the Italian territory, helped to better understand parent's needs.

According to the questionnaires Rett syndrome parents (mothers and fathers) seems enough satisfied with how the team works. The parents evaluated the team as a group of people that works together and give them enough time to talk and coherent information.

However these parents can be defined as "demanding" to the institution and attentive to the care given to their child. They express a need to receive information more in-depth, written information, as well as to be facilitated in having contacts with other parents.

### *Final considerations*

This model of approach to a rare disease characterized by multiple disabilities and complex and intense support needs let parents satisfied and made feel them less alone.

Girls were better assisted and involved in education.

Regulation of behaviour was possible during music therapy sessions. More research need to be done in order to measure long lasting effect of this practice, though it was evident how girls liked music therapy and their behaviour changed during the session.

Careful observation of motricity with motor, postural and walking assessment improved the quality of intervention of the professionals having in charge the girls in their own territory.

This model of approach, including intervention at different level of complexity, training of external professionals and parents, assessment of parents needs and element for research on evidence based practices can be apply to other rare diseases. It is an example of good practices and is in line with the domains of Quality of Life (QoL) as defined by Schalock & Verdugo.

# Innovative practices in Portugal

## From advocacy association to inclusive services: the Association of Cerebral Palsy of Évora

Bruno Martins, director

The Cerebral Palsy Association of Évora – was founded in 1991 by a group of parents and technicians, whose scope of activity includes the prevention, diagnostic, evaluation, rehabilitation and integration of children and young adults with Cerebral Palsy and other neurological diseases and problems.

**The Association of Cerebral Palsy of Évora goal is:** *“Provisioning quality services that promote autonomy, social inclusion, quality of life and well-being to all clients, nominally to people in disadvantage situations and/or disability with a special emphasis in those with **Cerebral Palsy and similar neurological impairments** with the purpose of global and integrated lifelong care and in active cooperation with families and collaborators.”*

In sum, we intend to promote rehabilitation, autonomy and social inclusion of all the people we support, working in a multidisciplinary and community-centred way. Even though we are an institution, we fight the institutionalization logic of people with disabilities that, just as any other citizen, should develop their life's in the community.

The main goals of the APCE are:

- To promote the rehabilitation of the patients affected by Cerebral Palsy and other neurological diseases on many different levels, with the main aim of helping them to develop their maximum potential;
- Along with the normal and specific therapeutic activities, we also seek to develop Sporting and reactive activities;
- To defend the disabled persons right to an education, professional training and to employment as well as developing his / her social and emotional skills so that they can easily integrate with the community;
- Develop training using adequate training programs and personalized therapy;
- To alert the public sector, services, institutions and public opinion to the problems related with all types of disabilities and more specifically with Cerebral Palsy.

APCE policies aim specially to promote full inclusion of citizens with disabilities, specifically people with cerebral palsy and similar neurological diseases, based on the assumption that the citizen with disability must benefit of positive action measure intending to assure the exercise of his/her rights and duties, adopting the Convention for the Rights of Man, the Rights of People with Disability and to the existing Social Inclusion Programs. APCE guides its intervention on respect for the dignity of all people, assuring non-discrimination and respect for privacy and confidentiality.

We intend to strengthen activities that aim prevention and inclusion of our clients, enhancing their socio-professional inclusion and stimulating the creation of mechanisms that promote acknowledgment of their skills through merit and participation on the environment and in

perception and discussion of problematic situations. The Association has as fundamental orientation the continuous improvement of services provided, betting on the qualification of human resources, preservation of material resources and in development of partnerships and engaging the community. Beside the enunciated policies, APCE is governed by ethics policies, participation, and patient-centred, inclusiveness, hiring of collaborators through clear and objective criteria and with a policy of quality.

Our day-to-day practice of a policy of quality is confirmed by the certification with Excellence level on European referential framework EQUASS, renewed on September 2016.

In order to fulfil its goals APCE has four social initiatives in practice:

APCE works on 4 social responses. We describe, thereafter, in a succinct way the work developed:

### **1) Centre for Development and Early Intervention**

Early Intervention in Childhood is a set of supporting measures integrated and centred on the child and family, including actions with a preventive and rehabilitative nature, in education, health and social action, in a way that prevents the emergence or worsening of problems with children and enhance the family or health carers' skills, so that they can deal with the problematic child in a more autonomous way.

In APCE, the social response is composed by a pluridisciplinary team, with a transdisciplinary functioning based on institutional partnerships. ELI develops its activity in children's residence, kindergarten, nanny, pre-school education, health centre, private social welfare entities or at APCE headquarters, being the service render in a schedule yet to set, considering the family needs and the balance between private life with professional activity.

On Évora District we support children between 0 and 6 years old.

### **2) Centre for Rehabilitation and Social Integration**

Gives a social response in outpatient treatment for children from six years old, youth or adults with Cerebral Palsy or other similar neurological pathologies in Évora District, intending to develop skills promoting full inclusion of the clients on society, in articulation with family, including also vocational training and development linked to adapted sports.

All the team activities are centred on expectations and needs of clients, and much work is done outside the institution, in inclusive environments.

### **3) Day-care and Kindergarten "Quinta dos Sonhos"**

These two social responses were planned, and are structured, in a way that fully enables inclusion of SEM children, whether they were initially evaluated on APCE, or referred by other institutions or services.

The day-care is constituted of a room with space for 15 children with 18 months (after gait acquisition) until 3 years old. Pre-school education is comprised of 2 rooms with space for 15 and 16 children, respectively, and targets children aged between 3 and 6 years old.

"Quinta dos Sonhos" has room for 46 children aged between 18 months and 6 years old, divided in 3 groups, of which only 10% are children with a disability, but where cultural and social diversity is seen as an advantage.



#### 4) Pomarinho's Pedagogical Farm

Pomarinho's Pedagogical Farm is a rural space, located 8km from Évora, on the road that connects Évora and Alcáçovas, allowing its visitors a direct connection with country life, interaction with animals, with horticulture and fruit farming, and living Alentejo's tradition.

The Farm was created, having as main goal, inclusion, and integration of children with and without disability, so that they can live and get to know country life, in its diversity and in a creative and interactive way, not only through pedagogy, but also giving opportunities for each one to transform the space in its own farm.

The country only by itself, can be considered a privileged playful area for diverse learning, such as, Nature cycles observation and exploration of the recreational side for development abilities and skills, motivating in a general way for the environmental issues.

This social response aims the school community of Évora District, as well as general community, and in particular children/youth that are monitored by different areas of intervention by the Association.





## Good practice of inclusive education with a children with multiple disabilities

Maria José Saragoça & Maria Paula Antunes

A successful history of inclusion within the school system is Maria's story. She is 9 years old and she was born with Angelman syndrome, diagnosed through cytogenetic analysis, when she was 15 months old (21/07/2008). The student was assessed by reference to ICF, in the end of her pre-school attendance, one month before entering first grade (July/2013). Maria began primary school in 2013/2014 school year. From that assessment, we keep here what has not changed and we mention the improvements that we have been recording. In accordance with ICF's Body Functions and Structure, Maria displays a non-specified impairment on intellectual functions and in cognitive dimensions. She has impairments in certain sleep functions, in attention, memory and basic psychomotor and cognitive functions. In regard with voice, articulation, fluency and speech rhythm functions, there is no verbal communication. She has impairments in digestive and urination functions, as well as impairment in stability of joint functions, muscular strength and tonus, involuntary motor reactions, imbalance impairment, exhibits a mild impairment in voluntary movement and muscles and function of movement. About ICF's Activity and Participation, Maria has a severe impairment in interaction with objects, has limitations in language acquisition and development, limitations in performing general tasks and demands, a severe impairment in body control, a severe impairment in communication, full impairment in self-care, a severe impairment in eating and drinking function. Concerning interaction and interpersonal relationship level, she also displays impairments. In the major life areas, she displays a complete impairment.

In relation with ICF's Environmental Factors (facilitators or barriers to participation and learning), we consider as a complete facilitator the use of medication to assure Maria's wellbeing as far as they prevent convulsive episodes that can harm her development, provoking a regression in her acquisition/skills. For communication as a moderate facilitator, the first phase of PECS was started, as an augmentative communication mean. For Education as a significant facilitator we consider that the utilization of general products and technologies for education could facilitate the acquisition of new skills.

Concerning the support and relationships we consider a full facilitator the immediate family, friends, peers, colleagues, neighbours, and community members.

As a complete facilitator, individual attitudes from the immediate family members, from friends, acquaintances, peers, colleagues, neighbours, and community members and from health carers and personal assistants that show complete receptivity to all of our suggestions and strategies.

As a complete facilitator, it is possible to register her good relationship with social security, with health (having a timely medical surveillance to the child's needs and referrals) and with work and with the job (because the mother's job allows her to take care and respond adequately to Maria).

Thereby, considering the assessment in reference to ICF, the measures that we consider more suitable to respond to the pupil's needs were:

#### Measures from Decree-Law nº3/2008

- a) Personalized Educational Support – a) The reinforcement of the strategies utilized in group or class at an organizational, space and activities levels; b) Stimulate and strengthen skills and competences implicated in learning; c) reinforcement and development of specific skills (Socialization, Autonomy, Communication, Motor Skills);
- b) Adjustments in the registration process – Attending school with a Unit of specialized support for the education of children with multiple disabilities, where these specific support are ensured at the speech therapy and physiotherapy levels. The pupil goes 3 weekly hours to APCE in order to attend Music therapy and Riding Therapy).
- c) Adjustments in the Evaluation Process – The evaluation is qualitative and based on criteria such as attendance, behaviour, motivation, evolution, attitude facing tasks (availability, attention, rejection), on the diverse areas from ISC.
- d) Individual Specific Curriculum – Removal of common curricular areas (Portuguese, Mathematics, Environmental Studies) and introduction of specific curricular areas (Augmentative Communication, Socialization, Autonomy, and Motor Skills).
- e) Supportive technologies – (tablet, suitable software, adaptive writing material)

#### Other measures:

The pupil benefits from a class with a reduced number of students, as required by the law, establishing that groups integrating children with special educational needs cannot exceed 20 students nor include more than 2 pupils in those conditions.

Bearing in mind that social interaction constitutes an important basis of development and learning, we intend Maria to be, when possible, in the classroom so she can have access to a diversified set of information and experiences that serves as a foundation for her cognitive and socio emotional development. One of the strategies utilized is to match, in the class' schedule, more inclusive moments (musical expression, dramatic expression, reading histories), with the time that the pupil is in the class. Her severe impairments at the activity and participation level imply educational approaches that combine opportunities to explore the environment with opportunities of interactive communication. In the classroom, the work with the pupil should have as a starting point group work, so that she has points of contact with her peers (the pupil studies numbers when her colleagues are studying Mathematics, she works with words when her colleagues are studying Portuguese, she works rudimental Environmental Studies contents from her colleagues' curriculum, but in a very rudimental level and with adjusted activities).

Maria stays more than 60% of her school hours in the classroom (8h in therapies/17h in classroom = 25 weekly hours). She has Personalized Pedagogical Support from the Special Education teacher, 8 weekly hours; Speech therapy from a speech therapist 3 weekly hours; Physiotherapy from a

physiotherapist, 3 weekly hours; Music Therapy from a musical therapist, 1 weekly hour; therapeutic riding from a physiotherapist, 1 weekly hour).

The pupil has an educative action assistant that provides support to the moments in the classroom when the special education teacher is away, in extracurricular activities, while eating and personal hygiene.

Finally, we review the inclusion of the pupil in a regular class at the Basic School of Portel, considering as strong points that Maria learned how to be in diverse contexts, adopting a correct behaviour in the classroom and in other environments she attends. The importance for the peers to interact with the difference, being able to learn about respect and compassion. As a weak point the great difficulties in attention/concentration that become serious challenges to learning and the amount of stimulus naturally present at the regular classroom does not always help in attenuation. Also, some adapted tasks developed with Maria are, sometimes, distractive for her colleagues. But in spite of the less positive aspects, we will always turn difficulties into challenges to our capability of increasingly improve our response to Maria making the difference our biggest wealth.



## **Part III**

# **Approaches and methods in supporting care & education of children with complex and intensive support needs**

## Introduction

In part III, we focus on some methods and ways of approaching integrated support to children in areas such as: learning, communication, health and self-care, participation, movement, mobility, arts and play, communication. What follows is not the product of systematic search, but just a selection without pretending completeness.

### Methods and participants

We asked professionals and parents from the eight partner countries to nominate examples of approaches to work with children with CISON, which have some evidence base (without however requiring published quantitative research) in being effective in dealing with children with CISON, with respect to the above mentioned themes. The way of gathering data was similar to a scope review, however in this case not based on literature, but on networking contacts with experts in the field.

Some of the approaches have been presented during the train-the-trainers training workshops and conference in Milan (September 2016), and are reported in Workpackage 5. Others have been presented during pilot trainings in the various partner countries.

Then we compared the approaches in the light of the criteria of good practices, which have been elaborated by the Enablin+ project team.

### Results

Twelve approaches have been selected so far. Evidence is often qualitative and experiential. The list is far from complete. Due to time and other restrictions, the descriptions of the approaches are sometimes rudimentary or limited to powerpoint presentations, which are not reproduced in this report, but are available on the website [www.enablinplus.eu](http://www.enablinplus.eu)

The research is ongoing. It would be good to pursue this research in a more systematic way. But within the scope of the Enablin+ project and its limited financing this was not possible. We hope the project has generated enough interest to continue the gathering and exchange of information.

# III. A - Approaches facilitating learning and relating

## Communication, intentionality and capacity to make choices

Juliet Goldbart<sup>21</sup> (Professor of Developmental Disabilities, Manchester Metropolitan University, UK)

### Stages in Early Communication Development (from Coupe & Goldbart, 1998)

Level 1: *Pre-intentional – Reflexive*: The child's limited repertoire of mainly reflex behaviours can be interpreted by familiar people. Internal stimuli are as significant as external ones.

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

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

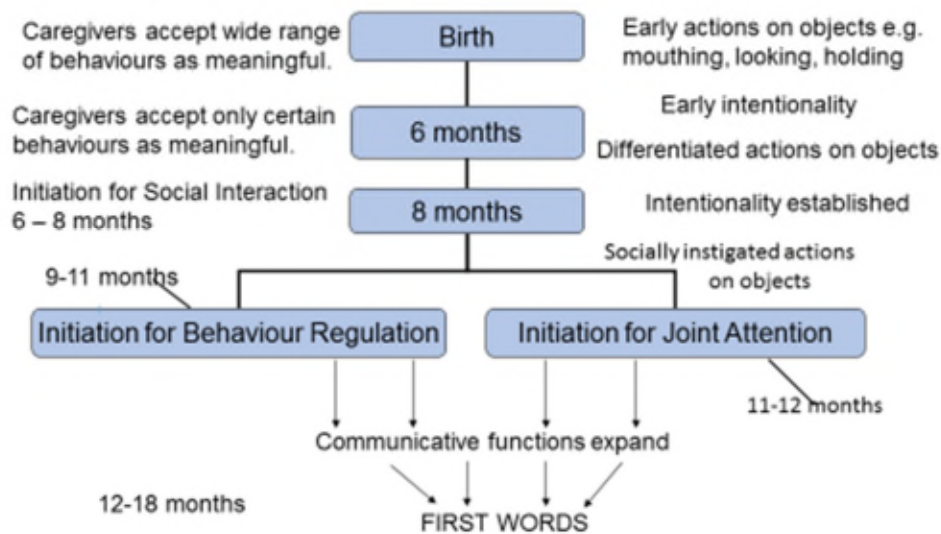
Level 4: *Intentional – Primitive*: The child has learned to affect the environment by acting on another person. Interpreting "primitive" communicative acts relies on the context. The child understands other's nonverbal communication and starts to show situationally cued understanding.

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<sup>21</sup> Juliet Goldbart PhD is professor of Developmental Disabilities and Associate Dean for Research at Manchester Metropolitan University in the UK. A psychologist by background, she has taught speech and language therapy students for over 30 years. Her research interests include communication and complex needs, and appropriate service delivery models for families in the UK and in under-served countries. She has a longstanding involvement with the Indian Institute for Cerebral Palsy, including an evaluation of innovative approaches in establishing disability services in slum areas of Kolkata.

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

## Development of early communication



### Contingency Awareness and Intentionality

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

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

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

Probably the most important thing you will ever learn!

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

### Secondary Motivational Impairment

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

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

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

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

## Intervention Approaches

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

## Key references

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## Resources

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

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

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

RfL Assessment Booklet: [http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/downloads/m08p020c/assessment\\_booklet.pdf](http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/downloads/m08p020c/assessment_booklet.pdf)

Quest for Learning: [http://www.nicurriculum.org.uk/docs/inclusion\\_and\\_sen/pml/quest\\_guidance\\_booklet.pdf](http://www.nicurriculum.org.uk/docs/inclusion_and_sen/pml/quest_guidance_booklet.pdf)

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

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

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



# Augmentative & alternative communication in children who cannot speak

Anna Dal Brun

Case studies presented during train-the-trainer course : preference of choosing examples of children with aphasia and intellectual disability who are integrated

Marlène Grégoire: case study of Mariame, with cerebral palsy, presented during the train-the trainer course

See the example on the DVD belonging to the Enablin+ training manual:

Grégoire, M. (2017) Assistive Communication, in: Lebeer, J., Nijland, M., Grácio, L. & Schraepen, B. , *Enabling activity and participation. Supporting young people with complex and intense support needs*, Varna: Helix Press, pp. 58-59

## Enabling interpersonal relations

Sara Nijs<sup>22</sup>

Long lasting and supportive interpersonal relations are important in everyone's life as they may positively influence various developmental and quality of life outcomes. The foundation for these long lasting supportive interpersonal relations are social interactions. Social interactions are dyadic and mutually rewarding activities in which the interaction partner is the focus (Beauchamp & Anderson, 2010). During these social interactions concrete social behaviours can be observed. The social behaviours of the interaction partners follow one another (Rubin, Bukowski, & Parker, 1998). Various personal and environmental factors may influence the amount and nature of the social interactions and personal relations.

A personal factor which may impact social interactions negatively are disabilities. It can be assumed that the complex disabilities of persons with profound intellectual and multiple disabilities (PIMD) may impact the social interactions and interpersonal relations (Nakken & Vlaskamp 2007). The profound cognitive disabilities (IQ < 20-25, developmental age below 24 months) of persons with PIMD impede their understanding of verbal and symbolic language and social cues. They communicate on a pre- or protosymbolic level making use of body movements, muscle tension, vocalisations, and other subtle signals which are context bound and idiosyncratic (Hostyn & Maes, 2009). Persons with PIMD have profound neuromotor dysfunctions which may keep them from presenting social behaviours such as waving, smiling, pointing, or touching that draw attention from others and can initiate a reciprocal interaction. Additionally their sensory impairments and delayed information processing which is seen in persons with PIMD may impede the presentation of behaviours which initiate interactions and attract the attention of others. Often interaction partners of persons with PIMD experience difficulties

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in understanding the idiosyncratic signals which may lead to misunderstanding and negation of the person.

Persons with PIMD build interpersonal relations with, among others, parents, siblings, therapists, teachers, and peers. Looking more specific at children with PIMD two main groups of social interaction partners are distinguished. On the one hand the more hierarchical relations with for example teachers or parents. These relations are important for the socialization process in childhood (Rubin et al., 1999). On the other hand relations with peers such as friends, classmates, and siblings are formed. These relations are horizontal, equivalent, and egalitarian. As a consequence children are responsible for continuing a conversation and they need to cooperate with each other (Berk, 2003; Selby & Bradley, 2003). This makes these peer interactions far more demanding, complex, and unpredictable compared to the hierarchical interactions (Guralnick, 1999). Successful peer relations may promote development of interpersonal skill, may positively affect mental health and may benefit the social confidence of both interaction partners (Parker et al., 2006).

Because of the importance of peer interactions for every child attention needs to be paid to these interactions in children with PIMD. A systematic literature review showed that an increased amount of peer interactions can be observed during interactions with typically developing peers compared to interactions with peers with PIMD. Although, typically developing peers as well as peers with PIMD can be trained to interact or to use technological support systems during peer interactions (Nijs & Maes, 2014a).

Looking more closely to the peer interactions between persons with PIMD, research demonstrated that the profound and complex disabilities of persons with PIMD impede them to present behaviours of looking or directing at the peer in combination with social behaviours. These are called multiple peer directed behaviours. However, an alertness towards the peer could be observed by presenting singular peer directed behaviours for example looking at the peer or touching the peer without looking or directing at the peer. This clearly demonstrates their social interest in their peers with PIMD (Nijs, Penne, Vlaskamp & Maes, 2016b).

Various environmental factor may influence the amount and nature of the peer directed behaviour presented by children with PIMD. First, as persons with PIMD need support in all aspects of life it can be assumed that teachers or direct support workers are needed to support mutual peer interactions between persons with PIMD. However, research showed that children with PIMD presented more peer directed behaviours in absence of the direct support worker compared to a situation in which the direct support workers is present (Nijs, Vlaskamp, & Maes, 2015). Training and informing direct support workers positively impact their supporting behaviour and the peer directed behaviours of children with PIMD directed towards each other (Nijs, Vlaskamp, & Maes, 2014b). Second, the positioning of children with PIMD has an influence on the amount and nature of the peer directed behaviours. Children with PIMD who could see their peers with head movement and touch their peers from rest presented most peer directed behaviour (Nijs et al., 2016b). Third, the interaction partner may influence the nature and amount of peer directed behaviours in persons with PIMD. Comparing interactions among persons with PIMD and between persons with PIMD and siblings an increased amount of peer directed behaviours is presented by the children with PIMD during interactions with siblings. Siblings attract the attention of their brothers and sisters with PIMD by using nonverbal behaviours, such as simple comments or vocalizations and physical support (Nijs et al., 2016a). Looking at interactions between a direct support worker and a person with PIMD, direct support workers mainly use complex communicative acts and less nonverbal behaviours (Bradshaw, 2001; Hostyn, Neerinckx, & Maes, 2011).

These studies revealed the ability of persons with PIMD to direct their attention on each other and to search for each other's company. In organizing high quality activities and a high quality living environment for persons with PIMD, must not solely focused on 'what' will be provided. It is as important to find someone to share the activity with and to create a way to let persons with PIMD experience together.

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## More information

Doctoral dissertation: Nijs, S. (2015). *Experience together. Peer interactions in persons with profound intellectual and multiple disabilities*. KU Leuven, Belgium.

# Dealing with problem behaviour

Petra Poppes<sup>23</sup>

The term 'challenging behaviour' is generally used to refer to 'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 2001, p.3). The consequences of challenging behaviour can be far-reaching. First of all, challenging behaviour can cause physical harm to the individual or their environment. It can limit personal development and can make it difficult for the individual to form and maintain social relationships. The result can be a severely reduced quality of life. The literature shows a correlation between the presence of challenging behaviour and various factors such as motor and/or sensory impairments, epilepsy, communication problems, sleep problems, chronic pain and psychiatric problems. Research also shows that people with a profound intellectual disability and/or communication problems are at greater risk of exhibiting stereotypical and self-injurious behaviour. In addition to these conditions, some genetic syndromes, such as Rett syndrome and Cornelia de Lange syndrome, also involve challenging behaviour.

It is therefore clear that people with many of the above conditions also exhibit challenging behaviour. This is certainly true of the category children and adults with profound intellectual and multiple disabilities (PIMD), who are characterized by a profound intellectual disability and profound motor impairments, which manifest as a complete or almost complete lack of ambulant mobility. In addition, they frequently have sensory impairments and additional health problems (constipation, reflux, chronic respiratory infections), with chronic pain as a possible consequence. People with PIMD are also unable or barely able to use language to explain what they want and/or need. Despite all this, little has been known thus far about challenging behaviour in this group. We need to have a good picture of the prevalence, frequency and severity of challenging behaviour in people with PIMD in order to understand the nature and background of such behaviour and the factors that may influence it and to offer tools for its prevention or reduction. This is why research was done by the University of Groningen in collaboration with the 's Heeren Loo Service Group: Challenging practices. Challenging behaviour in people with profound intellectual and multiple disabilities and its consequences for practice (Poppes, 2015). The results of this research show that 82% children and adults with PIMD display one or more kinds of self-injurious and stereotypical behaviour. In all, 45% of the target group exhibit one or more forms of aggressive/destructive behaviour. Withdrawn behavior is also seen in more than 80% of these children and adults. The frequency of challenging behaviour is high for all four types of challenging behaviour. Despite high prevalence and frequency figures, direct support staff generally view the

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consequences of this behaviour for the person with PIMD as 'not severe' and the support given to people with PIMD who display a high frequency of challenging behaviour is scarcely aimed specifically at reducing this problem. However challenging behaviour always influences the ability of people with PIMD to gain experiences and forming relationships with others.

## Implications

It is important to note that in the literature (e.g. Borthwick-Duffy, Lane & Widaman, 1994; Emerson et al., 2001; Holden & Gitlesen, 2006; Jones, Cooper, Smiley, Allen, Williamson & Morrison, 2008), the term 'challenging behaviour' is generally used when at least one behaviour problem perceived as severe has occurred, and the term severe challenging behaviour is used when at least one behaviour perceived as severe occurs on a daily basis. However, 'challenging behaviour' according to this definition remains a difficult term in the support of people with PIMD. The emphasis is generally on what direct support staff perceives as problematic behaviour. This measure is more or less subjective and at least partly determined by individual knowledge of challenging behaviour, staff experience, how staff attribute behaviour and the vision staff have for the support of people with PIMD. Even though behaviour may not be perceived by direct support staff as severe, frequently occurring behaviour such as stereotypical behaviour can still have major clinical, social and educational consequences (Crocker et al., 2006; Lowe et al., 2007; Lundqvist, 2013). Accordingly, we feel that it is not primarily the extent to which a behaviour is disruptive to the environment but *the extent to which the behaviour creates barriers to the individual to gain experience in relationships with others* that should determine whether behaviour can be considered to be problematic. Future debate and research should focus on whether frequency is a more appropriate operationalization of the term challenging behaviour in people with PIMD.

## Causes of challenging behaviour

Our research has yielded knowledge on challenging behaviour in children and adults with PIMD, with a clear focus on the role of direct support staff. Much research shows that the causal and maintaining mechanisms underlying challenging behaviour are multifactorial. The origin of challenging behaviour is normally understood using a multifactorial biopsychosocial model (e.g. Došen, Gardner, Griffiths, King & Lapointe, 2007; Lambrechts, 2010). This model does not regard challenging behaviour as a characteristic of the person with intellectual disability, but *as a result of the dynamic interaction between the individual and his environment* (Emerson, 2001). The behaviour of the person with intellectual disabilities and the behaviour of the direct support staff who support him or her are intertwined. This model suggests that biological, psychological and environmental factors explain challenging behaviour. These factors can influence each other to a greater or lesser extent. Behaviour is viewed as an observable phenomenon of interaction between an individual and his or her external world, whose components are defined as follows:

1. the person (biological and psychological factors and medical, functional and psychological problems)
2. the environment (material, personal, social, educational and cultural factors, and system characteristics) and
3. the interaction between person and environment (the externalized behaviour resulting from processes between the person and the environment).

Within this triangle, factors adverse to the person (e.g. a mood disorder) can have a significant effect on how the person relates to others in the social environment (e.g. a change in normal conditions). This can then lead to negative reactions from the environment (e.g. staff behaviour based on attributions). These reactions can result in the creation of a particular pattern of interaction (for example, aggression) between these two components. Adverse environmental conditions (e.g. an environment which does not provide stimulation) can also lead to an interaction pattern which has negative impacts on the person (e.g. boredom). As a result, existing interaction patterns can change and be accompanied by maladaptive behaviours (e.g. stereotypical behaviour). The role of direct support staff is crucial in terms of identifying challenging behaviour, providing meaning and responding adequately to it.

Challenging behaviour can be caused by seemingly unmodifiable factors within the person with PIMD (e.g. auditory impairment, sleeping problems or mental health problems), but if this is considered from the perspective of a multifactorial biopsychosocial model (Došen et al. 2007), having a hearing impairment (a biological factor), for example, could be understood as leading to the person feeling unsafe and displaying challenging behaviour. If direct support staff fail to understand the cause of this behaviour, or fail to adapt the environment to ensure that a safe auditory environment is created, the person with PIMD will continue to display challenging behaviour. Personal, environmental and interactional factors are thus intertwined, and one cannot be considered without the other.

Furthermore, given the great dependency children and adults with PIMD have on others, it seems important to view behaviours in this target group from a relational perspective. Relationships are of the utmost importance for people with PIMD, because the world around them can be made recognizable and predictable through these relationships (Vlaskamp & Van der Putten, 2009). These relationships ultimately provide them with the opportunity to develop. Behaviours which make it difficult or impossible to enter into these relationships should therefore be viewed as problematic. Direct support staff are, first and foremost, instrumental to establishing such relationships and through these relationships, they can respond adequately if challenging behaviour occurs.

Awareness of challenging behaviour – behaviour that impedes the building of relationships – is immensely important because direct support staff play a key role in both identifying and preventing or reducing such behaviour in this target group. An interdisciplinary personal profile needs to be drawn up to identify challenging behaviour and to reflect on the degree to which it is problematic for the person with PIMD. The profile should provide information on the individual (biological and psychological factors and possible medical, functional and psychological problems), the environment (material, personal, social, educational and cultural factors, and system characteristics) and the interaction between the individual with PIMD and significant others. The personal profile should also include the challenging behaviour identified for that individual, together with its possible explanations and consequences. The Behaviour Problem Inventory for people with PIMD (BPI-PIMD) (Rojahn et al., 2001; Poppes, 2015) can be a useful tool in this process. During interdisciplinary sessions with parents, supporters, medical/paramedical care and behavioural scientists, the outcomes of this inventory can serve as the starting point for discussing the consequences of certain behaviour for an individual's opportunities to build and maintain relationships.

The explanations of staff and parents/legal representatives for the behaviour can also be addressed during this training. The session outcome could be incorporated into the individual support plans. Objectives can then be formulated for the prevention or reduction of this behaviour.

## Case description: Eva

Eva is 27 years old. Eva is described by her parents and staff as a cheerful lady who likes to be around others. According to all those involved Eva enjoys listening to music, playing with soft materials, swimming and being outside (no matter what the weather is like).

Eva has a profound intellectual and multiple disability. She has microcephaly, epilepsy (seizures don't occur because of the medication she is taking) and diabetes. Eva has a visual impairment. She has trouble seeing contrasts. A yellow cup on a white table is difficult to see for her. Colour contrasts are important. There does not appear to be a hearing problem.

Eva cannot walk and is in a wheelchair. Eva can hold objects, explores them with her mouth but according to staff she mostly throws the objects on the ground. Staff say it is difficult to capture Eva's attention and they fear she gets bored.

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

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

## Resources

**General** – film about individualized support program

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

Links:

[www.rug.nl/news-and-events/video/archive/unifocus/0525-unifocuspoppes](http://www.rug.nl/news-and-events/video/archive/unifocus/0525-unifocuspoppes)

[www.rug.nl/news-and-events/video/1021-unifocusvandenbosch](http://www.rug.nl/news-and-events/video/1021-unifocusvandenbosch)

## Triple –C: restoring life to “normal”

Hans Van Wouwe & Dirk Van de Weerd<sup>24</sup>

Triple-C is a treatment methodology for people with intellectual disabilities, who also have behavioural or mental problems. The three Cs of Triple-C stand for Client, Coach and Competence.

Triple-C does not focus on controlling problem behaviour, which is in contrast with other treatment models. Instead, our focus is on ‘restoring life to normal’. Care workers, behaviour specialists, managers and doctors build unconditionally supportive relationships together with the clients. On the basis of that relationship, clients participate in a meaningful day program together with care workers. This relationship increases their self-confidence and they develop competencies that have a therapeutic effect.

### *People make people*

A normal, dignified environment elicits normal human behaviour. In other words, when you put people in an inhumane situation – for example in solitary confinement – you cannot expect them to demonstrate normal human behaviour. According to Triple-C, isolation and confinement are, therefore, absolutely unacceptable.

### *Behavioral problems: the tip of the iceberg*

In our opinion, behavioural problems are the tip of the iceberg – an expression of underlying problems. That is why we do not think it is a good idea to root out behavioural problems by means of protocols, medication, fixation or separation. That is why we create an unconditionally supportive relationship, provide clients opportunities and challenges, give them tasks, responsibilities, and room for them to take initiative. By doing so, clients acquire more experience with being successful, more self-confidence, and they develop their competencies. This causes the behavioural problems to fade into the background. More important, the underlying problems – the ones that cause the behavioural problem – diminish.

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figure 10 the Triple C values and how to interrupt the stress circle

The Triple-C values



figure 11 the Triple-C support pyramid

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Van Wouwe, H. & Van de Weerd, D. (2015) *The Triple-C treatment method: A pathway to experiencing a normal life*.  
 Slidrecht: ASVZ . Downloadable from [www.asvz.nl/triple-c/en/publications/](http://www.asvz.nl/triple-c/en/publications/)

## Contact

[www.asvz.nl/triple-c/en/triple-c/](http://www.asvz.nl/triple-c/en/triple-c/)

## **Enablin learning, activity and play**

### **Multisensory story telling**

## Experience it!

Thyra Koeleman

"Experience it!" (in Dutch: "Ervaar het maar") is a methodical process for stimulating the motor skills, senses and communication in the supervision of children, adolescents and adults with a (severe multiple) intellectual and physical disability. "Experience it" was developed in 2001 by Thyra Koeleman from her experience as a counselor and speech therapist.

The method "Experience it" always starts at the base, that's to say the own body, how it functions and how the other communicates with the world around him or her. From there it is examined (decided) how (in what way) the development can be stimulated in a so complete possible way.

The method "Experience it" recognizes (knows) five principles including:

1. The theory of Experience Planning (by Dr. D. Timmers-Huigens) or development according LACCS (by K. de Geeter and K. Munsterman)
2. Total Communication
3. Basal stimulation (Andreas Fröhlich)
4. Sensory Data Processing
6. Locomotion

Experience planning, (arrangements and regulation) and communication model are to be used as a framework.

These principles are necessary to look at a complete manner to the child with a (severe multiple) intellectual and physical disability. One does not go without the other, and therefore a multidisciplinary collaboration is of great importance. The method 'Experience it' is a practical method that can be used at any time of the day, at various moments and (theme) activities. "Experience it" is primarily an approach which is in interaction with the other, the way the other act or behave, watched constantly or follows what is happening and whether it is properly connected to the way the other his experience are organised (processed) and communicates. Only then will work on development possible.

"Experience it" within a framework

Guidance Plan / treatment plan / education system (pedagogical) program

personal image

Perspective

Main goal

(Work) goals

Means to achieve goals: Method 'Experience it and / or other incentive (stimulating) or development programs.

This method is well applicable within the education (system) because it always starts with the basic needs of the child. If this condition is met (answered) the child is open to be able to develop further on his and her own way.

Meanwhile there are written five books and some DVDs have been published about the method 'Experience it'.



Basics “Experience it”



Experience it with crafts



Experience it with care

Web booklet Free to download: [www.ervaarhetmaar.nl](http://www.ervaarhetmaar.nl) (in Dutch)



Experience it with practical skills  
Practical skills



Experience it with physically oriented activities with  
Folding laundry; Baking apple pie; polish shoes



Youtube:

## Vita-Motion: robotics to increase passive movement

*Objectives* Improve wellbeing and QOL and cost reduction

*Main activities* Development of multi-sensory passive movement experiences

Moving and especially the lack of movement is one of the major challenges of healthcare. Vita Motion offers, with userfriendly multi-sensoric robo-technology, a broad range of cost reducing and sustainable solutions. Especially people with difficulties in moving can experience on an attractive and safe manner the benefits of movement.



More information: [www.vita-care.eu](http://www.vita-care.eu)

## On the move with “force in simplicity”

*Objectives* a simple method to help people with severe restrictions in movement to become more active and “on the move”. The approach stimulates overall development, not only movement.



To move is not easy for children and adults with complex and intensive support needs. In their daily life they are almost always dependent from others for their mobility. The method “Force in simplicity” is a movement method which tries to challenge children and adults to start moving themselves, thanks to simple techniques.

Compared to the more active group of people with multiple disabilities, their movement range mostly confines them to activities such as swimming and horse riding. This requires a lot of effort from the person and the professional and the intensity is limited to once or twice a week. The rest of the week they are mostly very passive, as regards movement. Scientific research shows that activation of this complex group truly benefits from a high frequency of very simple activities throughout the day, with a lot of social interaction which is tailored to the client. This is rarely offered in regular circumstances.

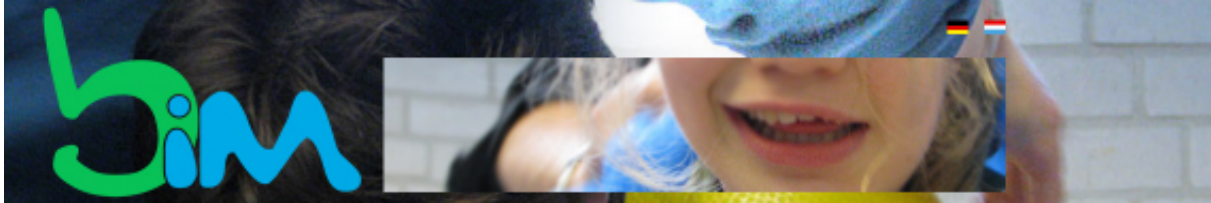
Cello, a service provider for people with intellectual disability in the Netherlands, has therefore looked for alternatives. It developed a set of stimulating movement activities which are fully integrated into the daily life of the living unit of the care facility. The activities are represented on “movement cards”. They can be used frequently by their simplicity, safety, and fun; they don’t require a lot of time, 15’ a day, adaptable to the person. They are simple to offer and to carry out. The materials used are cheap and require little human effort. Pleasure is key. Theoretically, this approach fits very well with the findings of scientific research.

[www.cello-zorg.nl](http://www.cello-zorg.nl) [only in Dutch]

[www.opleidingscentrumcello.nl/aanbod/bij-en-nascholing-beroepskrachten/47:kracht-van-eenvoud-cello-in-beweging.html](http://www.opleidingscentrumcello.nl/aanbod/bij-en-nascholing-beroepskrachten/47:kracht-van-eenvoud-cello-in-beweging.html)

## Working with music

### BIM – experiencing music



Fröhlich's Basic Stimulation and has been developed by Patrick Meuldijk.

The counselor 'interprets' music by bringing it into contact with the child's or adult's body, allowing them to experience it physically.

The bim-method offers a practical way of using music activities to teach and care for children and adults with complex and intensive support needs. The method is designed so that the music activities can be carried out either in a group or in individual, one-to-one sessions.

The physical perception of musical sounds increase the awareness of one's own body, one's environment and the people around. This is the basic purpose of these music activities. Then you can work on musical and general goals. The musical goals are primarily focused on the experience of the various sound aspects such as hard and soft or fast and slow.

The way of working is shown in a video which can be seen on [www.bim-werkwijze.info/index-english.html](http://www.bim-werkwijze.info/index-english.html)

Courses are organized for teachers and educators working with this target group



## Music Therapy with Girls with Rett Syndrome

Marina Luisa Rodocanachi Roidi, Kumiko Toshimori, Angelo Colletti and Alessandra Gandini<sup>25</sup>

### Rett syndrome: a high complexity disorder

Rett syndrome (RTT) is an X-linked neurodevelopmental disorder. Mutations in the X-linked *MECP2* gene can be found in 95% to 97% of individuals with typical RTT. The syndrome is one of the main cause of severe intellectual disability in females, with approximately 1:10,000 females worldwide affected.

Neul *et al.* (2010) described the revised diagnostic criteria. Classic RTT requires apparently normal psychomotor development in the first 6 months of life followed by a period of regression, which is not due to brain injury secondary to trauma, neurometabolic disease or severe infection. Regression involves partial or complete loss of acquired purposeful hand skills and language, gait abnormalities and the development of stereotypic hand movements, lowering of cranial circumference growth and autistic like behaviour, followed by stabilization or even some degree of recovery. Epilepsy, respiratory dysfunctions with hyperventilation, breath holding and apnoea, bone deformities with severe scoliosis and osteoporosis, gastrointestinal problems and behavioural problems are common comorbidities.

RTT is a very high complexity syndrome and intensive support is necessary for the girls and their families. Treatment approach to RTT in term of rehabilitation is not standardized and have low evidence based strategies. Intervention must be oriented to improve quality of life. Behavioural problems are some of the most burdening symptoms and emotional regulation is very low. Hand stereotypies appear to be pervasive and prevent functional hand use. Girls often present teeth grinding, sleeping difficulties, screaming, anxiety or inappropriate fear, problems in mood regulation, crying and laughing at night time, mouth/tongue movements and facial grimacing, impulsivity and overactivity, repetitive or self-injury behaviours (Mount, 2002). In a recent survey study 46% of families reported RTT girls to have screaming spells during the day (Anderson, 2014).

### Music therapy in Rett syndrome

Music therapy is a valuable approach for Rett Syndrome rehabilitation. First recommended by Rett (Rett, 1992) who recognized the power of music to penetrate the heavy barrier of disability.

Clinical Reports describe how music promotes the motivation of girls with Rett Syndrome to interact and communicate with their environment and to develop cognitive and emotional skills.

Girls with Rett syndrome are known to be very responsive to music and show behavioural modifiability. Eye contact, attention, cause/effect relationships, emotional expressions, ability to choose, intentional

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vocal sounds are described to improve during music therapy session (Weseky, 1986, Wigram, 1991, Hill, 1997, Elephant and Lotan, 2004).

Music therapy through vibro-acoustic approach (Wigram, 1996 - 2005) where pulsed, sinusoidal low frequency tones between 35-80 Hz. are combined with relaxing music and played through bass speakers built into a treatment couch or chair is shown to have positive effect by reducing the over arousal state which is typical in RTT, with changes or reductions in hand stereotypic behaviours, in hyperventilation, in muscle tone and arousal levels, improving relaxation, interest and pleasure.

Through the use of songs in music therapy, girls showed emotional and communicative behaviour and an ability to choose (Elephant C. & Wigram T. 2005).

Children with severe and complex disability have an extremely low level of expression, interaction and social communication, as a result of physical and mental rigidity. Their learning styles are based on repetitiveness and imitation. They have restricted affective and emotional development.

Intervention with music is oriented to improve affective and social interaction, expression and communication with the aim to support individual integration and harmonization. Harmonization is a process that makes individual functioning more elastic, flowing and aimed at interaction with the environment, moving from an archaic and sensorial to a mental and symbolic level. Affect attunement processes support the transition from disharmony to a harmony stage, thanks to non-verbal sound communication. In our experience, music therapy integrated in an individual rehabilitation programme, associated with other rehabilitative intervention, helps to increase:

- ✓ Exploration of the environment
- ✓ Activities and participation
- ✓ intensity's profile and duration of activation
- ✓ Ability to choose and to take initiative
- ✓ Vocalisation
- ✓ Memory
- ✓ Attention
- ✓ Listening ability
- ✓ Interaction ability with sound proposal

A transdisciplinary approach, which includes intervention with music, makes the care process more pleasant, empathic and confident and improves child and family wellbeing enhancing quality of life.

#### *Experience with music therapy at the Don Gnocchi Centre*

Our model of intervention in rehabilitation of severe and complex disabilities is a family centered multidisciplinary approach in which all the members of the team interact with the patient and his family to improve quality of life.

Music therapy is proposed as part the rehabilitation intervention in children with severe and complex disabilities (Colletti & Rodocanachi, 2002-2005).

Music therapists apply their skills to create a therapeutic relationship based on non-verbal communication, and by means of this relationship they pursue the desired aims.

Based on our experience, the specific goals for girls with Rett Syndrome are the following:

- ✓ promoting and supporting relational, emotional and communicative abilities
- ✓ enhancing better emotional command
- ✓ promoting relational autonomy and the desire to face the environment
- ✓ preventing relational, emotional and communicative complications
- ✓ supporting self-esteem
- ✓ physical and psychic relaxation

### *An assessment tool for music therapy*

We developed an evaluation tool based on our clinical experience of music therapy in the Don Gnocchi rehabilitation ambulatory Centre for children with developmental disorder, out of our need to have an indicator of the process.

The evaluation instrument consists of a table through which changes in music therapy sessions can be registered and the child's integration and harmonization in two music therapy areas (active and receptive) in terms of activation and countenance can be assessed.

#### *Table structure*

- 2 areas of music therapy: active (songs, sound dialogue)/receptive (listening)
- Each area is divided in two sections, activation and countenance, each of which contains observation - assessment items;
- A third part considers musical activities and observation about non-verbal and expressive data

#### *Table function*

Patient's observation and assessment in order to:

- Define a rehabilitation plan,
- Evaluate the time course of the rehabilitation process through qualitative and quantitative items analysis ;
- Share data with the rehabilitation team.

#### *Evaluation model*

- Every section has at its end a score related to patient integration
- Each area has at its end a score related to global individual harmonization
- One more index allows to quantify the individual's level of functioning (integration and harmonization are qualitative indicators) useful as additional information to compare different patients or different moments during the treatment of one patient.
- Due to the peculiarity of girls with Rett Syndrome, we prepared a specific assessment tool for them, in which the receptive area is not inserted and many specific items are present

COLLETTI-TOSHIMORI ASSESSMENT TOOL OF MUSIC THERAPY					
Name		Date		Signature	
<b>GENERAL OBSERVATION</b>					
Posture					
Facial expressions					
Global motricity					
Stereotypy (yes/no, examples, seriousness)					
Eye contact					
Breathing difficulty (yes/no, examples, seriousness)					
Muscle tone					
Communication aid					
<b>MUSICAL ACTIVITIES (yes/no, which)</b>					
Songs					
Sound relationship: sound tracing, sound mirroring, sound dialogue					
Music listening					
Integration with other expressive activities (dancing, drawing,...)					
<b>Observations:</b>					

<b>COLLETTI-TOSHIMORI ASSESSMENT TOOL OF MUSIC THERAPY</b>			
Name		Date	
Signature			
<b>SONGS AND SOUND DIALOGUE EVALUATION TABLE</b>			
<b>ACTIVATION</b>			
Interest in instrument/voice			
Communication through eye gaze			
Level of eye exploration			
Level of haand exploration			
Other modalities fo exploration (level)			
Participation in activities			
Activation level (energetic level)			
Duration of activation			
Initiating skills			
Initiating skills with communication aid			
Vocalization			
<b>Integration</b>			
<b>Functioning level (0-100)</b>			
<b>COUNTENANCE</b>			
Memory of musical activities through sessions			
Attention to task			
Ability to stop or doing pauses during musical activity			
Ability to Interact through sounds proposals			
Interaction skills with voice			
Variability in the modality ofexploring instruments			
Variability in producing sonorities			
Rhythm			
Intonation			
Variability in vocality			
Authonomy in activating rlationships			
Autonomy with communication aids			
Frustration Tolerance			
Modifiability after MT session			
<b>Integration</b>			
<b>Functioning level (0-100)</b>			
<b>PERSONAL HARMONIZATION</b>			
<b>FUNCTIONING LEVEL (0-100)</b>			
<b>Legend</b>			
	<b>Frequency</b>	<b>Degree of authonomy</b>	
<b>0</b>	Never	None	
<b>1</b>	Seldom	With continuous support	
<b>2</b>	Sometimes	With support (sometimes without)	
<b>3</b>	Often	Often withou support	
<b>4</b>	Almost always	Almost athonomous	
<b>5</b>	Always	Completely authonomous	

## Results

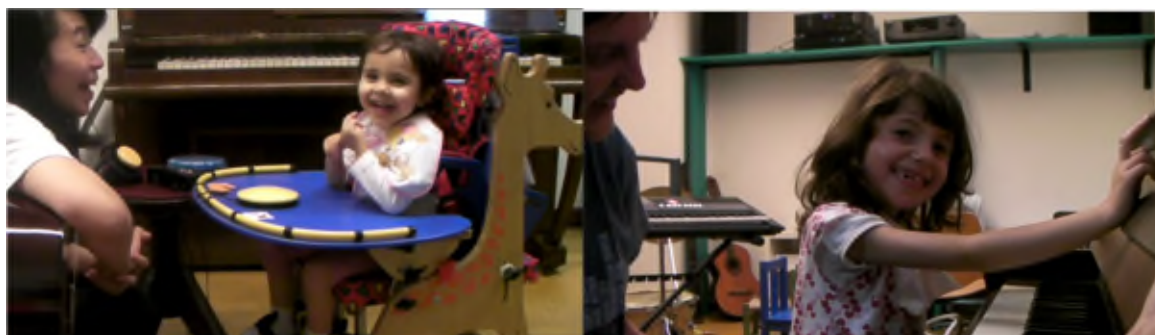
We are able to report here our results with music therapy in 8 girls with REtt syndrome. A scientific study is being carried out and will be published elsewhere. We could see an improvement in harmonization index and in level of functioning in 7 out of 8 girls. We can observe that some items, not utilized at the beginning of therapy, can start to be used while other items stop. We can observe a positive dis-harmonization (that is as an increase of items used with a decrease in the result of harmonization) as in case 3 who showed a better harmonization index and a lower index of functioning at 6 months of therapy. In all cases is important to sign and take into account general conditions as physical data (fits, apnoea...) which are not part of the scoring but are collected in a section of the tool. Looking at the single profiles it has been possible to recognize in girls with Rett syndrome a good propensity to intervention through music and the presence of empathic skills. The three girls with independent walking had a tendency to go around without purpose and had a low level of attention at the beginning of treatment. This tendency decreased with treatment.

Though more data have to be collected in order to verify improvement with music therapy in Rett Syndrome and statistical analysis is necessary, we found this tool useful in clinical practice because it allowed:

- To observe each item and follow general evolution during musical setting and to see if some items are acquired or lost during therapy
- To measure personal harmonization and level of functioning as two separate factors (a low level of functioning with a high harmonization indicates an emotional well-being beside the severity of the disease)
- To make some factors of the emotional behaviour measurable and to put them in relationship with distressing environmental factors

Measuring results of music therapy intervention is not easy as we deal with observation in an inter-subjective setting. We adopted the concept of “affect attunement” (D. Stern) processes in the relationship between the therapist and the child yielded through sonoro-musical parameters facilitating the Self-development in a relational context. Affect attunement processes support the transition between disharmony and harmony stage thanks to non-verbal sound communication.

The utilization of a measurable tool allowed the music therapist to build a personalized setting, to share data with the rehabilitation team. Our data need to be studied in a larger sample in order to define possible patterns of music responsiveness in Rett Syndrome, although we found the tool very useful in measuring the impact of music therapy in individual Girls with Rett syndrome.





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## III B - Enablin well-being and health

### Basal life<sup>26</sup>

Andreas Fröhlich

#### Escape from depression

The many obstacles of the developmental delay might lead to desperateness among pedagogues and educators. However most of us are professional optimists. We won't let that get us down and try to find the hidden capabilities of severely disabled children in order to support their remaining potentialities.

In my opinion, the crucial point for a successful support and promotion of children with severe disabilities is triangulation, i.e. the concerted action between a child, an adult and an object. The child needs reliable and constant guidance and assistance. The closeness of the grownup, the safety and security she/he provides is a basic prerequisite in this process. It is imperative that the adult does not push the child nor ask any questions or pass judgement. The grown up has to be present unconditionally without fuss or quibble. The child and his/her companion act "as a body", they approach an unfamiliar object or a new discovery together.

The adult relates the child's sensory experience to his/her immediate environment. New experiences get a name and a "face". If the child does not react, the grownup himself expresses the shared emotions and feelings verbally and non-verbally. It is somehow difficult to verbalise this approach. My explanations will be illustrated later on.

To explore the world children with severe and multiple impairments have to gather firsthand sensory experiences. They have to learn to feel, to see and to hear, to taste and to smell. They have to get opportunities to experience different smells, tastes, sounds etc. The world: These are other people but it's also our own body, our legs, arms, feet and hands. Exploring the world starts with exploring ourselves.

It isn't possible to eliminate a physical disability or a sensory disorder even with the best of therapies. Therefore one of the most important tasks of pedagogic-therapeutic assistance is to bypass or

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<sup>26</sup> From the booklet : Andreas Fröhlich, Basal life. *Texts for working with severely impaired individuals*. Ed. Int. Verein Basale Stimulation (2016) [www.basale-stimulation.de](http://www.basale-stimulation.de). Reproduced with kind permission by the author



compensate the functional limitations of severely and multiply impaired children by helping them to gather good and differentiating experiences based on their special individual condition of life.

### **Basal support**

The fundamentals of basal support may be summarised as follows:

- We do not draft any preconditions. The child does not have to meet any requirements. He/she only has to be physically present without having to perform in any way.
- Our assistance is truly basic. We provide only little support at a time, that means reduced but clearly perceptible experiences.
- We adapt our own pace to the pace of the children. We have to proceed very cautiously, because severely and multiply disabled children mostly understand and perform much slower than non-disabled children.
- Repetition is one of the most important principles of basal support. Consistent repetition gives importance to a certain experience and facilitates its assimilation.
- Pedagogic-therapeutic experiences have to be part of the children's everyday life (washing, dressing, eating, going to bed etc.). On every occasion we have to integrate new experiences into the individual daily routine of the child. Pedagogical parallel worlds would make learning much more difficult.

In conclusion I will try to illustrate what I mean with the consequent reduction of pedagogical requirements: Like a good cook, who lets a light broth simmer for hours on low temperature, we have to condense our stimuli, to intensify their "flavour", to offer more than the "usual". The figure-ground perception may illustrate this process:

We have the innate skill to differentiate a meaningful figure from a less important background. During the perception process we virtually cut the figure out of the background and isolate it as a carrier of meaning. The proper motion of our eyes, our head and our whole body plays a decisive role in this process. For a child that has no or not sufficient command of his/her movement abilities it is rather difficult to isolate a figure from its background. Such problems may be multiplied by additional sensory disorders.

Therefore a child with severe or multiple impairments needs our assistance in perceiving the objects in his/her surroundings, be it a doll, a toy or another important item such as a drinking bottle. That means we have to reduce all the concomitant impressions and influences and give priority to the "figure".

In this light, the expression "multi-sensory" or the popular phrase "learning with all senses" might be ambiguous. Severely and multiply impaired children should not be overstrained with too much sensory information. It is much more important to find the relevant significance of a single object and to help the child handle it in a satisfactory manner by giving him/her structured support and assistance.

Orientation, recognisability and safeness are very important aspects in the cooperation with severely and multiply impaired children.

### **Prospects: Basal pedagogical work**

Curiosity, play and exploration are the most important characteristics of childhood. Playing, being inquisitive and trying out anything and everything are the essential activities for a natural and healthy development – even if parents often think: 'That's enough now!'

This also applies to children with severe and multiple impairments even though they need much more support. Often their physical and intellectual functions are limited or inappropriate to such an extent that they are not able to play, to satisfy their curiosity and to explore in an adequate way. Education and therapy have to provide the necessary assistance and encouragement. We have to make sure that the child can maintain an appropriate position in order to get access to the surrounding objects. We have to present all the relevant objects in the proper light in order to attract the child's attention to excite his/her curiosity.

We can vary the presentation of the objects. We can encourage the child to imitate us. We even can act as objects of exploration ourselves, as we are able to show clear reactions. Successful activities confirm the child's efforts: Yes, I did act in the right way. I am able to induce something! In this way the child becomes the actor of his/her own development.

Therapists, pedagogues, educators have to give up the illusion that they can trigger a child's development. A child is a self-developing creature. His/her development may be obstructed by unfavourable or promoted by favourable surrounding conditions ("Ecology of Human Development", Bronfenbrenner, 1979).

We want the severely and multiply impaired children to explore the world. We want them to come to know and to make use of their own body. We want them to explore and to conquer their surrounding space. We want them to advance from using the 'close-up' senses (sense of taste, touch and smell) to using the 'far-distance' senses (sense of hearing and sight). All these activities should be practised on a sound and stimulating base in a relationship with inspiring human beings. Such experiences not only contribute to a successful individual development, but they are also an important component of inclusion.

### Approaching

Let me feel your nearness, So that I know,  
That you are close by.  
I need your warmth,

Your scent.  
I know you,  
When you are close to me.  
Your voice – so far away,  
Your face – a soft mist.  
I like to feel you,  
Your scent tells me that I am safe.

## **III C - Enabling participation, ethics & society**

# Participation in education; An integrated approach of care and education

Mia Nijland & Inge Kroes<sup>27</sup>

## Introduction: an example

*Sarah is a happy 6-year-old with delayed development. Due to her extensive care needs she lives in a residential care facility, close to the parental home. Because the day-centre wasn't a good fit for Sarah, she switched to a school for special education. At this school she is in a so-called education-care group. Sarah has spasticity and is wheelchair-bound. An unexplained metabolic disease causes a varying energy imbalance. She is quickly over stimulated and sometimes exhausted for several days. Her whimsical alertness and epilepsy go hand in hand with her changing moods. Sarah hardly speaks and is inaudible. Her language concept is unclear, but this is significantly better than expected based on the use of her language. Because her classmates do not or hardly speak, she recently started attending language stimulation classes for three mornings a week, with good results. She engages enthusiastically and actively and especially in making contact with the other children, she is developing her language comprehension. She makes herself more audible and is better understood by the staff members. Since moving to school, Sarah shows positive growth in moods and engagement.*

## Issues and challenges

*The educational world turned a blind eye for children with complex and intensive support needs (CISN) for a long time. Education did not seem to apply to them, and exemption from compulsory education was for children with CISN both in the Netherlands and in Belgium rather the norm than the exception. Children with CISN were supposed to have a too low developmental level to be eligible for school education. There would be an insufficient response to the multiplicity and complexity of their problems and to their, often extensive, medical care needs.*

Only just in the past decade more advocates of school education for children with CISN stood up. These supporters mainly refer to the Salamanca Declaration of 1994 (UNESCO, 1994) and the UN Convention (2006) for the Rights of People with Disability, underlining the right to inclusive education of each child. They also emphasize the developmental possibilities of children and youngsters with CISN and the fact that they should be utilized and developed optimally, including through education. For parents, it would be a different experience if they could also send their child 'to school'.

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<sup>27</sup> Mia Nijland & Inge Kroes are special needs psychologist. They founded the Expert Centre for Care and Education, Wijhe, The Netherlands. Mia also works in the "EMB Platform", which is an experts' network on people with PIMD.

How should inclusive education be realized? It is not easy for experienced group leaders to achieve purposeful development, let alone an inexperienced teacher who does not know the target group and is not educated or trained to teach these students. Education is characterized by a group-oriented approach; how does it combine with the necessary individual approach of this new group of students? There are also doubts about the feasibility of combining care, therapy and education into one individual programme. The question is how to adapt to specific care and treatment needs in a school environment that is not designed for that purpose.

In order to introduce the educational world to this new target group, partnerships have been established between schools and day-care centres in the Netherlands and in Belgium. School organizational protocols sometimes collided with well-known, valuable ways of working in day-care centres and schools were often insufficiently equipped to provide the necessary customization. For parents, bureaucratic procedures were found to be more rugged than ever before.

Cooperation between education and care for children with CISN within the existing school education practice is challenging. Although there is no straightforward solution yet, recent years have led to significant insights, which demands a follow-up. What has been put in place must be further expanded and developed.

## Profiling

Education for children and young people with CISN is tailor made. To make education suitable for these children, good “profiling” is crucial. What do these students ask and what can they manage and not? What are their interests? What possibilities and limitations affect the school programme? For the necessary alignments of the teacher and the right content, tools are available that contribute to the profiling of these students (see handbook). But instruments cannot fully reflect the possibilities and limitations of a child with CISN. An overall picture of the child with CISN is necessary, also within an educational context. Information can be obtained from conversations with parents, other caregivers, and observation data. Such a ‘dynamic assessment’ approach provides sufficient action-oriented information for a class teacher. This requires more than one moment.

The profiling process should not be limited to single momentary information about functioning in sub-areas, such as a sensory-, perception-, focus-, communication- or support profile. These lead to fragmented images instead of a broad integral image, and in education practice they would be more confusing than illuminating. Therefore, these different results and perspectives should be brought together to achieve an integral functional profile. An example of a parent-made video-portfolio is the movie Laura on the Enablin+ DVD.

## Action

In order to offer good education to a child with CISN, work has to be done on several levels. First of all, education for children with CISN can only be successful when there is a planned individual education arrangement. Inspiration can be obtained from curriculum and learning trajectories adapted to the target group, which provide useful tools to determine development-oriented goals and learning activities in various domains. Furthermore, it is necessary to create an individually tailored social and communication-rich learning environment, stimulating active involvement and learning processes of the child. Finally, it requires organizational work on an integrated education and care offer.

### Individual education arrangement

Education for children with CISN is tailor made. Based on the child's possibilities, support needs and interests, individual long and short-term goals are formulated. An individual education arrangement is elaborated, which will be continuously tested against the formulated goals. Specifically for the teaching context, we propose the Q-FIT model, consisting of seven steps: (1) foundation, (2) design, (3) formulating, (4) planning, (5) executing, (6) evaluating and (7) integrating an individual arrangement.

### Learning trajectories and curricula

Schools work with a curriculum, a framework with a blueprint of a particular study programme per academic year. For the pupil with CISN, a more individual approach will be needed. There are different approaches to learning trajectories and curricula for CISN students (Browder et al., 2004; Dymond & Orelove, 2001). Curricula drawn from a *developmental perspective* take the curricula of children of equal developmental age as base. For children with CISN, there is a curriculum for children with a developmental age under 2 to 3 years of age. A limitation of these curricula is that they are not adapted to the chronological age. Thinking in terms of "mental age" often underestimates the child's personal capacities. Most children with CISN do not follow a "normal" developmental framework.

Functional curricula still are based on a developmental approach, however it uses materials more adapted to chronological age, in order to promote functioning within a daily environment (kitchen, street). Criticism towards this approach is it is still devised based on development steps, and that it is ambiguous what should be regarded as "functional" learning activities.

Curricula developed from an *ecological* approach no longer take the developmental approach as base, but they are adapted to chronological age and are also much more individualized, adapted to the unique learning needs and shaped in conjunction with the pupil's surroundings. The difficulty with this type of curricula is that there are few frameworks or general learning trajectories that can be used in the search for an individual learning programme.

Within a *thematic* approach, one also takes the calendar age as a base and states that all children of a certain age, including children with CISN, must learn about the same subjects. For example, in the UK, a national curriculum has been developed for all children regardless of their limitations (Tadema,

2007). Curricula of this nature mainly result from the inclusion movement. A widely heard critique is that it is very difficult to find a balance between this thematic approach and the development and learning needs of children with CISN.

Some examples of curricula adaptations for children with CISN can be found in the handbook.

*The Elaborated 5-14 Curriculum - Scotland* (Calvert & Gargan, 2001)

*The Five-Way (Vijfwijzer) - The Netherlands* (De Vijfwijzer, 2008).

*Plancius programme - The Netherlands*

*Their good right - The Netherlands* (van Hoof & van Dijen, 2009).

Learning trajectories and curricula should not be considered as a strictly linear pattern. This involves the risk that they suggest a normal development. According to Tadema (2007), there is a chance that students will "have to" learn a new step as described in the learning trajectories, without the teacher questioning if it is an appropriate next step for this particular child. The curricula may provide inspiration, but the "learning material" that is selected and the order in which learning steps are taken must be fully tailored to the individual student. Learning is not equal to developing new skills. Also expanding existing skills, needing less support in performing a task, showing more involvement, maintaining skills in regressive conditions ... are forms of learning.

### **A stimulating social-communicative learning environment**

Children with CISN learn and develop from interactions with people around them. Active involvement and learning processes are associated with a stimulating social and communicative learning environment (Arthur, 2004; Arthur-Kelly, Bochner, Center & Mok, 2007).

A student with CISN needs a teacher who believes in his (learning) possibilities. If that confidence is not there, one will not be aware of the relatively small developmental challenges that a student makes, and one will be insufficiently stimulating.

Furthermore, a student with CISN will only really develop and be open to learning experiences when there is quality interaction with the teacher. The teacher should, for this purpose, have an open mind attitude and try to systematically discover signals from the person with CISN, try to interpret and respond in a consistent way. Also, the teacher will need to make use of appropriate interactive strategies. This means, for example, changes in the way of communicating (e.g. position, tempo), establishing positive interactions with the person (e.g. confirmations, ratifications, pleasant and enjoyable interactions), use of specific interaction forms (e.g. moving and mirroring of physic, mimic, sounds and language) and stimulating the initiatives of the child itself (Kroes, 2017).

A stimulating social-communicative learning context is also an environment in which the child gets opportunities for input and choices (see Goldbart and Kroes, this manual).

### **An integrated and complementary education- and care offer**

Education for children with CISN requires more than working individually based on learning trajectories and classroom adjustments. Due to the complexity of their needs, education for these students will have to be supplemented with a healthcare offering that includes medical care, paramedical treatment and parenting.

Planned thinking through learning trajectories and the expertise to work in a didactically based way on the development of a child is an input from education that is invaluable. From the point of view of healthcare, the centralization of the individual, the art of observing, connecting to the (limited) possibilities of these children, and seeing these possibilities, the knowledge of syndromes, illnesses and medical aspects is a major addition.

Education and care are therefore not separable for these children. There is a need for a multidisciplinary team, with not only a permanent team of teachers, supervisors/ childcare workers but also therapists, a remedial educationalist, psychologist, nurse, social worker, even a technical worker for, for example, adaptation of assistive technology. In addition, there must be sufficient flexible personnel; it should be possible to have several staff members attending the same class at certain times. More attention should be given to the education and reception of children with CISN in basic education, training and internal retraining.

Teaching children with CISN also requires a *customized infrastructure*: sufficiently large spaces for wheelchair users; for specific spaces (e.g. self-service area, snooze area); spaces must be accessible, comfortable and maintenance-friendly, etc. There should be *specific tools* available, such as beds, lifts, seat shells, computer adjustments, customized educational material,....

In terms of *education organization*, deviations from the current school system will be necessary. Class groups should be small, 5 to 6 students. One should also let go of school-based approaches to the class time duration. A child with CISN does not live according to an hourly schedule: if at the time of play time the child is aware and alert, why should there be a "forced" break at that moment? Due to their often medically complex problem, a smooth transition from part-time to full-time education and vice versa should be possible without too much administrative hassle.

The question of the *location* of education is secondary. Although a school that is as regular as possible on the basis of social participation opportunities has preference, in principle, every physical learning environment, if the appropriate expertise is applied in a demand-driven way, and the necessary facilities, resources and materials are available, should suffice. This means in the most exceptional situation that a bedridden student goes to school within the day-care area of the living facility where he or she resides.



Furthermore, *regional* agreements must be made on which schools and care organizations will receive mentioned target group. Examples are given of the “together to school” classes on the Enablin+ DVD and in this manual.

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## Accompanying families

Carlo Riva, Abilità

## Dealing with ethical dilemmas and family issues

Mario Mozzanica, Don Gnocchi Foundation

## Ethics of care

From the book by Emmanuel Hirsch & Elisabeth Zucman, *La personne polyhandicapée: éthique et engagements au quotidien*, Paris: Erès

# Video resources for training purposes

## Training materials available online

### Training support workers to deal with people with complex needs

Source: Department for Education UK.

[www.complexneeds.org.uk/](http://www.complexneeds.org.uk/) Free online training materials

### The Welsh Assembly Government's Routes for Learning materials

Also an excellent free online resource. You can find them separately or within the above resource, at <http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/m08p010c.html>

## Enablin+ Training DVD

With the Enablin+ project we have gathered video samples of some of the mentioned examples of good practice. They are collected on a DVD which accompanies a training manual (a process book) explaining and framing them.

## Conclusions

Support systems are often not yet continuous in many countries, for the category of the children who are most in need. Governments are rapidly adapting to the requirements of the UNCPRD, but financing in most partner countries – except perhaps The Netherlands, - falls short. We defined a set of criteria of good practices which is based on quality of life and the objectives of the UNCPRD. The harvest in search of examples of good practices has been rich. People do take various innovative initiatives despite this shortage of resources: towards inclusion, towards more activity, towards involving families as partners, towards a wider range of activities, towards an earlier intervention, towards more education (whereas before it was believed no education was possible, towards sharing knowledge. The nominated examples are far from complete, hence it is important to leave the list open. It is also important to differentiate and take into account that initiatives can be considered “good practice” is they are on the way towards a better quality of life and inclusion criteria. Practical examples are an excellent source of learning. Knowledge is spreading, but true sharing of knowledge and experiences

between parents and professionals, is an issue. Some countries have taken interesting web based sharing initiatives. It is absolutely mandatory to know what kind of approaches work and why.



