

Enabling Activity and Participation

Supporting Young People with Complex and Intense Support Needs: process book and DVD

Jo Lebeer, Mia Nijland, Luísa Grácio, Beno Schraepen (Eds)

With contributions from 50 professionals and parents

This book is the product of the Enablin+ project, a European partnership within the Leonardo Life Long Learning Programme. The project's aim is to enhance the quality of life of children with very complex and intensive support needs, by innovating interprofessional in-service vocational training.

The name *ENABLIN +* has three aspects. "Enabling" is the opposite of disability; it means: to enable the person to function; the IN stands for "inclusion"; and the "+" stands for "multiple disabilities" or "extra and multiple needs". Though they have serious difficulties in learning, communicating, mobility, often also in eating and other aspects of self-care, sometimes major health problems and/or behavioural challenges, these children are capable of developing and participating in many kinds of activities.

This book is meant to accompany the training process of the trainer as well as the trainee. It is not a recipe book or usual training manual. The training materials are to be used as sources of reflection. The book contains a suggested core programme and working methods. The attached DVD contains a few examples of good practice, which illustrate various initiatives towards more inclusive participation and involvement in activities for the children.

Jo Lebeer is a medical doctor and professor in Disability Studies at the University of Antwerp (Belgium); **Mia Nijland** is a special needs psychologist who founded an expert centre on quality of life in Wijhe (The Netherlands); **Luísa Grácio** is a professor in educational psychology at the University of Évora (Portugal) and **Beno Schraepen** is a lecturer in special needs pedagogy and inclusion at the AP University College in Antwerp.



Enabling Activity and Participation | Supporting Young People with Complex and Intense Support Needs

Helix Press PRINTING HOUSE

enablin+

Enabling & Including Young People
with Complex & Intense Support Needs

ENABLING ACTIVITY and PARTICIPATION

Supporting Young People with Complex
and Intense Support Needs



PROCESS BOOK
AND DVD

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Portugal

enablin+

Enabling & Including Young People
with Complex & Intense Support Needs



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<http://deseizoenen.be/Enablinplus/>.

Translation of subtitles in Dutch, French, Portuguese, Hungarian, Romanian, Bulgarian and Italian can be downloaded on this website.

Use the following key to get access:

Login: Enablin+

Password: including1

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Lifelong Learning Programme

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Introduction

Jo Lebeer¹, Mia Nijland², Luisa Gracio³, Beno Schraepen⁴

This process book is one of the products of the Enablin+ project.

The ENABLIN+ project is a European partnership within the Leonardo Life Long Learning Programme. The project's aim is to innovate interdisciplinary in-service vocational training, where different professionals and parents of various backgrounds learn together, with the aim of enhancing the quality of life of children with very complex and intensive support needs.

It is a training manual, destined to accompany the on-the-job Enablin+ training modules to improve inclusion, communication, behaviour management, activities and learning, and support for daily life activities. It contains a DVD with videos of "good practice" which illustrate these aspects. It explains and frames these short videos, in order to maximise their potential learning opportunities. It should help professionals and parents to gain insight and to illustrate the various topics which are relevant when dealing with children with complex and intensive support needs.

Why this Enablin+ training?

This training is based on research that the project partners did in eight countries during 2014-16, regarding the needs of children with very complex and intensive support needs (CISN), their parents and supporting staff. These needs are very similar in richer as well poorer EU member states⁵.

Children and young adults with complex and intense support needs (CISN) are difficult to put into one project category. They have indeed multiple needs: they have serious difficulties with learning, communicating, mobility, often also in eating, continence and other aspects of self-care, and with participating in social activities. They often have major health problems (e.g. respiration, epilepsy) and/or behave in ways that are difficult to understand or are extremely challenging. Inclusion in a regular school is therefore difficult. They need a lot of care and attention. Staff need extra preparation and parents have many needs too.

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5 Lebeer, J. (Ed.) (2015), Who are they ? Assessing the needs of children with intensive and complex support needs in eight European regions. Antwerp (BE) : University of Antwerp Enablin+ Research Group. Downloadable from www.enablinplus.eu/en/results/wp1

The name “ENABLIN +”, has three aspects:

- (1) Enabling = the opposite of disability; it means: to allow the person to function;
- (2) the IN standing for “inclusion”;
- (3) The “+” stands for “multiple disabilities” or “extra and multiple needs”.

We wanted to find a better name for these children than is currently used in English literature “profound intellectual and multiple disability” (PIMD), to avoid a connotation that there is no education or development possible. Some of the parents protested against having their children classified with the term PIMD, because they found this term too negative, only stressing deficits. Also the French definition of “polyhandicapé” – which literally means “multiple disability” – is larger than the Anglo-Saxon concept of PIMD. Therefore we chose the name “Complex and intense support needs” (CISN). This includes the group of children with PIMD, but is larger. The concept of CISN stresses “needs” more than “deficits”, and therefore is more optimistic and more in line with modern thinking about quality of life. Some of the contributors continue to use the term PIMD, to designate a more specific group.

According to the 2006 Convention of the United Nations on the Rights of Persons with Disabilities (UNCRPD), countries that ratified this convention now have a duty of “deinstitutionalising” children and to organize the possibility of including children with a disability in normal schools, to promote social inclusion. This is not obvious.

First, these children need adequate early intervention and intensive parental support. The habit of taking care of these children in separate specialist environments will have to change into looking for more inclusive activities. In some countries, education is very basic or absent. An often-heard complaint is that there are not enough professional staff. A question is how to organize 24 hour support. Dedicated professionals, who support or teach these children, need to have concrete ideas how to assist these children in mainstream schools or other inclusive settings. This has to do with expertise, learning from example, becoming creative, etc. Support staff need more time to reflect on their own actions and how children can be supported in this way. Recent research showed that supporting staff should be encouraged to pay more time and attention to their interactions with the children and the learning processes of children (Neerinx et al., 2013). This has to do with creating the time, believing it is possible, and making it organizationally possible.

Professionals, when experiencing time pressures, run a risk of becoming overburdened and getting burn-out. Therefore, they need more suggestions, in order to know more concretely how they can deal with children in a different way and organize their work differently. The training aims to empower support people by reinforcing their belief system that they are capable in supporting children with CISN to facilitate meaningful learning, and to set up meaningful learning environments, which facilitate maximum

participation in society. We want to elicit capacities and values, in order to enable them to fulfil their work with an even greater motivation.

An often reported problem is the lack of stimulation of many children with serious intellectual disability: it is not evident to find activities which are suitable and adapted to the many complex difficulties, but which at the same time are challenging and stimulating development. People do learn various techniques in their basic training (e.g. “snoezelen”, “basic stimulation”), but more than techniques and methods, the question is with what mind-set people apply them: a “fixed mind-set” or a “growth mind-set” (Dweck, 2006). A fixed mind-set means that people believe that there is little or no change possible. With a “growth mind-set”, people are convinced that change is possible, hence they look for possibilities. A strong belief that it is possible and worthwhile to stimulate children with severe intellectual impairment is necessary; that it is possible and worthwhile to take inclusive initiatives and that in the long run the quality of life of everyone (including those who support) can be enhanced. This requires more effort, but it is more rewarding.

In training, it is important to involve all people, from all disciplinary fields, who come into contact with a child. People need to acquire an inquisitive, explorative attitude to look for solutions which work; to look for ways to participate in life’s opportunities as much as possible, including going to school; to understand that the way you address these children matters, etc. Therefore, training needs to address attitudinal and ethical issues, as well as practical aspects. It needs to work towards a shift in belief systems and conceptual systems, as well as to provide hands-on practical advice.

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

Acknowledgements

Hundreds of people have collaborated to make the Enablin+ project a success. We run the risk of forgetting people who made substantial contributions, so we would like to thank them collectively. We would like in the first place to thank the authors of the texts and videos included in this process book. We thank all professionals and parents who gave permission to use their video clips for training and the volunteers who collaborated in translations of texts and subtitles into English and other languages. Special thanks to Luk Dewulf and his team for the production of the DVD and corresponding website; to Nagley Bertoldi for translating, to Clare Chalaye for proofreading the English, to Magdalena Tsoneva and Helix Press for the production of the publication.

The editors
June 2017

How to use this process book

This process book is meant to accompany the training process of the trainer as well as the trainee. A process book is distinct from a recipe book or a typical training manual. The suggested training materials are to be used as sources of reflection. The book contains a suggested core curriculum with session scenarios and suggested working methods. For each module a set of desired competencies is described. It provides a particular type of resources, i.e. videos which illustrate several core aspects of interdisciplinary in-service vocational training.

The attached DVD contains a few examples of good practice, which illustrate various initiatives moving towards more inclusive participation and involvement in activities for the children. No example is in itself perfect. You can watch the DVD sequences one after the other, or you can pick out a theme, and then answer the questions accompanying the theme. You can also bring your own videotaped sessions to share.

This process book is complementary to the Enablin+ training handbook (Candeias e.a., 2017), which is more conceptual and academic.

What do we understand by “good practice”?

With the Enablin+ partners, we organized several discussion rounds to establish ‘criteria of good practice’. We took the ‘quality of life paradigm’ as a starting point. 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 explanation of why these are considered good practice, and to what degree they correspond to the 12 criteria.

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

1. Good practice must reflect all eight domains of Quality of Life (QoL) as defined by Schalock & Verdugo
2. Good practice 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 focused on physical, emotional and social well-being must not be a barrier towards an inclusive life.
4. Good practice should focus on the family; care schedules should be organized around the needs of the families, not for the convenience of the staff.
5. Good practice should integrally include teamwork
6. Good practice promotes 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 according to age as well.

7. Good practice must put a belief in educability 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 to actively participate. Time, patience and mediating skills of supporting staff are key.
8. Good practice uses 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 practice must show that inclusion is enriching for all, that children with CISN have a positive role in society, and are not just a burden
10. Good practice must have flexible and innovative rule systems
11. They must be evaluable
12. They must be accessible to people with limited resources. This has a political aspect, because it will require political action

Reflective learning

Beno Schraepen⁶

This course is meant for the training of professionals and parents. We have to consider that the learning of professionals, and adults in general, has to be treated in a different way to the learning of children or students. The professional's starting position for learning is not a 'not knowing' position but is rather situated between 'unconscious knowledge' and a 'not yet knowing' position. Professional knowledge is based on basic professional and theoretical knowledge, provided through training. When applied in their daily professional practice, new knowledge is continuously generated. Parents also develop practical knowledge on a daily basis and construct (unconsciously) 'practice theories' about their child.

Parents and professionals (adults in general) are 'educated'. They are socialised, have developed a self, a value system and a set of espoused and practice values. During their life they've incorporated strategies and structures for action and there's a continuous search for a goodness of fit between what they do, feel, think and want in their professional as well as in their private life.

Reflective learning is all about:

- Thinking
- Self-awareness
- Values
- Consideration
- Understanding
- Analysis
- Evaluation

⁶ Special needs psychology, AP University College & University of Antwerp. INCENA Study Centre for Inclusion and Enablement

To activate learning in order to create new knowledge we therefore have to focus training on the following:

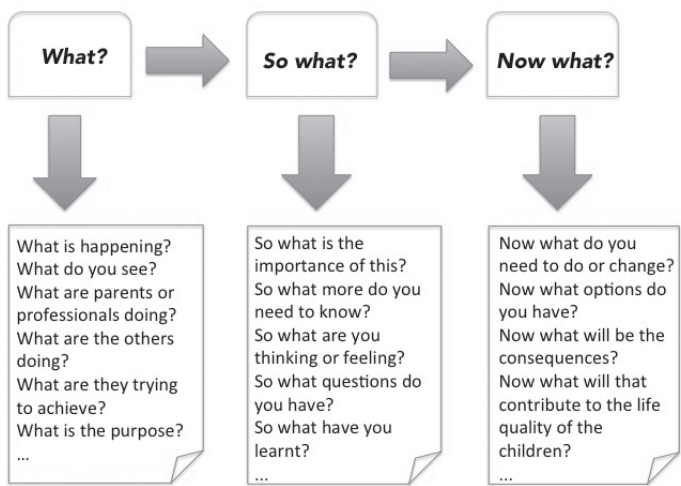
- To connect with previous knowledge
- To make unconscious knowledge conscious
- To look for discrepancies between espoused and practiced values
- To look for discrepancies between acting, feeling, willing and thinking
- To activate knowledge together

A general framework for reflective learning

Reflective learning and the development of reflective skills creates the ability to improve some aspects of our professional and private life by questioning the ‘common’ in our common sense and making assumptions explicit. Reflective frameworks are often visualized in a cycle or spiral. At the end of your reflective learning you will have to take some action which consequently, will lead to new situations to reflect upon and so the cycle starts again. Good reflective learning involves change, change in thinking, feeling and in new ways of action. We can say that reflective learning is not a process of learning about; it is more a process of learning what and how to act⁷ (Ramsey, 2010).

Because we use the training videos as input for reflection and not primarily of experiences or actions, we introduce a simple framework for reflective learning that can be used with all videos.

Figure 1



Stages in reflection process

⁷ Open University BU130/Course reader Ramsey, C. (2010). *Introducing reflective learning*. Milton Keynes: Open University.

Instructions for the trainer:

1. In the *What? phase* the trainer asks the participant to look carefully at a specific training video clip. They have to give a written description (in their own words) of what's happening, of what they see or what this clip is about. When the video is finished the participants share their observations. The goal is to connect with previously acquired knowledge. Questions are used to explore the different perspectives of the participants:
 - a. Is the situation recognisable? In what sense (not)?
 - b. What did you learn from training about dealing with this kind of situations?
 - c. And from experience?
 - d. What questions do you have about the video clip?
 - e. ...
2. In the *So What? phase* the trainer explores the meaning and significance of the video. The goal is to connect with values, strategies and structures that influence how the participants (would) act in that specific situation. This phase is a crucial phase because it will determine how successful the next phase will be and thus the reflective learning activity as a whole. It is here that the participants are brought into a reflective learning cycle. This form of questioning can be seen as a group learning activity, so therefore the learning environment has to be a safe one. The participants depend upon the creativity of the trainer in constructing reflective questions, and on their ability to make these increasingly challenging in difficulty (shallow to deep). To create a safe learning environment it's recommended to start with easy questions and build towards a deeper level of questioning. For example:
 - f. So what do you like/dislike about the video clip? Do you agree with how the people react?
 - g. So what were your thoughts during the video clip? How do you feel about it?
 - h. So what is important for you when dealing with a similar situation? How would you act? Why?
 - i. So what if it's your child ... what would you expect as a parent? Is that different from your expectations as a professional? (and vice versa)
 - j. So what if you are the child with CISN or one of the other children ... what support would you need?
 - k. ...
4. In the *Now what? phase* the goal for each participant is to integrate what has been explored in the previous phases and to develop new insights or strategies for future action. It must be clear that again the participants need to be challenged by the reflective questions of the trainer (or the other participants). Another objective is to connect with new content of the course. For example:
 - l. Now what did you learn about life quality/inclusion/capabilities ... by reflecting on the video?

- m. Now what is the effect of the reflective activity (video + reflection) on your thinking about (support of) children with CISON? How will this influence your future actions as a professional/parent?
- n. Now what change is needed? What do you need?
- o. ...

The challenge is to bring each participant into a reflective cycle at the same time. Teaching the participants how to reflect on their actions and come to self-reflection is a secondary objective of this type of learning activities. Putting reflection into action is one thing, helping each participant to become a reflective practitioner at the same time, is another. This process becomes visible when participants start to formulate reflective questions for themselves and to each other. It's obvious that proper feedback regarding which questions help people towards this reflection is appropriate here.

The videos can be used in several learning activities:

1. Thematic discussion – to stimulate thinking; draw on the knowledge and experience of all members of the group; assisting trainees to assess their understanding of the material.
2. Observation – less threatening than other approaches, whilst generating interest and enthusiasm; it promotes sharing ideas and observations.
3. Case study – allows the development of skills in problem solving, analysis and finding solutions; it facilitates the development of skills for teamwork, communication and presentation of the findings.

The videos are intended to provide illustrations that can inspire adults to set up similar initiatives, or to reflect on their own daily practice.

Design of a Common Core Training: Enabling Quality of Life through meaningful learning

Mia Nijland, Inge Kroes, Jo Lebeer, Beno Schraepen,
Heleen Neerinckx, Rianne Kleine Koerkamp

For whom is this training intended?

The Enablin+ training is oriented at everybody who is involved with children with *complex and intensive support needs* (CISN), including:

- Mainstream and special education staff,
- Personal daily living assistants (professional assistants, educators, volunteers),
- Educational psychologists
- Parents
- Medical & rehabilitation staff (e.g. nurses doctors, physiotherapists, speech therapists, occupational therapists, psychologists)
- Representative organizations for the disabled
- Vocational training staff at secondary and continuous professional development level

When the term '*support people*' or '*support staff*' is used in the following text, we mean professionals of all professions or parents, unless otherwise specified.

General objectives of the Enablin+ training

1. To raise awareness in *support people*, that it is possible and worthwhile to stimulate and educate children with complex and intensive support needs (CISN).
2. To train *support people* to become aware of their mind-sets (belief systems) regarding the possibilities of this target group, regarding learning and participation.
3. To train *support people* in implementing the quality of life-framework in supporting the development and participation of children and young adults with complex intensive support needs (CISN).
4. To enhance the quality of support in important aspects of daily living, such as feeding, hygiene, communication, relationships, learning, and play, etc.
5. To raise awareness that children with CISN, even those with the most severe impairments and restrictions in participation, are entitled to be recognized as full members of the community; hence the course will contribute to the transformation of segregated institutions towards service-centres oriented at inclusion.

6. To train *support people* in facilitating social and educational participation, activities and learning.
7. To increase self-efficacy of parents and professionals supporting children and young adults with CISN.
8. To increase the motivation, fun, satisfaction and inspiration in supporting children with CISN, in order to prevent burnout and empower professionals and parents.
9. To facilitate Quality of Life (QoL) of children with CISN through a focus on meaningful learning.
10. To explore and create individually adapted and supported learning curricula for children with CISN.
11. To provide a framework, plan for action and toolbox for professionals in special and mainstream schools or care centres for children with CISN.
12. To promote a standard of guidance/support which provides enough space for individual differences and approaches.

Course organisation & structure

We propose a basic stand-alone training consisting of 6 modules, corresponding to 72 – 84 hours or 3 credits (within ECTS). Each module consists of a minimum 10 hours (preparation time, contact hours, deepening or reflection time), including a minimum of 4 contact hours.

These can be concentrated into 1 week, or spread over a longer period of time, e.g., 6 weeks, 2 months, or even one year, depending on circumstances.

Part of the training can be carried out via an online learning platform, including access to all the teaching materials. Divergent (diversity in methods and outcomes) and convergent learning (oriented to the same learning goals) are used.

This course will take place through facilitated training sessions (contact hours) and independent work (preparation time, application or sharing experiences of change).

Preparation time

Preparation time can consist of: reading an article, a chapter of a book, watching a video, preparing a case study, ...

Contact hours

These are sessions with input from trainers, participants and discussions.

The 'common core' training is a general, introductory, interdisciplinary course for all. Because its organisation is flexible, it can be easily transferred to different countries. It must be seen as part of a training trajectory. It can be adapted to local needs and circumstances: it should not be presented in one whole, it can be divided in many pieces, e.g. into ½ day workshops.

After following the common core training, the student can take different specialisation workshops in specific topics, as suggested in Figure 2.

Working methods

The **teaching and learning methods** are essentially based on:

- Problem-based learning
- Case-based learning: participants present a case to each other, exemplifying a situation which they have experienced
- Exchange/ professional consultation
- Dialogue, discussion
- Reflective learning, empathy, respect for diversity of opinion
- Analysing videos showing concrete examples of 'best practice'.
- Feedback on self-made video recordings
- Role-play
- Web seminars and digital learning

Individual learning and considered practice is fostered through activities such as:

- Reading core theory (home-based self-study). The more theoretical parts can be found in the Enablin+ handbook⁸.
- Individual reflection and study time can be used for homework, reflective case studies, teaching videos, and application of the models and theories.

The perceptions of the participants/students and their learning process in supporting children with CISN is the starting point for all learning. Therefore, the training starts with the exploration of the learning goals and motivational drive of each participant, through a self-assessment tool. The focus of the trainer is to connect with, and stimulate the personal motivational aspects of each participant. Reflective learning, learning from peers and consultation with professionals, are key elements of the training.

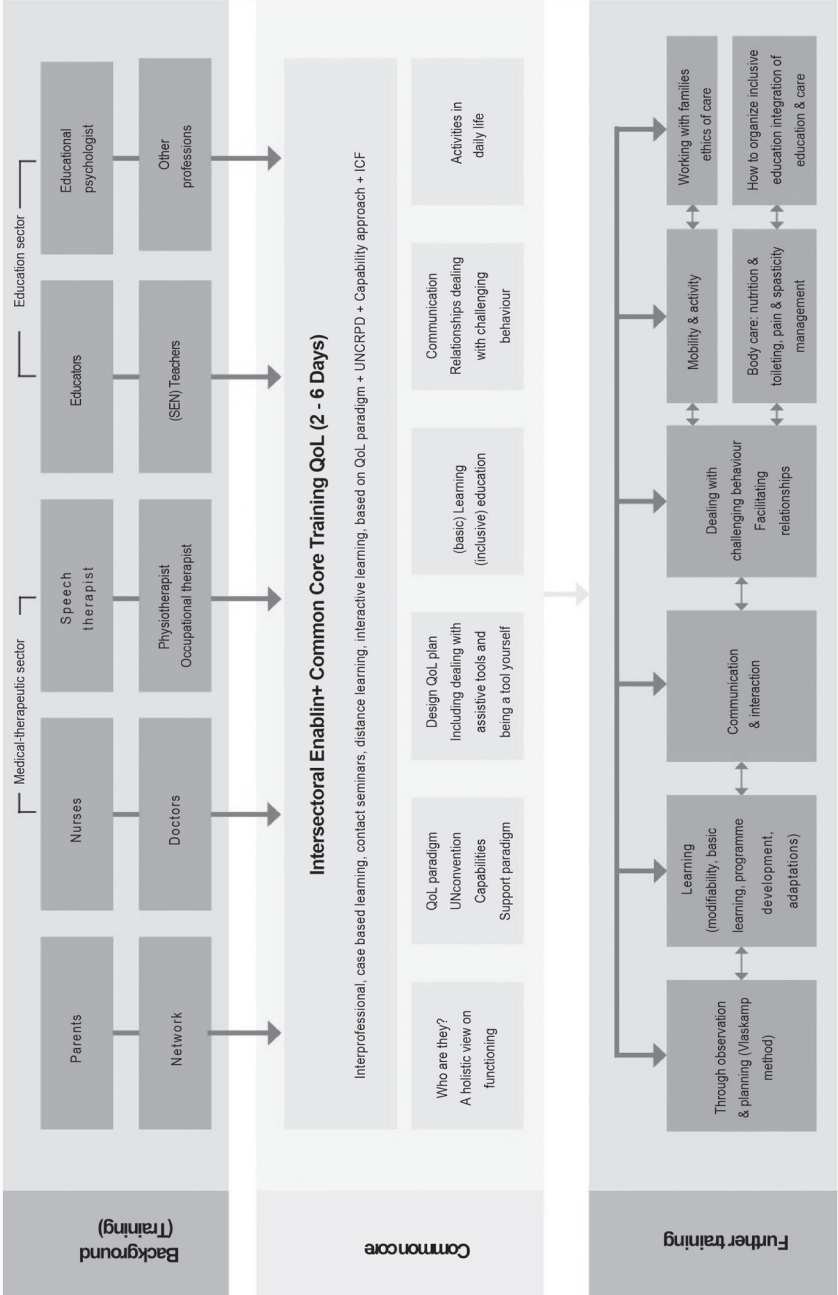
Obtaining transference and generalization of knowledge is also a central goal: starting from practical experiences then moving to generalization, so that the approaches learned can be applied in other situations.

The course has an evidence based core, which take into account the cultural differences of each country or participant. A qualitative and value-based approach to learning is essential in education relating to the support of children and young adults with CISN. It creates the foundations for further professional development.

⁸ When we refer to the Handbook, we mean: Candeias, A., Lebeer, J., Batiz, E., Orban, R. (2017) *Enability. Enabling Quality of Life in Young People with Multiple Disabilities and Complex and Intense Support Needs: Concepts & good practices*. Antwerpen/Apeldoorn: Garant

Enablin+: training for a better Quality of Life of children with complex and intensive support needs

Knowledge: based on experience, practice and scientific evidence



Enablin+ - Project Work Package 3 - Delivery 8 © Enablin+ project & Quality of Life Centre 2016



Figure 2
Model of a staged
training approach
for professionals
supporting children
with complex and
intensive support
needs (Mia Nijland,
Inge Kroes & Rianne
Kleine Koerkamp.
Infographics: Tom
Oosteweche)

Assessment

The evaluation is carried out with a preparatory, follow-up and retrospective character.

For the evaluation of each participant and their personal objectives, assessment takes place in different ways at different times:

1. Self-assessment:

- At the start: the participant will write a short introduction document with general information about: why this training, learning goals, organisation and what he/she wants to achieve
- After module 6 there will be a follow up session

2. Ongoing assessment:

- Sharing, discussions, reflections and input during the sessions
- Preparation and developing assignments, ...

3. Final assessment:

- Will be via a presentation of actions taken, and of insights gained from what has been learned from the training. In accordance with the Universal Design learning principles, there is a choice of presentation modality: PowerPoint, video, vodcast, paper, artwork, ...

Principles of the training

The training is based on four frameworks:

1. The principles of the UN Convention on the Rights of People with Disability (UNCRPD).
2. Quality of Life principles (Schalock & Verdugo, 2002).
3. The Capability approach (Martha Nussbaum).
4. The Supports Paradigm (Buntinx & Schalock, 2010).

These frameworks are valid for children and young adults with very complex and intense support needs but may require more creative practice in their implementation. All children are capable of learning, if they receive the necessary support within an appropriate learning environment. The UN Convention also states the right to an inclusive learning and living environment.

The curriculum assumes an ecological approach, in the sense of Bronfenbrenner's "ecology of development". This revolves around the person with CISEN as a whole person-in-context. In everyday life, vulnerable persons with (intensive) support needs are often reduced to their role as client, their diagnosis or their (hard to understand) behaviour. This course wants to overcome this reduction by giving attention to and reflecting on starting viewpoints, value systems, conceptual systems, prejudices and mind-sets, to link these to actual and desired practice.

Suggested course programme

Time frame for each session

- ½ hr reflection and summary of learning points of previous session (per group 1 theme, article, movie or observation);
- ¼ hr → then the trainer asks every group to take on a learning point, conclusion or learning question
- 3 hr/ 5 hr session content
- ¼ hr introduction to homework task, needed for practical application.

Introduction to the roadmap and basics of the training

We know that children with CISN often need full-time support and assistance 24 hours a day, 7 days a week – 24/7. In seven steps, the curriculum helps professionals and parents to design a roadmap and to keep track of the quality of life programme of the child or young adult.

The curriculum is a roadmap (with room for individual adaptations). It is based on the methodological framework of Carla Vlaskamp of Groningen University. It consists of seven steps, which can be taken by the person himself (and parents) together with a relevant professional (family coach, advisor, lifestyle coach, health coordinator, etc.). These are:

1. How do we perceive the person
2. Current 24/7 arrangement
3. Desirable 24/7 arrangement
4. Long- and short-term goals
5. Execution of (lifestyle) programme
6. Evaluation
7. Documentation

The seven main questions alongside each step should be answered and elaborated upon by following the corresponding instructions.

Table 1 Seven steps in the roadmap for a quality of life programme

| Process | Steps | Main question per step |
|---------------------------|---------------------|--|
| 1. Broad Diagnosis | Picture | Who is the person? What is his or her current living situation (holistic)? How does he/she live? |
| 2. Design | Current arrangement | What conditions and requirements are necessary for suitable 24/7 arrangements (integral)? |
| 3. Concretisation | Desired arrangement | What do the 24/7 arrangements look like if the conditions are met? |

| | | |
|-------------------------|--------------------|---|
| 4. Prioritizing | Goals | What goals are set for the (lifestyle) plan and (lifestyle) programme? |
| 5. Application | Application | What is the daily/weekly programme, and how do we achieve this? |
| 6. Evaluation | Monitor and review | How will the implementation be assessed and how are the results measured? How do evaluation results guide on-going change processes? |
| 7. Documentation | Lifestyle plan | Has everything been written down appropriately and is everything documented? |

Central facets of the curriculum are step 1 and 4, which are based on the support programme of Carla Vlaskamp (Vlaskamp & Vanderputten, 2009). In addition to this, the steps are also based on domains and principles from Nussbaum's Capability Approach (Nussbaum, 2011), the Quality of Life concepts of the IASSIDD (Schalock & Verdugo), UN Convention of the Rights of People with Disability and the ICF framework of the World Health Organisation. Furthermore, additional knowledge resources are used: learnability and modifiability (Feuerstein, 1991), criteria for person-centred planning processes (Schwartz, Holburn and Jacobson, 2000), and existing care and education curricula. In the lifestyle plan (step 7), information is translated and summarized by means of nine lifestyle domains related to the development tasks which are associated with the calendar age and different life events that could be going on in the life of the person (Youth Health in the Netherlands).

The roadmap facilitates the person with disability and those in their support system. A roadmap is more than a support plan. The roadmap is linked to a database coupled with information (see info graphic Figure 3). You choose from a wide range of applications with each step (which are available for health care and education). We collected some ideas for activities in this manual, as well as in the handbook. The plan is to construct a digital toolbox that provides (grounded) information for all steps (for example a list of profiles in step 1b or activity programmes in step 5). This gives a plurality of organized information and inspiration for support and learning questions for both the target and the individual. It helps to achieve balance and customized care in everyday life at home, leisure, school, daily activities and work.

The roadmap has three functions:

1. *Advisory system for professionals* – The roadmap helps professionals with assessment, arranging, imaging, and diagnostics for healthcare, education, care, treatment and rehabilitation. For example, governing bodies or allocation committees are potential users.
2. *Individual roadmap* – For individual applications the roadmap provides guidelines for a (lifestyle) programme with fixed steps, always with a personal interpretation. It helps:

- a. To complete and direct daily life.
- b. To choose and track a (healthy) lifestyle.
- c. To create and track a lifestyle plan.

Self-management (by the person with the disability and their direct environment) and lifestyle of a person are inextricably linked. The roadmap brings both together and provides advice for an adequate and appropriate lifestyle. A personalised lifestyle programme is fundamental, from design to evaluation. By assessing someone's lifestyle (adjusting and guiding this where necessary), a contribution is made towards a better quality of life for the person. It guarantees the necessary balance between, for example, physical and psychological approaches to certain questions or problems. The individual (or their most relevant supporter) manages their personal roadmap using an online version of this. The individual can do this with parents or their family coach, process coordinator, mentor or these representatives can do this on their behalf. Through an electronic (shared) platform everyone can be involved. Professionals have access and can connect and add things. In this way, the person does not insert in various professional sub-plans, but he or she manages their own (lifestyle) process and plan.

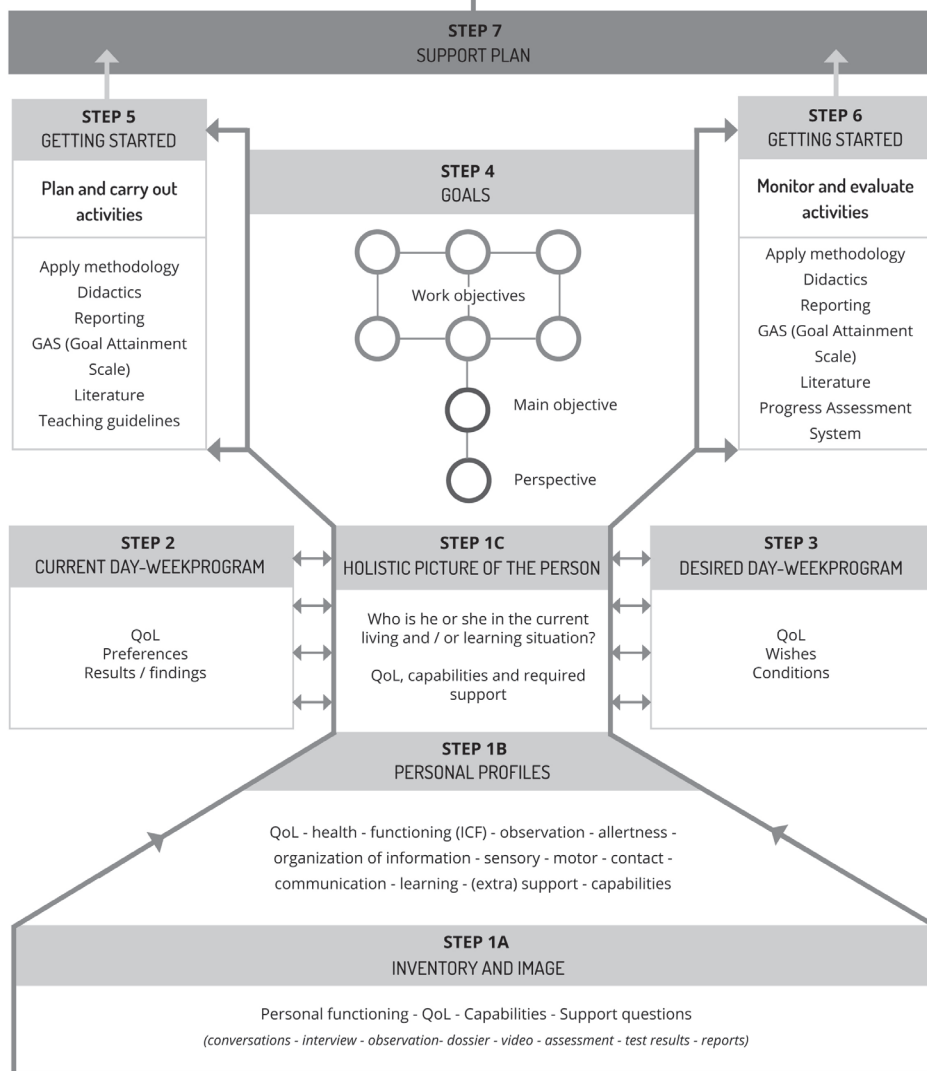
- 3. *Systematic working for professionals* – The roadmap provides support for professionals in care, treatment and education in the form of a work standard and (remote) monitoring system, which helps to design, facilitate and achieve an appropriate (lifestyle) programme. The organization is not in control, the person himself is (or his parents or mentor).

Integrating care and education

The roadmap helps to establish cooperation between different disciplines. It can be used to achieve integration and cooperation between care and education for the target group (on a target group, group and individual level). The roadmap provides opportunities to bring the best of both worlds together, through combining (existing and evidence based) a methodical framework and existing didactic frameworks.



Use  Use



*Figure 3 Road map Flourish and Stimulate
(Mia Nijland & Inge Kroes, Wijhe, The Netherlands. Infographics: Tom Oosteweche)*

Module 1

Who are the children with CISN and what are their needs?

Desired Competencies

Knowledge:

- The participant has basic knowledge about the target group of children with CISN: needs, capacities, level of functioning, how they experience the world, milestones in development
- The participant has basic knowledge and can critically reflect on concepts of developmental age and chronological age.
- The participant has basic knowledge of frequent physical and health problems of children with CISN (epilepsy, swallowing difficulties, reflux – (GER), sleeping difficulties, respiratory tract infections, constipation, etc.).
- The participant has basic knowledge about taking into account the needs and interests of a child with CISN (contact, communication, alertness, tempo, under- and overstimulation).
- The participant has basic knowledge about the “Q-fit navigation” system (Q-fit = quality-fit, a step-by-step navigation system integrating the Vlaskamp approach).
- The participant has basic knowledge about how to take into account the real needs and interests (motivation) of the child (how to get to know the child).

Attitude:

- The participant is ready and able to empathize with a person with CISN.
- The participant is aware of how to deal with the (lack of) autonomy of the person with CISN.

Typical professional conduct

The professional conduct of someone in charge of supporting a person with CISN in care and education, is characterized by being oriented towards a child’s physical and psychological well-being, building trust, empathy, openness to observation, willingness to maximize potential, focusing on development; integrity, helpfulness, flexibility, sensitivity, creativity, patience, cooperation; seeing things from different perspectives, prioritising communication and problem-solving.

A good and equal relationship with families, and to sharing information with them, is of great importance for adequate care for and support of the individual. Collaborating with families requires an empathetic, communicative and cooperative and flexible attitude. The professional reflects on his / her actions,

asking for feedback and uses feedback from colleagues and family members. He or she contributes to the constant evaluation of the actions performed.

Skills

- The participant is able to reflect on his or her own vision for the target group.
- The participant is able to reflect on the needs of his or her case, taking into account body functions, activities and participation, personal and environmental factors, as described in the ICF-framework.
- The participant is able to analyse and process personal information obtained in the comprehensive profile of the person.
- The participant has a clear idea about, and is able to write down, the person’s current daily programme.
- The participant recognizes and signals changes, and situates them in the whole picture of the person (think of physical, communicative, developmental and functional possibilities)

Possible scenario during the session

Preparation

Choose a ‘case’ that you can follow during the whole training and for whom you are going to apply some of the practice examples. Write down the goals you want to achieve for this particular child with CISN you have in mind.

| What | Time required | Topics to be covered | How? | Literature/ materials |
|-------------------------------|----------------------|--|--|--|
| Introduction group | 5 minutes per person | Free (to fill in) Also, the students will introduce their case. Self-assessment | Individual presentation | |
| Introduction training | 15 min | <ul style="list-style-type: none"> • Why? • What’s the problem for the child with CISN and their parents and also for the involved professionals? • Desired situation | Plenary To discuss: <ul style="list-style-type: none"> • how is this for you as a person? • how is this for you as a supporting person? | NL: movie: Laura (see Enablin+ DVD in training manual; BE: the Hopping path, part 1 : “me” |
| Introduction theme of the day | 10 min | Who are “they?” | Plenary and discussion in the group | |

| | | | | |
|--|--------|---|---------------------------------------|--|
| Objectives and competencies | 10 min | A short conversation about the goals and competencies. Where is the challenge for the students in this class? | Dialogue in the group | |
| Programme and work methods | 5 min | | plenary | |
| Who are they? A holistic view of functioning | 2 hr | Describe physical questions Psychosomatics Assessment Numbers ICF-cy AAIDD development tasks Activity programme | plenary | Article: 'Who are they? Assessing the needs of children with intensive and complex support needs in eight European regions. Antwerp : Enablin+ Research Group' DVD Enablin+ 'together with Koert' |
| What do they need? (the person with CISN) | 1,5 hr | Step 1a, 1b, 1c, 2 and 3 | plenary | Video: https://www.youtube.com/watch?v=bWEyt-n0ylrs or watch Enablin+ DVD: NL Laura or BE Hopping path, or BG bridging the gap or PT Maria |
| What do they need? (from you?) | 1,5 hr | Obstacles and chances for the target group. Which obstacles do you recognize in your practice? | Plenary and conversation in the group | |
| Evaluation | 15 min | The students receive an evaluation (hardcopy or digital), so they can fill out this form later. In class, we look back and discuss the session with each other. | Reflection in the group | |
| Practice: Observe a child and describe their real needs using infographic curriculum 'flourishing & stimulearning' | | | | |

Module 2

Quality of Life

Desired Competencies

Knowledge

- The participant has basic knowledge of quality of life and the importance for children with CISN
- The participant has basic knowledge on how you can let the child with CISN participate in a social life.
- The participant has basic knowledge about the UN Convention of the Rights of People with Disabilities
- The participant knows what the domains of QoL are (as defined by Schalock) , applied to children with CISN

Attitude

The participant is willing and able to reflect on the meaning of QoL and participation for children with CISN.

Skills

- The participant is able to name what is needed to increase the QoL for children with CISN.
- The participant is able to pinpoint what is needed to increase the participation of a child with CISN in social life.

Preparation

- Read UN Convention on the Rights of People with a Disability
- Read Schalock & Verdugo's Quality of Life Model (see topic further in this book and Handbook Enablin+ chapter by Claes)
- Read Nijs, S. & Maes, B. (2014).

Possible scenario for a session plan

| What | Time required | Topics to be covered | How? | Literature/ materials |
|--|---------------|---|-------------------------|--|
| Review day 1 Theme of the day | 15 min | Reflection | Reflection in the group | |
| Objectives and competencies | 10 min | Explanation | Plenary | Read: Lyons (2014) |
| Programme and work methods | 5 min | Explanation | Plenary | Watch Enablin+ DVD: NL: Laura; or Koert; BE: Villa Clementina or FR: CESAP |
| Improving Quality of Life by meaningful learning through person and environment. | 1, 5 hrs. | Explanation quality of life | Plenary | DVD: Enablin+ "Laura" |
| Human vision and values | 1, 5 hrs. | Present the 4 frameworks: UN Convention; Quality of Life, Capability approach & Supports paradigm | Plenary | Literature: see topics |
| Current situation target group | 1 hr | Dialogue about QoL in children with CISON. How is the situation now? | Group discussion | |
| Wished situation target group | 1 hr | How could it be? And what is needed in order to improve? | Group discussion | DVD Enablin+ 'Bram' Or pick any other video clip on the DVD. |
| Evaluation | 15 min | | Group reflection | |

After the session

Reflect using the questions of Petry & Maes. What do the QoL principles mean for our target group?

Module 3

Basic learning, (inclusive) education

Desired Competencies

Knowledge

- The participant has a basic knowledge of learning conditions in children with CISN
- The participant has basic knowledge of methods and techniques to activate and stimulate children with CISN (experience-oriented, sensory- oriented)
- The participant has basic knowledge of the notion of mediated learning and how that relates to children with CISN
- The participant can translate Vygotsky's concept of Zone of proximal development to the target group children
- The participant has basic knowledge of group and class management.

Attitude

- The participant is able to approach education in a broad perspective

Skills

- The participant is able to use the regular curriculum as a resource for adaptation
- The participant is able to anticipate individual support and learning possibilities
- The participant is able to make meaningful learning possible
- The participant is able to see and experience the balance between individual and class management
- The participant knows how to connect to a child's present "developmental level", and to explore how to go beyond this

Preparation

- Make a quick scan of your class management/ family situation
- What does this mean for your 'case'?
- What do you want to change?

Possible scenario for a session plan

| What | Time required | Topics to be covered | How? | Literature/ materials |
|--|---------------|--|--|--|
| Review day 2 Theme of the day | 15 min | | Group reflection | |
| Objectives and competencies | 10 min | | Plenary | |
| Programme and work methods | 5 min | | Plenary | |
| Meaningful learning. | 1hr | Alertness, confirming initiatives, co-regulation, mediation | Plenary | |
| Using curriculum as a resource for the individual learning programme | 1hr | Learning system 'Development domains' 'Learning to learn' | Plenary | DVD: Enablin+ PT: Maria IT: Stefania |
| Learning in a natural way Peer interactions | 1hr | How to put this into practice? | Group discussion | DVD: Enablin+ BE: hopping path IT: Stefania PT: Maria NL: Bram |
| (Inclusive) and suitable education | 1hr | Watch different models of inclusive education organisation: full inclusion, partial inclusion, to school together classes | Small groups, followed by plenary discussion | Enablin+ Teaching video NL: NSGK & Bram BE: Hopping path FR: les enfants de l'école IT: Stefania PT: Maria BG: bridging the gap |
| Evaluation | 15 min | Self-assessment | Group reflection | |

After the session

- What is meaningful learning/ inclusive learning for your case?
- What is the opinion of the family?

Module 4

Dealing with a quality of life plan including assistive tools and support, based on careful observation

Desired Competencies

Knowledge

- The participant has basic knowledge of a planning and monitoring system to monitor and register progress in well-being and development.

Attitude

- The participant is willing to observe, listen to and be sensitive to their communication partner.

Skills

- The participant has knowledge of the GAS (Goal Attainment Scale) (Kirusuk e.a., cited in Vlaskamp) and is able to use it.
- The participant is able to make the right choice from a range of available methods and techniques to activate and stimulate the child, and is able to apply these, personalising them as appropriate.
- The participant is able to develop and implement a daily structure and daily and weekly programme.
- The participant is able to work inter-professionally, in order to reach a good quality of life.

Preparation

Read article Carla Vlaskamp and Annette van der Putten (2009)

Possible scenario for a session plan

| What | Time required | Topics to be covered | How? | Literature/ materials |
|---|---------------|---|-------------------------------|---|
| Review day 3 Theme of the day | 15 min | | Group reflection | |
| Objectives and competencies | 10 min | | Plenary | |
| Programme and work methods | 5 min | | Plenary | |
| Step 4: based on the complete picture you have of your child, and their programme, determine the long-term goals Design a plan; short and long term goals | 2 hrs | We continue our work, based on the Q-fit maps (a step-by-step navigation system integrating the Vlaskamp approach). | Plenary | Enablin+ DVD: BG: Maggie and Chrissy |
| Step 5 of the roadmap | 1,5 hrs | Make and apply the individual programme and combine it with the group programme | Plenary and group discussion. | |
| Step 6 of the roadmap | 1,5 hrs | Monitor and evaluate the results by using the GAS- score (and other monitoring systems for individual pupils). | Plenary and group discussion. | |
| Evaluation | 15 min | | Group reflection | |

After the Session

Practical applied task:

- Write a short-term goal for your case-study child , using the planning system you've just learned about.
- Write down the results in your support plan (step 7)

Module 5

Dealing with challenging behaviour

Desired Competencies

Knowledge

- The participant has basic knowledge about challenging behaviour carried out by children with CISN
- The participant knows the consequences and recognizes the risks

Attitude

- The participant is willing to look at challenging behaviour from a different perspective

Skills

- Applying an instrument to identify the challenging behaviour
- The participants will have the List behaviour problems-CISN and will learn to work with this.

Preparation

- Read Poppes (see section on topics):
- Read Juliet Goldbart's basic text (see section on topics)

Possible scenario for a session plan

| What | Time required | Topics to be covered | How? | Literature/ materials |
|----------------------------------|---------------|-------------------------------------|------------------|-----------------------|
| Review day 4 Theme of the day | 15 min | | Group reflection | |
| Objectives and competencies | 10 min | | Plenary | |
| Programme and work methods | 5 min | | Plenary | |
| What is challenging behaviour? | 1 hr | Definition of challenging behaviour | In small groups | Enablin+ DVD: |

| | | | | |
|-----------------------------------|--------|-------------------------------------|------------------|--|
| Risks and explanation models | 1,5 hr | | Plenary | www.rug.nl/news-and-events/video/archive/unifocus/0525-unifocuspoppes |
| Identifying challenging behaviour | 1,5 hr | The list 'behaviour problems-PIMD ' | In small groups | |
| Evaluation | 15 min | | Group reflection | |

After the Session

Include in your support plan some actions to deal with potential challenging behaviour and prepare a presentation for the follow-up reflection day.

Module 6

Promoting Activities in daily life

Desired Competencies

Knowledge

- The participant has knowledge about implementing learning and developmental activities: music, play, movement, communication, computers, creative expression, language, reading, manual abilities, and sensory-motor activities.

Attitude

- The participant shows an attitude of a “growth mind-set” (belief in potential, and willingness to engage with the child to realize this), is a responsive communicator, shows willingness to be engaged in a true contact, to explore, to change things when needed and to cooperate in a team.

Skills

- The participant is able to integrate and implement the acquired knowledge.
- The participant is able to transform new ideas into actions.

Preparation

- Read the bibliography belonging to module 6.
- Use the handbook as a source of inspiration.

Possible scenario for a session plan

| What | Time required | Topics to be covered | How? | Literature/ materials |
|----------------------------------|---------------|-------------------------|------|-----------------------|
| Review day 5 Theme of the day | 15 min | Reflection in the group | | |
| Objectives and competencies | 10 min | Plenary | | |
| Programme and work methods | 5 min | Plenary | | |

| | | | | |
|--|--------|---|----------------------|--|
| Divide into small groups Every group studies 3 methods or tools | 2 hr | A comprehensive education, activity & participation plan, to be carried out in an inclusive way | Working in groups | Enablin+D-VD: Watch and analyse one of the following videos on the DVD: The hopping path (BE); Koert (NL); Going out (FR); Stefania (IT); Maria (PT) |
| Presentation | 2 hr | The groups come together and present the methods and tools to each other | Presentation plenary | |
| Evaluation | 15 min | Reflection | | |

After the Session

Finish your support plan and prepare the presentation for the follow-up reflection day.

Overview of the video clips used to illustrate good practice

On the attached DVD you will find several movie clips from the involved partner countries. These are illustrations of potentially useful good practice. Not all of the clips meet all of the selection criteria, but together they form an inspiring body of work. The videos are organized by country of origin and are explained here. The content description is followed by some key concepts that describe the clip, some theoretical concepts around which the video can be discussed, and more specific reflection questions that complement the general reflection framework.

The Netherlands

1. Koert – eating ice cream in the park

Summary

In this short video from the Netherlands, we see a boy, Koert, who is in a wheelchair, cannot talk and can hardly use his hands, due to a spastic tetra paretic cerebral palsy, enjoying licking an ice-cream, presented by his younger sister. This scene illustrates many aspects of quality of life of children with CISON. It is just about life: being part of a family, enjoying simple things, and making contact.

Key-words: *inclusion in life*
contact between children
contact with siblings
capability of enjoyment
quality of life

Production: Alberta Roodzant albertaroodzant@comveeweb.nl

Link to the topics

- Quality of Life
- Capability approach
- Communication

Additional reflective questions

- How would you describe the interaction or communication?

- How do you look at this video clip from your professional point of view?
From a parental point of view?
- Why do you think the parents are not intervening?
- How would you look at this fragment from a Quality of life perspective or from a capabilities approach?

2. 'To School Together' classes

Summary

There are two videos from the Netherlands which show "To school together" classes. *To School Together* classrooms make it possible for children with severe disabilities to learn in a mainstream school with support specially tailored to their needs. The children receive exactly the same amount of professional support as they would if they were in a separate specialist institution, in addition to that from the other children and staff of the regular school. They perform a number of activities together, as far as possible. *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. The first video is a general overview of the concept and practices of To School Together classes, made by the NSGK; it has interviews with parents, teachers and care staff. The second video is a particular class in Ridderkerk (near Rotterdam), founded by a mother of a child with CISON. The videos can be used to illustrate many aspects of the integration of care and education of children with CISON: the concept of "participation" and "activity" in practice; how to set up such projects; how to organize them; how children with disability and without disability make contact, carry out activities together and separately, what parents think about it, and how professional support enables the children to function and to participate.

Key-words: *a special education class in an inclusive setting
together to school class
inclusion in education
integration of care and education
group-based inclusion
parent empowerment*

Production:

- NSGK (Nederlandse Stichting voor het Gehandicapte Kind – Dutch Foundation for Children with Disability), Wibautstraat 212-214, 1091 GS AMSTERDAM, tel ++31 20-6791200.
Contact person Mariël Verburg MVerburg@nsgk.nl
more information about the Together to school classes: www.nsgk.nl

- Bram Foundation, Marjon de Vries info@stichting-bram.nl
www.stichting-bram.nl



Link to the topics

- Quality of life
- Capability approach
- Support paradigm
- Inclusive education
- Daily life support
- Continuous support systems

Additional reflective questions

- What happens when children from the mainstream class are participating in any way in the class with children with CISON?
- How would you value this?
- What support is needed for the children with CISON? And for their peers without disability?
- What support is necessary for a teacher or for the school environment?
- How can you contribute from your professional field and expertise to this kind of education?
- How would you look at this video from the Quality of life perspective or from a capabilities approach?

Background information

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 centres. 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, and reading time; you quickly see that children can do a lot together.

It Started in Alkmaar

'To School Together' is inspired by the 'Classroom on Wheels' project in Alkmaar. The instigator, Roeland Vollaard, wanted to break down societal barriers between children with and without a disability, so from 2011 children with and without disabilities have attended mainstream schools together. *"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 foundations 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 were 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 from 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 neighbourhood.

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 first-hand how we are working towards 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 at 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.

3. Laura

Summary

Laura is a 14-year-old girl with very intensive care needs because of a congenital developmental impairment (cystic fibrosis). One of her problems is difficulty with respiration. She regularly has to go to hospital. Doctors didn't know very much about her condition, and were reluctant to do a lot of treatment, assuming that her quality of life was too low to take vigorous measures. Then her mother made a video to show them Laura in various daily life situations: with her family, with friends, at school, etc., to show the doctors that she is "more than her bodily impairments". This video demonstrates the possibility of a high quality of life despite appearances to the contrary. It is accompanied by a song of the famous Dutch singer Marco Borsato, who says it better than any theory could do. The doctors at the University hospital were so moved that they invited Laura's mother to have a talk at a doctors' meeting.

Key-words: *domains of quality of life*
 human capabilities in a child with complex and intensive support needs
 participation in ordinary daily life
 breathing difficulties
 Multiple health problems
 complex and intensive care needs at home
 inter-professional team work
 together to school class: a special education class in an inclusive setting
 prevention of self-harm

Production: Alies Kap, Stichting Gewoon Bijzonder (Foundation "Ordinarily Special"), The Netherlands. stgewoonbijzonder@gmail.com

Link to the topics

- Quality of life
- Capability approach
- Daily life support

Additional reflective questions

- What do you think is important for Laura?
- How do you see Laura's quality of life?
- What possibilities do you see to enhance Laura's quality of life?
- What could you contribute from your professional expertise in the support of Laura and her family? How could you contribute from your own life experience?
- How would you look at this video clip? From the Quality of life perspective or from a capabilities approach?

Background information

Alies Kap⁹, Laura's mother

Hello everybody,

My name is Laura and I am 14 years old. I have seriously complicated multiple disabilities. I do not talk, I am unable to walk and I am not able to eat and drink by myself. I am totally dependent on others. I am not always in full control of my muscles. I'm nearly blind and do not even have 10 % sight. I also have a serious scoliosis, which affects a lung. I have two heart defects and I have to spit a lot. Occasionally I am absent-minded.

As regards my behaviour, I function as a baby; I am still in the so-called attachment phase. Because of that, I need a lot of familiar people and love. Quite often I cannot handle all the stimuli I experience. It frightens me; I get into a stress. I can only deal with stimuli one by one.

If I am able to do something I often do so in an unorthodox way. Then I do not know whether the things I do are dangerous. If I feel unsafe I can seriously hurt myself. Then I pinch and scratch myself, I pull out my hair and eat it. If I feel unsafe for a longer period I disconnect from everything and don't react to anything at all. It is not possible for me to do things by myself, for example any self-care. I am totally dependent on others for everything 24 hours a day, 7 days a week.

⁹ Trained as an MBA financial analyst, mother of four, one of whom having complex and intensive care needs. Works as financial administrator at Foundation 't Gerack, an institution for care. Founder of Foundation "Ordinarily Special" which has set up a "Together to School" class for children with CISEN in a regular school at Uithuizen (The Netherlands)

Because of my disabilities, I am often ill. It is quite a job to keep me healthy and help me through the day in a positive manner. If, for example, I produced excess secretions, I can aspirate – get secretions in my lungs-which can make me so ill that it's life threatening and I need to be taken to the children's intensive care unit by ambulance at great speed. Then I get pneumonia and can't breathe properly. I then lie connected to the "opti flow" to help me to breathe, and the doctors work frantically to get me better again. I am still alive thanks to excellent medical developments like a "mic key button" (for my nutrition), receiving oxygen and medication, in combination with good care from the doctors, the hospital and very intensive home care.

Earlier on it wasn't possible but now, thankfully, it is possible to do a lot at home, but this means that a lot of care and work needs to be done at home.

Still, thanks to the good care, I quite often feel rather fine. I am a very happy and cheerful girl and I enjoy a lot of things. I love to feel the wind on my face and if I hear the leaves rustle I move my legs happily and I feel very glad.

I dearly love my Mum and Dad, sister and brothers and they love me. Quite often I sit cosily on the lap of one of them, and I enjoy their close proximity – that makes me very happy. I especially like Daan when he is running around and loudly screams; then I happily scream along with him. I especially like to play together in the playpen and cuddle.

I was at home full time; it was too intensive, too far away and not adequate enough to go to the special children's day care centre in Visio. Recently, through the initiative of my mother, a nice "together to school class" was made for children like me, which means going to school together with my brother, combined with good care.

Fortunately my dear caretakers often come here. I know them all and I know precisely who is who and they all totally know me. If I am sad and something bothers me they, like my Mum, can react quickly and then everything is good again.

Alida comes to help me mostly in the mornings. She helps me out of bed, gives me my nebulizer on the couch and helps me into the bath. I love this very much and play "knocking games" with her. I knock fiercely on the edge of the bath and Alida then knocks back. I think that is very cool and I laugh very loudly.

When out of the bath I am fed. This is a very slow process but I like it very much. Often we play a little afterwards and then together we read a book, a very beautiful special book of Mum's. I also often "walk" through the room and of course knock again on the window. Ellen the physiotherapist comes along regularly too. With her, I also "walk" and do very nice exercises. Janniene comes in the mornings and afternoons; she also takes care of me. I have my nebulizer, get medication and get a clean nappy. My bottom is sometimes red and great care is taken that it doesn't get worse. My thumb means everything to me; I suck it a lot. This damages the skin which is then taken care of. Everybody takes into account that I want to suck it, so that bandaging doesn't take too long. Janniene also plays with me a lot, we read from the Multi-sensory storybook, get into the "standing up table" or the walking cart. I get totally relaxed and enjoy Janniene's massage in the playpen very much, when I am very sad or do not feel very well. Oh, they know me all too well!

Janniene also takes me to kindergarten. Mum is our taxi driver to kindergarten. Janniene and I play and sing together and in the meantime she takes care of me and keeps an eye on me. I love being in the kindergarten. I enjoy all the sounds and the children and the things we do together. It is conveniently close by. If the weather is good we go 'walking'. If I'm not too well, we only go there for a short while. That is the beauty of living close by.

Trijn sings many songs to me while she gives me my nebulizer. It makes the nebulizing bearable. I sit on her lap safely with a nice soft swaddling blanket around me. I have to use my nebulizer every day, three times a day. This is unpleasant but thanks to the extra care and attention given to me, most of the time this is not too stressful.

Now Liesbeth comes instead of Eline, who is at home because she has recently had a baby. I had to get used to Liesbeth and she had to get used to me. Because of that, things didn't go well at first: I produced excess secretions more often and had a lot of stress. Although Liesbeth works in health care she needed a lot of time to get to know me. Mummy made sure that there was a lot of extra time for that, luckily, before Liesbeth had to take care of me alone. Now I enjoy Liesbeth around me and she knows me much better. Still it is a heavy burden for her to take care of me.

Eline now is home for a short while. Eline has been taking care of me for a long time. She saw me growing up, like Alida. She can hear with every breath I take how I am. Oh, I am taken care of by her so well because of it and therefore I am very relaxed with her. All treatments she repeatedly has to carry out for me are swiftly and subtly done. Mummy also takes care of me a lot when one of them is ill and of course in the evenings and the weekends. It is very difficult for me to fall asleep. Often I am awake for a long time and I also need a lot care during the night. I am troubled a lot by my cystic fibrosis and occasionally spit excessively then my saturation levels drop and then Mummy is there for me. She sleeps close by. Everybody watches me closely. I can get seriously ill quickly which is not nice, but the doctor also knows who I am and quite often she comes to me quite quickly and helps me or calls the doctor in the hospital and then the ambulance.

Everybody is also always very busy with all sorts of care-things for me: medication, diapers, food preparing and feeding, suction of secretions, nebulizing, monitoring my oxygen saturates, moving me about by mobile patient lift (yippie!) etc. etc.

At home

It is so good to live nicely at home in trusted surroundings. Lovely to be with my family who love me best. Because I am after all their daughter and I do badly need a lot of extra care and love. It is great that every time the same people come round, they know me thoroughly. I know who they are and they know me so very well that they can give me the best possible care. In the hospital I lie alone a lot and they don't know me there. I then self-harm: I bite myself, pinch myself and pull out my hair. I then become totally self-absorbed and there are also other things that do not go well. This year I lay fixated in a special bed and I had two bruised legs from the knee and nobody seems to know how long I was lying there being fixated. And then I needed to be on my Mum's lap for a long time before I start to react to outside stimuli. This was awkward for my Mum.

When I am in hospital my parents often visit and babysitters stay at home to take care of the other children or one of the carers comes to visit me.

Because help is available my Daddy can run his own business. He is always at work and is very busy. They phone my father all the time, every hour of the day. He has seen to it that we now have a house that is totally adapted to my needs. I will be able to live there for a very long time. Mummy still works part-time, which she likes very much. Just doing her thing. On top of that she also does a lot of voluntary work. I think she is being inspired by me because she is also in the WMO (Social Support Act) advisory board and is working for the kindergarten. Also she now has founded the “Gewoon Bijzonder” (Just Special) Foundation.

Because I am very often ill and the future is unpredictable, everybody takes care of me and the goal for me is “Make every day a happy day”. Our world is literally and figuratively turned upside down once in a while.

Mummy is seriously “multiply and complexly” worried, she says, because all sorts of powerful people are concerned with PGB (Personally Allocated Budget) and she does not know yet what that will mean for me. If she phones them for confirmation she is sent from pillar to post time and again. I find things work best as they are organized now, exactly right for me and my family. But I know for certain that Mummy does her utmost to organize matters in the best possible way for me, because she always does.

Love Laura

4. Villa Clementina

Summary

Villa Clementina is a nursery centre for young children (0-6) with and without special needs, which opened in January 2013. It is a pioneering centre in Belgium. It was founded by three energetic and inspiring ladies: a former estate agent, a paediatrician and a special needs psychologist, whose dream was to develop an innovative model of care and support. They first wanted to respond to the local needs of a regular nursery, but also took on board some children with disabilities, some of them having very intensive care and support needs. They have a regular and specialized support staff. The contact between “typically developing” children and their peers with disability creates a very special effect on all parties. The video is relevant because it shows how inclusive initiatives can be created “from scratch”, when involving many people in the community, if you start from a commonly felt need. Now the first children have “grown out” of the nursery age, there is a need for them to go to school. Because the advantages of inclusion have been acknowledged by everyone concerned, the parents and staff wanted to create a follow- up inclusive schooling project, based on the “to school together” class model, from the Netherlands. The Minister of Welfare and of Education noticed the importance of such a project and came along for a visit.

Key-words: *inclusive nursery*
early intervention
integration of education and care
organisation of inclusive care

Production: Libelle TV, reproduced with permission.

Link to the topics

- Support paradigm
- Inclusive education
- Daily living support
- Organisation of continuous support systems

Additional reflective questions

- Why is it a good idea to start with inclusive care centres for children at this young age?
- What support do parents and caregivers need, to think and work in an inclusive care centre?

- How would you look at this video clip, from the Quality of life perspective or from a capabilities approach?

Background information

Kathleen Ballon¹⁰ , Mieke De Strooper¹¹ & Katia Verhaeren¹²

Villa Clementina is a day care 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.

There are 7 places daily for 11 children with special needs, and 15 places daily for children who are “typically” developing.

They work with pre-school aged children: typically developing children normally start at school at age 2years and 6months. Children with special care needs have the possibility of staying until the age of 6 years.

The staff team consists of 5 full time equivalents of educators, a nurse, a paediatrician, a remedial educationalist, physiotherapists, a speech therapist and 16 volunteers.

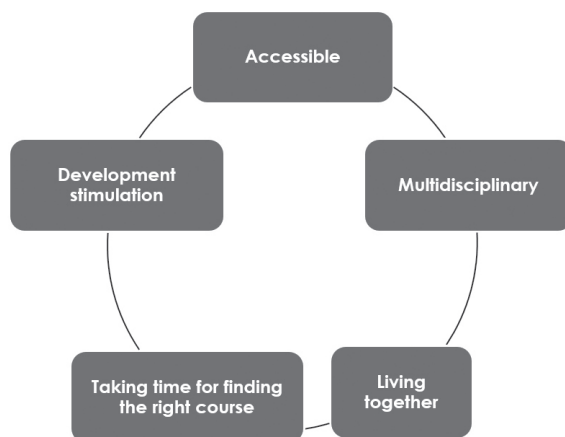


Figure 4 principles of Villa Clementina

The work is based on a number of 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

¹⁰ Paediatrician, University Hospital Leuven (BE), Centre for Developmental Disabilities

¹¹ Special needs psychologist, University Hospital Leuven (BE), Centre for Developmental Disabilities

¹² Director and founder of Villa Clementina, Zemst Belgium

- Giving time for acceptance
- Offering a stimulating environment
- Working together in a network
- Giving parents the chance to go to work, to study,

Another aspect is the goal of education. 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. The project receives some subsidies from the government, which are, however, largely insufficient to cover all costs. Therefore it depends on a lot of fundraising events.

Children play in vertical groups (all ages/with or without special needs). Typically developing children enjoy the stimulating environment and multidisciplinary team and learn that there is diversity in our society. Children with special needs have an individual programme with speech therapy and physiotherapy. This programme is at their pace, in the peaceful space of Villa Clementina. Often they have therapy together with typically developing children.

The therapists share their knowledge (e.g. advice concerning feeding difficulties, alternative communication, positioning in orthoses, ...) with the rest of the staff. At regular times there is also individual contact with the parents to discuss progression and prognosis.

The 'inclusive school project' is also very innovative : they strongly believe in the strength of and the right to 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 > 2 years 6 months via an individual and goal-directed programme, collaboratively, with the speech therapist.

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 avoid the need for long distance travel to specialized schools or day care centres.
- To stimulate special needs children intensively but at their own rhythm, in a green and safe environment.
- For a multidisciplinary team to stimulate typically developing children e.g. every child can enjoy hippo therapy, themed 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 of persons with disabilities
- For our young adults with a disability (but also for the other members and volunteers of our staff) we work with 'talent management'
- By organizing inclusive events we hope to create an ideal space where everyone has his own talents and gifts.

Activities

Activities: weekly themed classes organized by our teacher and speech therapists, hippo therapy, creativity class, ...

Achievements

Villa Clementina has been running now since 4 years. In this time it succeeded to set up and operationalize the most inclusive child day care centre in Flanders. It attracted the government's attention and they invited them to be part of a think tank 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 centres 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.

Sustainability and growth

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 service, 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' or the 'Department for persons with disabilities' wanted to release any subsidies; 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 centres. However, not enough to cover the running costs.

Another big problem was to convince the professional field. Luckily scepticism has turned to enthusiasm!

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

More information:

www.villaclementina.be (in Dutch)



Villa Clementina

Geïntegreerde en inclusieve dagopvang voor
jonge kinderen met en zonder beperking

5. The Hopping path, an inclusive kindergarten

Jo Lebeer¹³, Beno Schraepen¹⁴, Inge Wagemakers¹⁵ & Luk Dewulf¹⁶

Summary

The “hopping path” shows the inclusion of a 6-year old boy with complex & intensive needs in a regular kindergarten. The movie was filmed during three successive years. It is built on presenting first the child “as a child”; then it presents the different circles of support around the child (family, school, educational support team, therapeutic support team). The video shows most of the issues which arise when including a child with complex support needs, and how these are dealt with through teamwork between teacher and supporting experts; also by the classroom peers, who spontaneously assist with mobility (e.g. pushing the wheelchair), feeding, playing together, doing activities together. It also shows how communication is enabled; how classroom tasks can be differentiated. Team discussion is also recorded, where teachers talk frankly about the “joys and pains” of the inclusion process, and finally, a day at the seaside illustrates how outings can be made successful, despite practical challenges.

Key-words *inclusive education at kindergarten age*
integrating care and education
circles of support
role of classroom teacher
role of teaching assistant
involving students
role of supporting therapeutic professions: physiotherapist, speech therapist, occupational therapist
mobile team
peer mediation
playing together
augmentative communication
promoting mobility
stimulating development
zone of proximal development
task differentiation & adapting tasks
interprofessional teamwork
experience of teachers

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14 MA in SEN, lecturer at University College AP, in disability matters; scientific collaborator at University of Antwerp, coordinator of INCENA, study centre for inclusion & enablement.

15 PhD in Development Studies, researcher and expert equal education opportunities, investigative journalist for broadcast media

16 Investigative journalist and director for broadcast & online media and print

Production: Luk Dewulf, media production house “De Seizoenen” (the Seasons)
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Link to the topics

- Quality of life
- Capability approach
- Support paradigm
- Communication and intentionality
- Inclusive education
- Promoting inclusive activities
- What kind of educational activities for children with CISN?
- Daily life support
- Organization of continuous support systems

Additional reflective questions

Reflective questions are included in each video. It’s recommended that students watch a video, write down the questions and pause after each clip to discuss the questions and explore the content. Each video can be used as a self-instruction video.

Background information

K. is a 6-year old boy. He is sociable, loves to play with other children, and loves being active. 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 Cerebral Palsy (CP) and multiple disabilities. He has severe difficulties in language expression (he speaks a few words and uses gestures to make himself understood), with mobility (he cannot walk alone; he is able to sit and stand with support; he has severe difficulties in hand/eye coordination so that drawing, eating, playing are difficult); he is dependent on others for all daily activities and needs permanent support.

The video shows K. in various situations at school, where K. learns a lot and he is challenged. The school is also the place where K. is “receiving” all his therapies. In Belgium, it is still exceptional that so much therapy is organized in a regular school. There is an inclusion law, but the official system of support falls short¹⁷. Just recently,

17 For an overview of current support systems, see Lebeer, J. & Neerinx, H. (2017). The Report WP2-Deliverable 4 can be downloaded from www.enablinplus.eu

the Disability Agency allowed the Care institutions to set up “mobile outreach teams”, who are allowed to work at home and in schools. Despite this scarcity in official support, K’s trajectory proves that inclusion is feasible, thanks to the good will and energy of many people around him.

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 into 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 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. The speech therapist also 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 are doing, he wants to imitate and do 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. K. is the first child with this degree of complex needs in that school. The teachers adapted the activities so that K. could join in with the group. Children spontaneously help each other, play together, help him with eating, with pushing his wheelchair, etc. For a lot of the school time there was an extra adult to give support; professionals and students. 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.

The video shows various situations in the class (welcoming, play, mealtimes, gym lesson, staff meetings, and a day at the seaside). 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; and how to set up teamwork.

6. Les enfants de l'école – a special unit in a regular school in France

Summary

This film shows an example of an outsourced teaching unit organized in a regular school for children with very complex and intense support needs. The children stay in a medico-pedagogical care centre and go to school part-time. Up till recently, most of the children with 'polyhandicapé' – as they are called in France – would spend most of their lives in separate care institutions. In the transition to a more inclusive society, this video shows pioneering work of “opening up” to society, in both directions.

Key-words *a special education class with children with multiple disabilities in a mainstream primary school*
outsourced teaching unit
inclusive education
integration of care and education

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Link to the topics

- Human rights approach
- Inclusive education
- Promoting inclusive activities

Additional reflective questions

- How are care and education organised? What is needed to get this kind of education organised?
- How would you value this?
- What happens when children from the mainstream class are participating in any way in the class with children with CISN?
- What support is needed for the children with CISN? And for the peers without disability?

- What support is necessary for a teacher or school environment?
- How would you involve the parents of the peers without disability?
- What possibilities and obstacles do you see?
- If you should support or work in this kind of project, what do you see as possible? How can it be more inclusive?
- How would you look at this clip, from a Quality of life perspective or from a capabilities approach?

Background information

Florence Bergamasco¹⁸, Lauratie Krouit¹⁹

ADAPEI de la Corrèze²⁰ 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 learning that could not have happened elsewhere, such as in a residential care facility where conditions for assis-

¹⁸ Director of Children's Services ADAPEI de Corrèze

¹⁹ Teacher (National Education)

²⁰ 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.

tance and care are more favourable, but where learning opportunities are lacking.

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 CLIS²¹ of Louis Pons and individually for some.

21 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.

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.

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.

7. Going out – how the SESSAD helped a child to leave his house for the first time

Summary

This is a short piece of film showing a boy whose difficulties are of such a degree, that he was not able to leave his house; he was confined to his bed, dependent on constant care. With the help of the SESSAD, a centre for home-care and support for children with disability, you can see how the challenge to allow the boy to sit up and go out is taken on. His mother admits that she was very afraid. Going out in the park opens up a new world for this child. It shows how “small things” can have a huge effect, to change the quality of life to a higher level. Many people cooperated to realize this outing.

Key-words *Home-based support team*
SESSAD (service for education and care at home)
interprofessional collaboration
enabling activity and participation in a bed-ridden child
dealing with pain
changing posture
micro changes

Production CESAP FORMATION DOCUMENTATION RESOURCES
Comité d’Etudes,
d’Education et de Soins Auprès des Personnes
Polyhandicapées
62, rue de la Glacière – 75013 Paris
Tel ++33 1 53 20 68 58
www.cesap.asso.fr – formation@cesap.asso.fr



Link to the topics

- Quality of life
- Capability approach
- Communication and intentionality
- Daily life support
- Organisation of continuous support systems

Additional reflective questions

- How can we consider this as a first step towards inclusion?
- What would be the next step?
- What does this mean for the quality of life of the boy?
- What aspects of quality of life should be focussed on next?

Background information

Eric Zolla²², Christine Plivard²³ & Anne-Marie Boutin²⁴

The Services for Education and Care at Home (SESSAD – Service d’Education Spéciale et de Soins à Domicile) have a legal recognition in France, in their current form since 1989. SESSAD professionals (social workers, allied health professionals) visit children in their school or at home.

CESAP (*Comité d’Etudes, d’Education et de Soins Auprès des Personnes Polyhandicapées*) manages 9 SESSAD.

The mission of these services is set out in French law:

- early care for children from birth to 6 years, with advice and support of families in the familiar surroundings of the child, to refine the diagnosis, assess the initial psychomotor development of the child and to prepare for future collective orientation
- support the integration or acquisition of autonomy with medical, paramedical, psychosocial, and educational intervention and adapted teaching

CESAP wanted the SESSAD’s to offer a window on the world. The establishment of an inclusive policy allows parents to leave their isolation on the one hand and on the other hand, to try to preserve socialization in the mainstream, inasmuch as the child’s capacity, location, and their impairments allowed. But the SESSAD’s also helped families to accept, longer-term, transition to a specialized, better adapted setting, if deemed necessary.

22 Assistant Director General of CESAP (Study & Training Centre for People with Polyhandicap), Paris, France. He has a DESS degree in Cognitive Ergonomics, DEA of Sociology, DESS Social Policy and Management Strategy

23 physiotherapist with a specialisation in Psychomotor therapy and Master in Training Engineering. She is Director of training, documentation, and resources at CESAP (Study & Training Centre for People with Polyhandicap), Paris, France

24 Retired paediatrician who is part of the CESAP team

8. Assistive Communication

Summary

A child with cerebral palsy who cannot speak is assessed in her communicative abilities. After exploring various AAC (Augmentative and Alternative Communication) solutions, an eye-tracking system operating a Tobii device is explored

Keywords *augmentative & alternative communication*
assistive speech & language technology
Tobii eye-tracking device

Production: ASFA (Association St François d'Assise), Isle de la Réunion, France.
Contact person: Marlène Grégoire, Cem Sainte Suzanne.
marlenegregoire@yahoo.fr

Link to topics

- Communication and intentionality

Background information

Marlène Grégoire²⁵

The need for communication is a priority in the daily life of human beings. So, it is our mission as therapists and carers to answer that need. Children with CISN (Complex and Intense support Needs) are not always capable of oral communication due to intellectual deficiencies, organic causes, etc. So it is important to find tools that allow access communication via “augmentative and alternative communication”. Augmentative means: to enhance and expand more communication ways, e.g. adding gestures or pictures. Alternative means: when one mode does not work, to look for substitutes.

²⁵ occupational therapist, graduate of the Institut de Formation en Ergothérapie (Montpellier – France), working in an Institute for disabled children (Centre D'Education Motrice – Association Saint François d'Assise – Reunion Island – France)

There are now computerized voice output devices, which are efficient tools for our population – even if they are expensive. In the video you will follow the journey taken by Mariame, a girl with tetraplegic cerebral palsy, who cannot speak. She attends the “motor education centre” (CEM) of the St Francis Association ASFA on Reunion Island, France. In the video you see her from the beginning, her attempts to communicate, the process and training at different levels, the exploration to find out which communication device would be most suitable, and finally discovering how to enable her to use a communication device that is controlled by her eyes, the Tobii Dynovox Communicator 5.

Mariame is a young girl of 15 years old, born pre-term at thirty six weeks, weighing 2.6 kilograms at birth. She was born in Madagascar in a context of consanguinity. She has a spastic tetraparesis with multiple disabilities. Different events in her life have worsened her condition (traumatic brain injury, reaction to antibiotic treatment.) She has received enteral nutrition since 2008 and had spinal fusion in August 2014. Mariame uses a manual wheelchair. She is dependent on carers for her daily living activities (mobility, toileting, personal care). She cannot articulate her speech but uses a reliable code for yes/no with her eyes.

Device Information: Mariame uses the Tobii Dynovox Communicator 5, a software package designed to help individuals with communication disabilities. It works on computers running Windows 7/8/8.1/10 and Microsoft Surface. Website link: <http://www.tobiidynovox.com/>

9. La Vie c’est Comme-ça? l’inclusion à travers les arts (Life’s like that. Inclusion through art)

Summary

This video documentary follows a few youngsters with disabilities, who are hosted in the social medical disability hub of ASFA. Some of them have multiple disabilities. ASFA invests a lot in artistic expression and tries to involve all children. They created several pieces of music that have been shown to the public. The film follows the ASFA-created theatre group ‘Tipas Tipas’ (which is creole language for ‘small steps’) whilst preparing a performance at the famous summer theatre festival in Avignon (France). The project has been beneficial for the youngsters as well as for their carers.

Key-words *working with music & artistic expression*
 art therapy
 inclusion through art

Production: ASFA (Association St François d’Assise), Pôle Médico-Social et Handicap, Ile de la Réunion, France. Marika Rieth, Coordinatrice Art et culture marika.socha@asfa.re

Link to topics

- Promoting inclusive activities
- Activities through art

Additional reflective questions

- What is the value of art, artistic or creative activities for the development of and the quality of life of a person? What is the value for you as a person?
- Why in particular is this of value for people with disabilities? What is the potential of these kinds of activities?
- How are art, artistic or creative activities part of your support of children with CISM?
- What is needed to support children with CISM in or towards these activities? What barriers do you see?

Background information

Marika Rieth²⁶, Nacer Djoudi ²⁷, Elisabeth Houot²⁸

The social-medical disability hub of ASFA hosts 3 to 20 year old youngsters with mobility- and intellectual disabilities or 'polyhandicap' (multiple disabilities). ASFA has a great emphasis on activities related to "art & culture". Its aims are: to enhance the youngsters' artistic potential (creative abilities, memory...), to promote their aspirations and use art as a means of expression; to promote their personal accomplishments by valuing their differences, and to experience the demands of various arts. All this serves to promote social inclusion.

It also aims to train support staff to help with inclusion through art and culture, to develop individual and collective competences with training and support. One of the main goals of ASFA is to increase inclusion in cultural and artistic domains, by initiating and sustaining partnerships with mainstream services. This requires creating high quality, innovative artistic projects, to demonstrate the creative and artistic capacities of the different people. We also want to raise the awareness of the general public.

By using the arts as a tool for inclusion and enablement for people with disabilities, the social-medical department and the ASFA Association, , affirm a certain institutional dynamic. It strives to reinforce measures taken for the inclusion of people with disability into society.

²⁶ Coordinator arts and culture ASFA and film director

²⁷ Director Social-Medical Disability Pole, Association Saint-François d'Assise (ASFA), Réunion (FR)

²⁸ Former Deputy Director of the Centre for Motor Education (Centre d'Education Motrice) ASFA, Réunion

These workshops and their public appearances are also an occasion for the youngsters 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. 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, ...).

Structuring the system of the socio-medical department

System implementation for the 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.

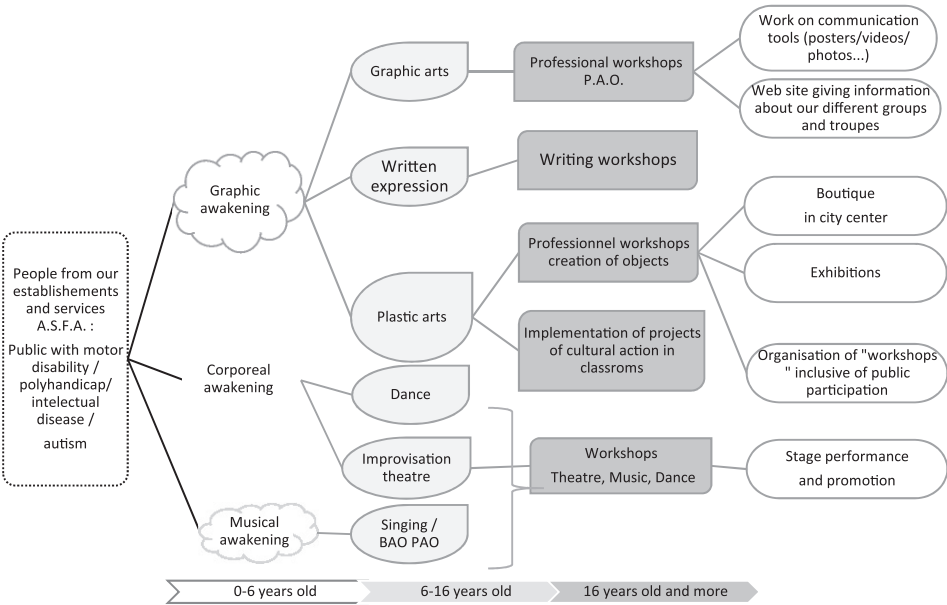


Figure 5 Process of inclusion through art and culture

Development and creation of artistic projects

The realisation of a project requires a network of partners to facilitate, organise and promote this. Thus, meetings and interviews are necessary to introduce the projects to the various role players who will eventually co-build the project. Our aim is to sustain this partnership and to enhance our work to access cultural and leisure activities in the mainstream environment. This project needs to promote an awareness of disabilities aimed at:

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

Inclusive artistic projects

From workshops to shows

The work carried out in workshops can provide the youngsters with the desire and the competence needed to integrate their skills into a show project. Selection is based on casting, as it would be in any 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 together and rehearse for the period of time required to produce the show.

Promotion of the show

Our aim is to perform in front of large public audiences, in famous venues, at festivals and at other public events. The final step is to find venues, to promote the show and to sell tickets by disseminating information through the creation of posters and press kits. The project can also include a way of evaluating its progress through a video documentary that can keep 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



10. Bridging the Gap between therapy and inclusion

Summary

This video shows the work of the Karin Dom Centre of Varna, Bulgaria. Part 1 follows a girl with multiple disabilities (she lacks speech and has frequent epileptic attacks) due to a rare genetic condition, assisted by Karin Dom's Early & Home Intervention team. She is included in a mainstream kindergarten. Part 2 follows two children with spastic quadriplegic cerebral palsy in a Montessori kindergarten therapeutic playgroup.

Key-words *comprehensive management of children with multiple disabilities;
early intervention;
home-based support team;
integration of care and education;
inclusive education in kindergarten age
making Montessori pedagogy suitable for children with multiple
disabilities
adapting activities
multisensory approach
interactive books*

Production Karin Dom Centre, Mestnost "Sveti Nikola", P.O.B. 104, Varna 9010,
BULGARIA
Creation: The training movie was created by Zvezdelina Atanasova &
Stanimira Atanasova.

The movie uses footage from the private archive of Karin Dom as well as footage from the movies "Karin Dom – 20 Years Ambassadors of Goodness" and "Karin Dom – Together at the Kindergarten". All rights for distribution of the video footage included in the movie belong to Karin Dom.

Link to topics

- Human rights approach
- Quality of life
- Capability approach
- Support paradigm
- Inclusive education
- What kind of educational activities for children with CISEN?
- Organization of continuous support systems

Additional reflective questions

Kalina's fragment

- What do you think are the family's needs?
- How would you describe Kalina's needs?
- How does the centre support the family?
- How do you see the inclusion of Kalina in a mainstream group?
- What could goals for Kalina's future plan be?

Maggie & Chrissy's fragment

- How do you connect with what Chrissy and Maggy are doing? How would you value this?
- How can therapeutic activities be organised in daily or school activities?

Background information: Bridging the gap between therapy and inclusion

Zvezdelina Atanasova²⁹, Andreas Andreou³⁰, Nikoleta Yoncheva³¹

Part 1. Shared by a parent

In the beginning of this video you will hear the story of Iliana Panchovska. Iliana is the mother of Kalina, a child with a complex, rare diagnosis: "Other types of generalized epilepsies, frequent seizures which are resistant to treatment. Point mutations in the CDKL5 gene". CDKL5 is a rare X-linked genetic disorder that results in early onset, with difficult to control seizures, and severe neuro-developmental impairment. There are 122 children with this genetic variation in the world, 106 of them girls; only 2 can walk and Kalina is one of those 2 girls.

When Kalina's family realizes that their child has developmental challenges, the initial stress turns into shock. The first step towards supporting Kalina is supporting her family:

- Early childhood development consultants from Karin Dom Centre begin visiting Kalina's home and support the family to adapt to the special needs of their child in everyday life.
- Kalina does not speak and does not know how to express her needs and desires, her parents are having difficulties understanding her. The consultants provide the necessary guidance.

²⁹ special needs teacher, speech therapist, Director of Karin Dom Training Centre, Varna

³⁰ physiotherapist, trainer at Karin Dom Training Centre, Varna

³¹ speech therapist, special teacher of deaf/hearing impaired, trainer at Karin Dom Training Centre, Varna

- Parents are trained to meet the needs of Kalina in the best possible manner without neglecting their own needs.
- Cooperation between parents and specialists is the key to success when it comes to the development of the child. Following the principles of a family-oriented approach, the specialists focus on the family's innate strengths and resources, and build trust in their relationship.

When she was 2 years old, Kalina began visiting the Karin Dom Centre for therapy. In the video we see part of a therapy session in which Kalina learns to play with toys, to understand causal relations, to participate in role-playing games, to give eye contact, to communicate and to smile.

This is preparation for the next important step, Kalina's inclusion into a group in a mainstream kindergarten. This is how we support the inclusion process:

- Parents make an informed choice of an appropriate kindergarten; they can consult and discuss options with the child's therapists at Karin Dom.
- Kalina slowly adapts to the new environment. She continues to visit Karin Dom and becomes more and more successful in applying what she has learned here in the games with her kindergarten friends.
- The therapeutic sessions at Karin Dom are open to the teachers from her kindergarten, to the resource teachers and support assistants. The specialists from Karin Dom share with them methods and approaches that can make Kalina's daily activities more effective and demonstrate how to support her in a manner that stimulates her independence.

The work with the parents continues; they actively participate in all interventions and continue to build their competencies. The goals we have set together with Kalina's parents are related to her becoming more independent and achieving the highest possible quality of life.

Part 2. Maggie and Chrissy

The main participants in the next part of the video are Maggie – a smiley young girl, and Chrissy – a patient young boy.

Chrissy is 6 years old, diagnosed with cerebral palsy, severe spastic quadriplegia, hydrocephalus and epilepsy. He eats through a nasogastric tube. He has a neurogenic bladder that is enlarged and is painful when full. His temperature often rises. He is moved around in a special wheelchair or is carried by an adult.

Consultants in early childhood development from Karin Dom started visiting Chrissy's home when he was 13 months old. Over the next three years rehabilitation and speech therapists have taught his parents how to position and feed Chrissy, how to communicate and play with him. In 2014 he began attending Karin Dom for therapy and inclusion in groups with other children.

The long-term goals we have set together with Chrissy's parents are to improve his ability to understand speech and to expand his communicative skills – to use a gesture to indicate “yes”, to get involved in a small group of children, to strengthen the muscles on the neck and torso.

Maggie is 5 years old, diagnosed with cerebral palsy. Spastic quadriplegia – mixed form; Convergent strabismus; Symptomatic epilepsy; Parents move Maggie around in an adapted stroller.

Maggie and her family also receive home visits by consultants from Karin home from an early age. In the autumn of 2013 Maggie began therapy at Karin Dom; she is progressing rapidly and is successfully included in groups to develop her skills in communication and interaction with other children. These combined efforts led Maggie to a kindergarten group for general education children, where she found many new friends.

The goals we have set together with Maggie's parents are for her to make progress in the following areas: motor, speech development and social skills in order to achieve greater independence. The main focus will be on communication, fine motor skills, expanding the notions of colour, shape and size, achieving spinal symmetry and strengthening her muscles.

Physiotherapy

An average day for Maggie and Chrissy starts with physiotherapy. For Maggie, the goal of physiotherapy is to achieve symmetry of the spine and to strengthen the muscles on her torso and neck. First, the therapists relax the muscles in Maggie's left arm, and then they place an arm splint on her, and start working on the lower limbs and body.

Physiotherapy sessions prepare the child to be seated in a special chair, to lift and hold her head up, to cross the midline (bilateral coordination) and to use her hands while participating in activities with other children later during the day.

For Chrissy it is important to conduct exercise which promote flexibility and avoid increased deformities, and to work on strengthening of the muscles of the torso and neck thus improving head control. The therapists use stretching and passive movements for upper and lower limbs. Such movements prompt Chrissy to be vocal. Maggie and Chrissy make emotional contact with the therapists.

After the physical therapy the children are placed in special chairs in which they feel comfortable during the group activities.

Inclusion in a Montessori group

In Karin Dom we have a pre-school group held in a Montessori environment that is open to both children with typical development, and children with special needs.

he group gives us a unique opportunity: in parallel with the therapeutic work we are able to work towards inclusive education and children with intense and complex support needs can be together with their peers. We have designed this opportunity as a stepping-stone towards larger groups in kindergartens and schools.

Maggie and Chrissy have already made friends in the Montessori group. These are the charming Ms. Miriam (Mimi), and young Mr. Andrew.

Games: aromas, cylinders and balls

Mimi has chosen to show Maggie and the rest of the group the new little boxes and flasks with different aromas. Meanwhile, the boys are “driving” around in a car. The speech and the physical therapists assist Maggie and Chrissy during the play by verbalizing the action to improve the children’s understanding of what is taking place.

Maggie and Mimi work together with a box filled with cylinder shapes in red, in various sizes that they can feel. The kids learn how to take turns, to wait when the shapes are moved, to interact.

Chrissy and Andrew play with little wooden balls. Chrissy learns how to take and drop the balls, while Andrew is carefully putting a ball in Chrissy’s hand. Andrew waits for his turn and counts the balls. While playing the children are making eye contact; with his eyes Chrissy tracks Andrew’s movements.

Modelling clay

The girls find the joint game with the modelling clay interesting, and the speech therapist encourages communication. Mimi explains to Maggie in detail where and how to make dots and is more and more skilful in holding her hand to help her. Maggie’s smile expresses the joy of the cooperative play. The children’s fine motor skills and focus are improving.

Interactive books

The interactive book in the video is on the topic of “Animals living in the forest”. Children take turns to switch the cards and push the buttons in the book. Maggie and Chrissy cannot imitate the sounds made by animals, but the book allows them to successfully participate in the game, and to enrich their cognitive skills regarding the various animals living in the woods.

This is a favourite activity – note that Maggie and Chrissy stay focused throughout the game with the book. At the same time we exercise the isolated movement of a single finger and improve fine motor skills.

Drawing onto a transparent surface

The session continues with drawing onto a transparent surface. Children truly have fun while drawing opposite each other and we see a lot of smiles. Miriam and Andrew are naming what they are painting – clouds, sun, grass.

Maggie and Andrew have discovered a new game: they mirror each other while drawing. Notice how Maggie, assisted by the therapist, follows Andrew’s movements with the coloured felt-tip pen; see how happy she is with their interaction and play.

Chrissy joins the kids in drawing after he has finished playing with his soft tactile book. Therapists work towards the correct grip of felt-tip pens. Cleaning the board in the end became the theme of a song by Mimi.

Work in small communicative group

In order to be active, Maggie and Chrissy put a lot of effort into other sessions as well, with other kids.

Through working in a small group, children with CISN receive the basis for communication and interaction. In this group, Maggie and Chrissy gradually started paying attention to the fact that there are children around them, not just adults. Participants in the groups learn to use and recognize alternative methods of communication – gestures, communicators, smiling or blinking.

In the video we see Maggie and Chrissy learning to use a communication device to get involved in telling the story of the hedgehog. They listen to a song with other children. Chrissy is getting better and better at holding his head upright, turning it towards the direction of a noise; during the activities he reacts with a smile, he is vocal.

For each child in the group there is a box prepared containing sensory stimuli associated with the story; you can see two of those boxes on the ground. Offering a variety of sensory stimuli in a certain order aims to improve sensory development and build a routine in which children feel safe and relaxed. Maggie, in turn, is more confident when counting to four, she has remembered the sequence in the fairy-tale and anticipates every following scene in it.

Musical activities

The advantages of creative therapies are seen in the following areas: imagination spontaneity, objectiveness, permanence, creative and physical activity and the possibility to use all these successfully with children of different ages and different clinical backgrounds.

In order to participate successfully in favourite musical activities, each child is assisted by an adult who supports their movements. When playing the drum, children clearly feel the rhythm and they try to convey that. Of course, if someone is having difficulties, friends are always there to help. Mimi is very eager to help every child and assists with the drum; children react positively, smile and make eye contact with her.

Thanks to the planned musical activities, Chrissy and Maggie are getting used to loud noises and are startled by them less and less frequently; this will help them remain more relaxed in different noisy environments such as the playground, the kindergarten, the store and others.

At the end of the musical session we see how Miriam says “Goodbye” to Chrissy by caressing him with affection.

In conclusion

Maggie and Chrissy’s parents are happy with their progress, how they regularly participate in sessions and successfully apply what they have learned at their home as well.

Both the therapists and the parents expect children to: continue expanding their sensory experiences and understanding of their environment; to initiate communication with adults and children; to participate in new activities for the development of adaptive and social skills; to be included in general education kindergartens and schools.

Acknowledgements

We would like to thank all colleagues from Karin Dom's team, who readily joined the filming of the movie. We are grateful to the children and their parents for their sincere desire to take part in the training movie and thus give their support to other children, parents and professionals whom the DVD will reach.

11. Stefania e la sua classe (Stefania and her class)

Summary

The clip is about inclusion of a 14-year old girl Stefania, who has multiple disabilities (severe communication, mobility and cognitive impairments) due to Rett syndrome, in a regular middle school in Trento (Italy). With the help of the support teacher and peers, the video shows how the classroom task (making a summary of a novel) can be adapted to involve Stefania in a meaningful way. Peers also help with augmentative and alternative communication aids.

Key-words *inclusive education in middle school*
augmentative and alternative communication
role of support teacher
task adaptation
peer support
peer mediation
integration of children with Rett syndrome

Producer: *Il Ponte, Cooperativa Sociale, Rovereto – Trento – Italy*
Website: www.ilponterovereto.it; info@ilponterovereto.it
<http://www.ilponterovereto.it>

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 Nagley Bertoldi, Milano, for translations

Link to topics

- Capability approach
- Support paradigm
- Communication and intentionality
- Inclusive education
- Promoting inclusive activities
- What kind of educational activities for children with CISON?

Additional reflective questions

- How would you describe Stefania based on what you see in the classroom? What support does she need? What resources are needed?
- Can you think of other specific tools that can be used to enhance communication, learning and/or participation?
- How would you adapt tasks?
- What do you think the other children need in order to include her in the group? And the teacher?
- How can a teacher integrate the necessary support in her education?
- What could be a next step?
- What other resources or tools could be activated or designed?
- How would you describe the status of Stefania in the group?
- Based on this video, how would you construct learning activities for children with CISN.

Background information: an example of inclusive education in Trento

Gabriele Baldo³², Barbara Bettini³³, Patrizia Lucca³⁴

This video shows just a part Stefania's inclusive education project. This particularly challenging inclusion project has been made possible through the creation of an institutional network, involving the school, the Independent Province of Trento, the Observation Diagnosis and Training Laboratory at the University of Trento, the Provincial Institute for Updating Research and Educational Experimentation, as well as a Social Cooperative Association "Il Ponte" (The Bridge) in Rovereto. The network has given life to the 'Autism Project' (created with the aim to manage the inclusion and the participation to school life of children with autistic spectrum disorders and similar impairments). The project took place in different phases. First we focused on building a relationship between the educator and the child. Then there was an observation stage, which was more systematic in order to identify critical and positive points. The following phase explored how to structure the environment. We then proceeded to the next phase: how to define the didactic objectives. Stefania improved at various levels. The video shows how much importance is given to the active participation on behalf of her classmates, who facilitated reciprocal exchanges and motivated Stefania to participate and to learn, and how this feature determined the success of the project.

³² Psychologist and psychotherapist at the ODF lab, University of Trento and "Il Ponte" Cooperative Association

³³ educator at the "Il Ponte" Cooperative Association

³⁴ Istituto Comprensivo Trento 3

Who is Stefania?

Stefania is a fourteen-year-old girl who has Rett Syndrome. This is a severe genetic disease that involves cognitive impairment, impairment of motor skills, as well as social and communicative impairment. Stefania has a severe muscular hypotonia and does not speak. She talks by using some facial expressions (she squints her eyes and looks upwards to say yes) or by indicating images and symbols with her eyes.

Explanation of the various stages of the video

This video is an example of inclusion of a girl (affected by a serious genetic disorder) in her class. The classmates are personally involved in helping her participate in class activities and are encouraged by the teacher to relate to her in the most appropriate manner.

In particular, the teacher gives a task to the entire class: they have to read a book ("White as Milk, Red as Blood" – by Alessandro D'Avenia) and summarize it. The students have to divide into groups, discuss the book and prepare a presentation for the class. Stefania, like everyone else, carries out this task with her classmates.

In the first scenes of the video, we can see the teacher giving the class the task to be carried out. On this occasion Stefania expresses her preference (helped by her teacher and classmates) to prepare a presentation, like everyone else, with her group in front of the class and not only in the presence of her teacher.

The following scenes relate to the moment when Stefania takes part in the creation of the billboard, summarizing the book, along with her teacher and the classmates of her group. To do this, flash cards/pictures are presented to Stefania and she chooses them by pointing to the pictures with her eyes.

Her classmates are very zealous at this point and help Stefania to list the main features of the protagonist and to summarize the main characteristics of the protagonists.

The next step is a meeting between Stefania and her teacher, where they transfer the pictures to the computer, so that she can study and memorize them better.

Then Stefania and her team commit themselves to the finishing touches on the poster, which is to be presented to the class. At this stage, Stefania takes part in choosing the information still to add, always communicating with the help of her classmates and by using her eyes.

In the last part of the video, we can see the presentation of the work done in front of the whole class. One of Stefania's classmates shows the poster and explains how it was created, as she carefully watches and is proud of herself.

12. Maria: welcoming a child with Angelman syndrome

Summary

This video shows various classroom situations of the inclusive education process in a primary school in Évora (Portugal), which is triggered by the participation of a girl called Maria, who has severe communication, mobility and cognitive problems due to Angelman syndrome. Nevertheless, she fully participates in school life, supported by many people involved: classroom teacher, special needs team, peers. The video also shows how inclusion is a process of constant exploration, how to improve activities and participation to realize full potential, not only for Maria, but also of everyone involved. Moreover, it is an example of how inclusion is a community-based process, right up to political decisions, in organising a continuous support system.

Key-words *inclusive education in middle school;
full inclusion
augmentative and alternative communication;
PECS (picture exchange communication system)
role of support teacher;
comprehensive ICF-based functional, activity and participation
assessment
task adaptation;
peer support;
peer mediation;
interprofessional collaboration
integration of child with Angelman syndrome
continuous support system*

Production Agrupamento de Escolas de Portel, Ana Paula Antunes, Ana Rita
Gião, Maria José Saragoça, Educal-TV- DGEstE – DSRA

Link to topics

- Quality of life
- Capability approach
- Inclusive education
- Promoting inclusive activities
- What kind of educational activities for children with CISON?
- Dealing with challenging behaviour

Additional reflective questions

- How would you describe Maria based on what you see in the classroom?
- What support does she need? What resources are needed?
- Can you think of other tools that can be used to enhance communication, learning and/or participation?
- How would you adapt tasks for Maria?
- What do you think her peers need to include her in the group? And the teacher?
- How can a teacher integrate the necessary support in her education?
- What other resources or tools could be activated or designed?
- How would you describe the status of Maria in the group?
- What could be a next step in the learning of Maria?
- Based on this video ... how would you construct learning activities for children with CISON.

Background information

Maria José Saragoça³⁵ & Ana Paula Antunes³⁶

Who is Maria?

Maria is a very nice girl, 9 years old. She was born with Angelman syndrome, diagnosed through cytogenetic analysis, when she was 15 months old.

An ICF-based map of Maria's functioning

As is customary in Portugal, to make up an individual education plan, Maria's difficulties and strengths were assessed using the ICF framework³⁷, at the end of her pre-school attendance, one month before entering first grade. From that assessment, we have included here what has not changed and we mention the improvements that we have observed and recorded.

Impairments in body structure and function

Maria displays a non-specified impairment in intellectual functions as there were cognitive impairments, but these functions were not quantified because of challenges while administering the test. She has sleeping problems, in that she struggles to fall

35 Special education needs coordinator in a public school group in Évora. She also lectures at the University of Evora and is making her PhD on the implementation of the International Classification of Functioning.

36 Trained as a primary school teacher, she specialized in Specific Educational Needs at the University of Évora. She is now a special needs teacher at the Group of Schools of Portel (Portugal)

37 See chapter in Enablin+ handbook, or : Saragoça, M.J., Candeias, A.A., & Varelas, D. (2016), The ICF (International Classification of Functioning, Disability and Health) as a reference in the assessment of functioning and needs of children with multiple disabilities, in Lebeer, J. (Ed.) (2015), *Who are they ? Assessing the needs of children with intensive and complex support needs in eight European regions*. Antwerp (BE) : University of Antwerp Enablin+ Research Group : 103-112

asleep, wakes up several times throughout the night, with short and agitated sleep cycles, resulting in a non-restorative sleep. Remarkably, since she started school, Maria normalized her sleep, to sleeping for periods of approximately 7 hours.

Maria, at the beginning of primary school, exhibited a complete impairment in the functions of attention, memory, and basic psychomotor and cognitive functions. She had a very short attention span, being incapable of executing a simple task and she does not maintain information in a systematic way, seriously compromising information assimilation and accommodation. Currently, she is capable of having a bigger attention span depending on the tasks she is carrying out.

Maria had no verbal communication. Right now, she utilizes a few syllables and words meaning: «ma» for *mãe* (means mother), «pa» for *pai* (means father), «grandma», «grandpa», «ba» for Bia. However, she uses those same syllables and words in other contexts and with other intentionality, which are often impossible to decode.

She has difficulties in swallowing food properly, complicating her digestive functions (she suffers from constipation). At 6 years of age, she was doubly incontinent. Bowel and bladder control was achieved over the last few years, getting her to the bathroom with controlled frequency and at regular schedules. Nowadays, she knows how to request the bathroom, but still has occasional accidents. She has stopped using continence pads.

Regarding motor functions, she has joint instability and hypermobility. She has low muscle strength and tone. She shows stereotypies and has a tendency to explore everything with her mouth. She has a peculiar gait pattern due to lack of balance and used to have difficulty in stopping and getting around obstacles. Nowadays, Maria can stop and get around some objects.

Activity and participation

Maria's *learning* is seriously hampered, given that she is unable to respond in an expected way, to stimuli or activities involving exploration of an object's functions, except when she is familiar with it and only on occasions. In relation to general tasks and demands, Maria has severe difficulty in performing a single task, and does not have any understanding of how to execute multiple tasks in everyday life.

Maria exhibits a severe limitation in *communication*, with expressive and receptive language, as well as non-verbal messages. However, she understands a lot of messages and she expresses meaning through intonation and facial expressions, but it is very difficult to understand her wishes and desires, sometimes. We tried to teach her how to use PECS³⁸ as an augmentative means of communication, but it proved to be too difficult for her to carry sets of cards to ask for what she wanted. We then opted for a communication programme on a tablet (Vox4All), however its use hasn't been successful, given that Maria has hand stereotypies that make her misconfigure the device every time she uses it. We will keep investing this as a means of communication, but simultaneously we are going to introduce MAKATON, which combines gestures/signs and symbols to communicate.

38 PECS = Picture Exchange Communication System

In relation to *self-care* Maria displays a full impairment in bathing, personal care, hygiene care related to toileting, dressing up and caring for her own safety. In the beginning she always needed help from an adult to orient cutlery and to hold a glass. Now, Maria needs less supervision from an adult and, she independently knows how to take the spoon to her mouth, as well as to drink from a glass.

Concerning *interaction and interpersonal relationships*, Maria, sometimes, understands when an adult uses different intonation and facial expressions. She is a very friendly, smiley girl, she likes to be with other people.

Environmental factors

In relation to environmental factors (facilitators or barriers to participation and learning), first we mention the importance of anti-epileptic drugs. As for communication we already mentioned the trial of augmentative and alternative means of communication, i.e. PECS. At the end of first grade, Maria knew how to select from two cards the one that corresponded to the object she wanted. In the second grade the augmentative communication programme Vox4All was presented in digital format. As we already addressed, because of her inherent difficulties with motor functions (involuntary movements and difficulties using her index finger) that affect her handling of the equipment, and cognitive functions (she did not understand the features of the programme), its use has not been as successful as we had hoped. Given that communication is the area that demands most attention, so that the pupil can be understood and interact in a more effective way with the world around her, we are investing in introducing another communication system that combines gestures and symbols, and hoping for better results.

For the rest, she does not use any special educational products; she just uses general products and technologies for education, which could facilitate her acquisition of new skills.

Concerning support and relationships, she has a very supportive network including her immediate family, friends, peers, colleagues, neighbours, and community members. Also, all these people have very positive attitudes, and are completely receptive to all of our suggestions and strategies.

Maria also relies on support from social security, regular medical check-ups, a flexible work system allowing her mother to take care and respond adequately to Maria's needs.

Systems measures to support inclusive education in this case

The ICF also requires taking support systems into consideration, whether they facilitate or inhibit inclusion. 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 used in groups or classes at an organizational, space and activities level; 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 specific supports are ensured at the speech therapy and physiotherapy levels. The pupil spends 3 hours weekly at 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, development, attitude facing tasks (availability, attention, rejection), in 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.

Organisation of inclusive education

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 serve as a foundation for her cognitive and socio-emotional development. One of the strategies used 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 group work as a starting point, 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 rudimentary 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).

She has a teaching assistant that provides support at moments in the classroom when the special education teacher is away, in extracurricular activities, while eating and for personal hygiene.

Strong and weak points

Finally, we review the inclusion of the pupil in a regular class at the Basic School of Portel, considering as strengths that Maria learned how to be in a variety of contexts, adopting appropriate behaviour in the classroom and in other environments she attends. The important things for her peers are to interact with people who can be perceived as being different, being able to learn about respect and compassion. A weak point is the great difficulty Maria has in attention and concentration, which could become a serious challenge for learning. The amount of stimulus naturally present in the regular classroom does not always help her with her attention. Also, some adapted tasks developed with Maria are, sometimes, distracting for her colleagues. But in spite of the less positive aspects, we always turn difficulties into challenges to our ability to improve our responses to Maria, making these differences our greatest asset.

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13. Early Intervention in Alentejo

Summary

This movie shows the history and characteristics of Early Intervention network in the Region of Alentejo, Portugal.

Key-words *early intervention*
 continuity of care
 home-based and family-centred care organisation

Production *ARSAletejo (Administração Regional de Saúde do Alentejo) –*
 Regional Health Administration of Alentejo, Portugal

Link to topics

- Continuous support systems
- Support paradigm

Additional reflective questions

- Looking at the fragment, how would you compare this example with your experiences with early intervention?
- Who should be part of an early intervention network considering your (professional or private) situation?
- What do you consider the strengths and weaknesses to how early intervention is organised?

Background information

The Regional Programme of the Region of Alentejo's Early Intervention on Childhood is based on a partnership between Ministry of Health, of Education, and Work and Welfare, and with Particular Institutions of Social Solidarity, or similar institutions, legally defined as entities that support Early Intervention teams.

In Alentejo³⁹, the Early Intervention network started developing in 2001. It is based in a decentralized framework, with 3 geographically organized levels: a Regional Team, District Coordination Teams in each district – assuring functions of management, supervision and monitoring – and Local Intervention Teams (LIT's), municipality wide, working directly with children and supported families, in association with local partners. In each county, Partner Teams were created, targetting the promotion, and narrowing the articulation of Local Intervention Teams and several community services, in a way that enables an integrated response to the supported families' needs and to mobilize existing resources.

These teams are multidisciplinary, encompassing kindergarten teachers, social assistants, psychologists, therapists, nurses and doctors from the primary healthcare network, working in a transdisciplinary way, in a family-centred model, in which families are simultaneously recipients, partners and decision makers through the intervention process.

Early Intervention in Childhood, just as it is organized in Alentejo, has innovative characteristics. It is acknowledged that the needs of children with developmental disorders may only be wholly assessed, interpreted, and responded to within the family and social context, through involving the development of community actions, by engaging all the locally existing resources and by disseminating the methodology of networking through all the region.

39 One of the Regions of Portugal, South-East of Lisbon

A few relevant topics

A human rights' approach

The UN Convention on the Rights of People with Disability (2006) is a milestone in the history of people with a disability. It has the same significance as the 1948 Universal Declaration of the Human Rights and was adopted by the General Assembly of the United Nations in 2006.

Before there were other important international declarations, such as the UN Convention on Children's Rights, Declaration of Equal Opportunities.

But this UN Convention is even more important, because it has the potential to radically change the way people with a disability are regarded by society, and to improve their living conditions and quality of life, which in many parts of the world are still appalling.

The UN Convention has the power of law, above the national laws. Its implications are far-reaching.

What do they mean in practice for our public, the child with multiple and severe disabilities who is completely dependent?

The UN Convention mentions eight principles:

1. Respect for inherent dignity, autonomy
2. Non-discrimination
3. Full and effective participation in society
4. Respect for difference and acceptance of people with disability as part of human diversity
5. Equality of opportunities
6. Accessibility
7. Equality for men and women
8. Respect for evolving capacities of children with disabilities and for the right of children to preserve their identities

Read the UN Convention's full text⁴⁰. Look at a situation you witnessed, regarding children with multiple disabilities. Then look at each of the rights. Are these children's rights respected?

40 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Watch the videos:

On this DVD:

2, 5, 6, 10, 11, 12, 13

Online:

To view a contrast: watch a documentary about abandoned and institutionalized children, e.g. the BBC documentary <https://youtu.be/UQZ-ERQczj8> . What about their rights? Please generalize from the country: in the meantime the situation in Bulgaria has improved a lot, as will become evident from the example of Enablin+ partner Karin Dom Centre (N°10). Besides, there are other countries where children's rights, especially of those with multiple needs, are violated.

Reflective questions

In general:

- What do you think about the rights of children with CISN?
- According to you, where do you see or have you experienced that the rights of these children are threatened? What are good and bad examples?
- Discuss the following statement: 'The guarantee that the rights are met for children with CSIN is more important than the quality of care.'

Pick one of the movies on the DVD: compare.

- How far has there been any progress in the realization of their rights?
- What can you do to improve the rights of the children on these various domains?
- How can you influence policy makers, and the "general public" to make improvements in the rights?

Quality of Life

The quality of life criteria as forwarded by Schalock, Verdugo et al. within the IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disability) are now well known in the professional world, but perhaps not so well by policy makers, the public and people working in daily support.

Schalock & Verdugo describe 8 domains of quality of life, each with their various indicators. Attempts have been made to develop validated checklists, adapted to people with CISON (Petry, Maes & Vlaskamp, 2015)

Table 2 Domains of Quality of Life, after Schalock & Verdugo

| QoL Factor | QoL Domain | Exemplary QoL Indicators |
|----------------------|-------------------------|--|
| Independence | Personal Development | Education status, personal skills, adaptive behaviour (ADLs, IADLs)* |
| | Self-Determination | Choices/decisions, autonomy, personal control, personal goals |
| Social Participation | Interpersonal Relations | Social networks, friendships, social activities, relationships |
| | Social Inclusion | Community integration/participation, community roles |
| | Rights | Human (respect, dignity, equality), Legal (legal access, due process) |
| Well-Being | Emotional Well-Being | Safety & security, positive experiences, contentment, self-concept, lack of stress |
| | Physical Well-Being | Health status, nutritional status, recreation/physical exertion |
| | Material Well-Being | Financial status, employment status, housing status, possessions |

*ADLs = Activities of Daily Living: IADLs =Instrumental Activities of Daily Living (From Claes, 2015)

Watch the videos:

On this DVD:

1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12

Additional reflective questions

- Focus on the Quality of Life model, what indicators of the model do you see in practice?
- Based on your practice give an example of good and bad practice or experiences within each QoL domain.
- How can you as a supporting staff, support the QoL of these children?

- Which of the QoL factors, domains or indicators are constantly under threat?
- Pick a video
 - What indicators do you see presented in the clip?
 - How are these supported?
 - Compare with your professional or private situation?

Further reading

Buntinx, W.H.E, Schalock, R. (2010), Models of Disability, Quality of Life, and Individualized Supports: Implications for Professional Practice in Intellectual Disability, *Journal of Policy and Practice in Intellectual Disabilities*, 7 (4): 283–294

Claes, C. (2015), Quality of Life in Supporting Children with Multiple and Profound Disability; a Promising Concept, in: Lebeer, Jo (Ed). *Who are they? Assessing the needs of children with intensive and complex support needs in eight European regions*, Antwerp: University of Antwerp, 2015, pp. 33-40 .Downloadable from www.enablinplus.eu

Petry, K., Maes, B., & Vlaskamp, C. (2015) *How to assess quality of life in children with PIMD?* In Lebeer, J. (Ed.) (2015), *Who are they ? Assessing the needs of children with intensive and complex support needs in eight European regions*. Antwerp (BE) : Enablin+ Research Group : 41-50 Downloadable from www.enablinplus.eu

Capability approach

People frequently wonder whether children with very severe disabilities and seemingly few possibilities lead a human life. Sometimes one can hear negative comments such as “They live like a vegetable”. In response to this discussion, it is interesting to listen to what American philosopher Martha Nussbaum has to say about what is meant by leading a dignified human life. Human beings are capable of ... being human. This has become known as ‘the capability approach’. Nussbaum bases her ideas on the capability theory of Nobel Prize winner Amartya Sen.

According to Nussbaum, a human being has 10 ‘basic constituent capabilities’:

1. To live a life (being able to live to the end of a human life)
2. To have bodily health
3. To have bodily integrity
4. To have senses, imagination and thought
5. To have emotions: attachment to things and people
6. Practical reasons (conception of good)
7. To experience affiliation (to belong to a group)
8. To live with concern for in and in relation to the world of nature
9. Play, laugh, enjoy
10. To have control over one’s environment

People who have serious multiple disabilities do not possess complete capabilities, e.g. bodily health and integrity or control. But human capabilities do not have to be perfect.

Watch the videos:

On this DVD:

1 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12

Online:

<https://youtu.be/cbcGbflpFzI>

Reflective questions

- Focus on the capability approach: which capabilities do they display to show they are living a “life of human dignity”?
- In what way are they capable of each of the basic constituents?
- How can you as a supporting staff enable the capability of these children?
- Are these capabilities within reach of children who have the most severe functional impairments or the severest restriction in their mode of functioning?

- Which of these capabilities are similar to any child, without impairments?
- Which capabilities are stronger
- Which of these capabilities are constantly under threat?

Further reading:

Le Fanu, G. (2014) International development, disability, and education: Towards a capabilities-focused discourse and praxis, *International Journal of Educational Development*, 38:69-79

Maes, B. (2014), Activity & participation of people with profound and multiple disability, in Van der Meulen, B.F et al., *Sporen van de reiziger [Traces of a traveller]*, Antwerpen: Garant

Nussbaum, M.C. (2006) *Frontiers of Justice: Disability, Nationality, and Species Membership*, Harvard University Press, 2006

Support paradigm

Claudia Claes⁴¹

The construct of *support needs* is based on the assumption that human functioning is influenced by the alignment between individual capacity and the environment in which that individual is functioning (Thompson et al., 2009). A person’s support needs are the result of either personal capacity or the context in which the person is functioning. As Thompson et al. (2009: 135) note: “Support needs is a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning”. The support needs construct focuses on the interaction between the person and his environment and puts attention to the role that individualized supports play in enhancing individual functioning (Schalock, Gardner & Bradley, 2007). The main question in the support paradigm is: *“what supports are needed to help people participate in their community, assume valued social roles, and experience greater satisfaction and fulfilment?”* (Thompson et al., 2002: 390).

From a social-ecological approach, supports are related to *organizational policies and practices*; these practices can facilitate or impede the support process, which is affecting human functioning or person-related quality of life outcomes. A system of supports is defined as the planned and integrated use of individualized support strategies and resources that encompass the multiple aspects of human performance in multiple settings (Schalock et al., 2010). The components of the system of supports are summarized in Table 3.

Table 3 Components and intent of a system of supports

| Component | Examples | Intent |
|-------------------------|---|-----------------------------------|
| Technology-based | Assistive technology Information technology | Cognitive functioning |
| Prosthetics | Sensory-Motor devices Environmental accommodation | Sensory-motor functioning |
| Staff directed supports | Incentives Skills/knowledge Positive Behavioural Supports | Behavioural skills and motivation |

41 Claudia CLAES, PhD. is Dean of the Faculty of Social Work and Welfare Studies of University College Ghent, visiting professor at the Department of Orthopedagogics, Ghent University (Belgium). She made her PhD with Robert Schalock, past president of the American Association of Mental Retardation. Coordinator of E-QUAL, an expertise centre on quality of life studies. Contact: Voskenslaan 363 – 9000 Gent (Belgium) Claudia.claes@hogent.be

| | | |
|-----------------------|---|------------------------------------|
| Professional services | Information technology engineer, occupational therapist, physical therapist, speech therapist; medical, psychiatric, and psychological services | Physical and emotional functioning |
| Natural Supports | Family, friends, colleagues Generic agencies | Social integration |

Watch the videos:

On this DVD:

1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13

Reflective questions

Looking at the table above, with the various kinds of support:

- What examples of support do you discover in the various examples?
- Who is giving support?
- Make a distinction between the support of professionals, parents, peers, volunteers ...?
- When support is needed?
- For what kind of activities is support needed?
- What is the result of the support (in terms of activities and participation)?

Communication and intentionality

Juliet Goldbart⁴²

Introduction

Children with complex and intense support needs are very likely to experience challenges in the development of language and communication. Many will be at preverbal stages of development, where they are communicating through, facial expression, arm, leg, head and body movements, and non-speech sounds.

To *become* a communicator, a child must be treated as a communicator. So we can conceptualise communication which is “pre-intentional” leading towards communication that is “intentional,” which then leads to more formal communication through gestures and then language. This progression is shown in the diagram “Development of Early Communication,” (see below). This diagram shows how communication develops through both cognitive and social routes, with interaction with objects coming together with interaction with people.

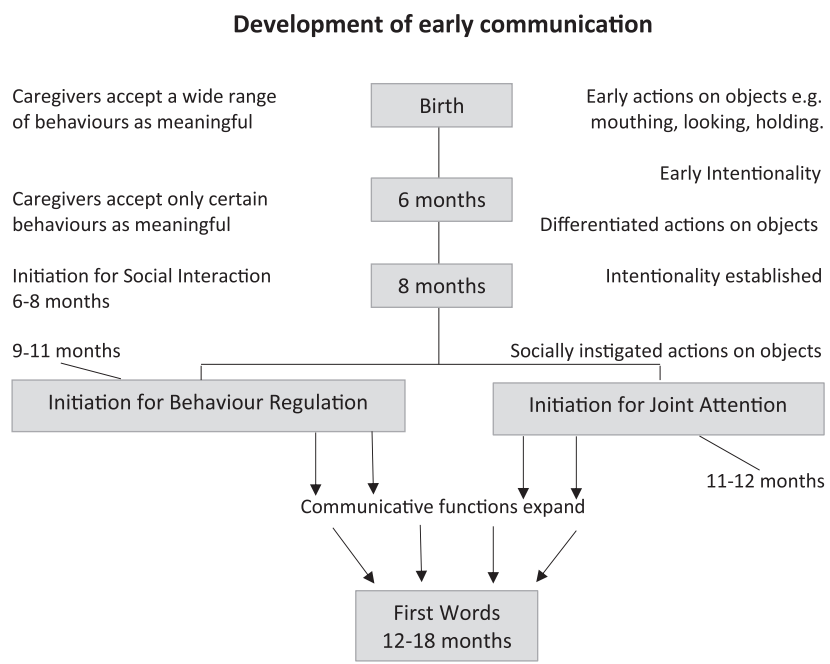


Figure 6 Early communication and intentionality

⁴² 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 and is currently part of an NIHR funded project: Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision-making.

One point in Development of Early Communication that needs some explanation is the transition from early intentionality through to intentional communication. Intentionality is the recognition that your actions have consequences; that you have an effect on the world around you. In typically developing babies, it develops between about 4 and 6 months of age, presumably as a result of repeated chance experiences of observing the consequences of our actions. For example, the baby brings a hand to her mouth and brushes the row of toys on a string in front of her. The toys spin round making a rattling sound. Eventually, the baby learns to swing her hand to make this happen. Intentionality is very important for two reasons. First, because if we do not acquire intentionality, if we don't learn that we can affect the world around us, we are at risk of the opposite; learning that nothing we do has any effect. This may partly explain the lack of engagement with the external world shown by some children with complex and intensive support needs. They gain stimulation from their own bodies through rocking, thumb sucking or other repetitive behaviours.

The second reason why intentionality is so important is that it leads towards intentional communication. While intentionality involves acting directly on objects, intentional communication can be seen as starting with acting on an object through another person.

For example, Peter reaches for his brother's banana. It is too far away, but his brother breaks off a piece and gives it to him. Through these experiences, Peter learns gestures for communication. He is now communicating intentionally.

Where children are developing communication slowly, it may be helpful to break development down into steps. This allows us to recognise and value each child's progress. One account of these steps is given in the table below: Stages in Early Communication Development. You will see the progression from pre-intentional to intentional communication. In the first three (pre-intentional) stages, the child is not aware that they are sending a message, but their behaviour can be understood and responded to by familiar people who are willing to pay attention to the child, leading to enjoyable interactions.

Table 4 **Stages in Early Communication Development** (from Coupe & Goldbart, 1998)

| | |
|--|---|
| Level 1: <i>Pre-intentional – Reflexive:</i> | 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: <i>Pre-intentional – Reactive:</i> | A wider range of voluntary behaviours is 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: <i>Pre-intentional – Proactive:</i> | 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: <i>Intentional – Primitive:</i> | 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. |
|--|--|

Using the two diagrams, we can see the importance of giving children with complex and intense support needs a range of experiences:

- Opportunity to engage with objects that vary in characteristics like shape, texture, colour, complexity. The selection of appropriate objects for the child and positioning so the child can access the objects are important.
- Jean may be able to use his arms more easily if he is lying over a wedge in a prone position, and the objects are in a bowl to keep them close to his hands.
- Julie cannot see objects even if they are close to her. If we seat her in a large box, we can put a variety of objects around her which cannot roll out of reach, so are available for exploration.
- Opportunities to engage in responsive and enjoyable interactions to support early social development. Video recordings may help us notice behaviours from the child that invite interaction.
 - Kiera leans towards her classroom assistant, Kate, who sits next to her for story time. Kate takes her hand and strokes her fingers, an activity she knows Kiera enjoys. Kiera brings her other hand up to touch Kate’s face and Kate blows gently on her hand.
 - Kai shouts when his class teacher comes into the room. She makes a point of coming straight to Kai and speaking to him. Kai smiles and they have a turn-taking game. Kai’s turn involves smiling and the teacher says “hello Kai!” She waits for Kai’s smile. “How are you today?” Kai laughs. “You are in a lovely mood today!” Kai laughs again, “It’s time for snack.” She shows him a bowl of grapes.
- Opportunities to develop intentionality. This involves giving children opportunities to affect and control the environment through their actions.
 - Leon’s teacher has arranged some bubble wrap on the floor around him. When he rolls across the floor the bubbles pop. Leon thinks this is very funny.
 - Leah’s therapist has attached a switch to the headrest on her wheelchair. When she tilts her head to the right it operates a flashing light display that Leah enjoys. She has learned to keep the light display on for short periods.
- How can we promote development of intentional communication?
 - Maia’s mother has recorded the message “come and play with me” on a BIGmack switch. Maia has the switch at playtime and the children in her class respond when she hits it.

- Marc's father noticed that Marc sometimes waves his arm when they are playing on a hammock. He developed this into a game where he rocked the hammock each time Marc waved his arm. After a few weeks, he started to pause a little before the next rocking action and Marc has started to use waving his arm as a signal to his father to rock again.

These are very general strategies that can easily be used at home or in the classroom. There are also some more formal approaches that can be used with children at these early stages of communication. Before using these approaches, however, it is helpful to assess the child's communication, to help identify which approaches would be most appropriate, and to evaluate progress over time.

Three assessments that are available, free, on-line are Routes for Learning, the Communication Matrix and the Affective Communication Assessment (see Resources, below). Routes for Learning materials are available in English and Welsh. The Communication Matrix is available in English, Spanish, Czech, Dutch, Chinese, Russian, Korean and Vietnamese. The Affective Communication Assessment is described in the U.K. Department for Education Complex Needs online training course in English only.

Intervention Approaches

One approach that is recommended for all children with complex and intense support needs is the development of a Communication Passport. This is a means of capturing and sharing information about how a child communicates, their likes and dislikes, and what they might want to communicate about. The process of making a Communication Passport is an enjoyable collaborative activity for parents, teachers and therapists, and can result in greater shared understanding about the child. Information on making and using Communication Passports, along with helpful templates, is freely available at <http://www.communicationpassports.org.uk/Home/>

The following intervention approaches have all been evaluated in at least one study. There is only room for a brief introduction; further details of each approach, and the evidence supporting them, is available from the resources listed below and online in Goldbart and Caton (2010).

Cause & effect – using simple switches

Using simple switches or other cause & effect devices can teach children that their actions have consequences, in other words, intentionality. First we teach the child to make enjoyable things happen by operating a switch, for example starting a fan or playing music. The switch can then be used to make or to convey a choice (Lancioni et al., 2006a & b), or gain social contact as in the example we have given of Maia. This intentional communication may lead into more advanced use of symbol systems through augmentative and alternative communication (AAC).

Intensive Interaction

Intensive Interaction (e.g. Nind & Hewett, 2006) is based on the highly responsive, individualised interactions between babies and their caregivers.

Intensive Interaction is a systematic and thoughtful approach to developing enjoyable interactions between children (and also adults) with complex communication needs and significant others, increasing their sociability. Useful information is available from the Intensive Interaction Institute.

Objects of Reference

Objects of Reference draw on the concept that an object has significance for the child at an earlier stage than formal symbols or words. Objects of reference can be used in different ways:

- to signal what is about to happen, for example giving the child a spoon would show that is lunch time.
- to offer choices; e.g. giving the child a choice between a favourite CD case and a favourite book to show their choice between a music and a story.
- a visual timetable which displays objects of reference for the activities that will be available to the child or that are going to happen during the school day.
- The child may progress from this to use the objects to request things or events.

Narrative-based approaches

The language of a story is combined with multisensory props, such as objects, smells, tastes and sounds, to construct a narrative, which provides the learning opportunities and pleasure of engaging with a story, without the need to understand the language used. Single message switches can be used to enable the child to contribute a line of the story, for example “We’re all going on a bear hunt!”

Staff and parent training

Discussion and sharing of information between teachers, parents, therapists and all other members of the staff team is very important in developing the communication of children with complex and intense support needs. All the approaches described above will involve some training of staff or family members in order to ensure the best possible outcomes for the learners.

Watch the videos:

On this DVD:

8, 11, 12, 1, 2, 5, 7, 10

Online:

Online training materials produced by Department for Education, UK: <http://complexneeds.org.uk>
Training materials on using RfL: <http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/m08p010c.html>

Intensive Interaction: <http://www.intensiveinteraction.co.uk/> and of YouTube, for example at www.youtube.com/watch?v=UvIEwUbzF4c

Additional reflective questions

Considering the video clips

- At which stage is the child is communicating? Why?
- Where do you see engagement to objects?
- Where do you see interaction with peers, parents or support people?
- Where do you see intentional communication?

Considering your practice

- How would you describe a child within the framework/matrix of Goldbart?
- Can you describe intentional communication?
- What steps are needed to develop intentional communication? Which method do you prefer?

Further reading

Goldbart, J. and Caton, S. (2010) *Communication and people with the most complex needs: What works and why this is essential*. London: Mencap <http://www.mencap.org.uk/page.asp?id=1539>.

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Iacono, T., West, D., Bloomberg, K., and Johnson, H. (2009). Reliability and validity of the revised Triple C: Checklist of Communicative Competencies. *Journal of Intellectual Disability Research*, 53, 44 – 52.

Millar, S. with Aitken, S. (2003). *Personal Communication Passports: Guidelines for Good Practice*. Edinburgh: CALL Centre.

Nind, M. and Hewett, D. (2006). *Access to Communication*, (2nd Ed.). London: David Fulton.

Petry, K. and Maes, B. (2006). Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual and Developmental Disability* 31(1), 28-38.

Other 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>

RfL Assessment Booklet: 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/d/quest_guidance_booklet.pdf

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

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

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Continuous support systems: parents in charge

Mia Nijland, Rianne Kleine Koerkamp, Inge Kroes⁴³

In daily life it appears that a normal life in combination with a special existence is difficult. The connection between the informal family network and the formal, professional network of the child is often insufficient. These two are now incompatible with each other. The system of care and education, is directly focused on the child's questions and financing solutions. The questions of the informal network are often unanswered, which affects children and families. Insufficient attention is paid to the problems experienced by parents and other family members. It does not really depend on the actual need they have for living and living together and what contribution they could and want to make. Our target group needs a support system that must be a good balance between ordinary and special, and between supply and demand. We think a way to achieve this is a continuous support system. With continuous we mean:

- During his or her whole life; from baby to adult
- During a week/day; 24/7
- The network around the person with CISON; The social network is fully on all domains

How?

By starting with the questions of parents and children, both on formal and informal choices and decisions. Using holistic approach to those questions and by looking for a suitable answer or solution. Step by step and only when it is necessary. This creates space for a beautiful, ordinary life. Thus parents stay in control and professionals do only what is needed. Step-by-step the system searches for value and adds value to the life of children and families. Again based on equal contributions from parents and professionals.

The expectation is that customization is more sustainable than current standard solutions. Enablin+ want to facilitate all the involved people so they can act in a continuous support system. A system that gives the proposed customization approach a chance. Customized routes for children, with their parents at the wheel and professionals as a guide. The aim is to map the route along with children and their networks, following a more beautiful life with their own (chosen) lifestyle and appropriate care and education. The lifestyle approach (just live) helps to see cohesion. The cohesion within – and between life and system-world.

*How do we keep in touch what is already present
and where should something be added?*

How do we anticipate a new situation in time?

How do we translate care into equivalence?

⁴³ Quality of Life Centre, Wijk, The Netherlands

Why is a customized approach so important?

In order to enjoy a beautiful life journey, families with a “care-intensive” child have a difficult path to travel. A journey that lasts for a lifetime and at the same time can also be short, for example because of a progressive disease of the child. A kind of world trip that is not prepared for and for which no travel insurance can be purchased. In all situations it turns out to be a tough journey, via fast and tourist routes. You want a straightforward life with your family, but it’s not possible. The complex disability of your child obstructs this and the system-world you end up makes it even more difficult. You are continuously organizing and multitasking. Working with your child, physically and emotionally. How about upbringing, tools, diagnoses and how to deal with epilepsy or nutritional problems? How do you organize care, education or therapy without compromising in complicated collaborative processes or money issues? Where do you find help and who will keep you safe? General tips are okay, but not what fits your specific situation. Continue your search ... Along the way, you get to know the hubs and unintelligible roads, you get stuck in a swamp of care systems ... bad roads, roadblocks, bumps and traffic jams. Government solutions are not always convenient and alternative routes are often inconsistent with the daily practice of the family. Sometimes the car is not available or you get bad luck: “unfortunately, the help will not be available until you are a member”. If you travel once by train, broken pipes or railways can be reason for delays. This situation requires rest, structure and serious solutions.

Real time Maps – navigation system (support system) with stops

This helps parents to choose their best route at every moment and advises them about convenient stops. The aim of these stops is to:

- Rest
- Hold on tightly
- Enjoy the beautiful life
- Organise and make plans

With the help of the stops, their child’s personal lifestyle is shaped in a personal programme. On the way, the parents decide when they want to make that stop and possibly with whom. The stops are suitable for any situation and age-independent.

This is not a linear process because human lives are not caught in such a plan. There are always unexpected situations. Maybe that’s the reason why it’s so nice that this route planner is available. It is generally applicable but also offers space for individual choices on the go. It also offers the necessary cooperation and the handling of questions and problems that arise on the way. It helps families to get hold of situations that are inseparable and difficult and helps people to speak the same language. For an overview of the steps and stops, see figure 3.

Integration care and education

A continuous support system supports the collaboration between parents and involved professionals but also between professionals. It is appropriate and necessary to realize the integration and cooperation between care and education for the target group (at a group and individual level). It offers the opportunity to bring together the best of two worlds, by combining a (existing and evidence based) methodological framework and (existing) didactic frameworks.

Watch the videos:

On this DVD:

2, 3, 4, 5, 10, 13

Combining care and education: individually tailored education

Mia Nijland & Inge Kroes⁴⁴

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 her 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 mood 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 for children with CISN both in the Netherlands and in Belgium was the norm rather than the exception. Children with CISN were supposed to have a too low developmental levels 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 recently, in the past decade, have 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 these 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'.

⁴⁴ Mia Nijland & Inge Kroes are special needs psychologists. They founded the Expert Centre for Care and Education and the Quality of Life Centre, 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 approaches for 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 difficult 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 demand 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, including within an educational context. Information can be obtained from conversations with parents, other caregivers, and observational data. Such a ‘dynamic assessment’ approach provides sufficient action-oriented information for a class teacher. This requires more than one assessment.

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 shown in the movie about 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 the 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 devised, 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 *development perspective* take the curricula of children of equal developmental age as a 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 are still based on a developmental approach, however use materials more adapted to chronological age, in order to promote functioning within a daily environment (kitchen, street). Criticisms towards this approach are that they are still devised based on developmental steps, and that what should be regarded as "functional" learning activities is ambiguous.

Curricula developed from an *ecological* approach no longer take the developmental approach as a 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 typical 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. Expanding existing skills, needing less support in performing a task, showing more involvement, and maintaining skills in regressive conditions ... are also 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) potential. 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 minded attitude and try to systematically discover signals from the person with CISN, and 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 ways 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 physical movements, mimicking sounds and language) and stimulating the initiatives of the child (Kroes, this manual).

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 package 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 adaptations, customized educational materials,....

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 duration of class timings. 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 needs, 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 may mean, 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 lives.

Furthermore, *regional* agreements must be made regarding which schools and care organizations will receive the aforementioned target group. Examples are given of the “together to school” classes on the Enablin+ DVD and in this manual.

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Watch the videos:

On this DVD:

2, 5, 6, 10, 11 12

Reflective questions

- Considering your professional or personal context (or a video clip), how is learning and care organised for children/your child with CISN?
- What possibilities and barriers do you see?
- Teaching and care: segregated, integrated or inclusive? What are the pros and cons?
- Considering one child with CISN from your practice or from a video fragment:
 - How do you think he/or she is learning?
 - How do you know that? How do you see that?
 - What could be a next small step in his or her learning process?
 - What do you think is needed to reach this next step?
 - On a concrete level, what support or material is needed?
 - What learning trajectory (and curriculum) could you develop? What do you have to take into account?
 - How can you integrate the learning activities in daily life? Who is or has to be involved?

Meaningful learning activities for children with complex and intensive care needs

Experiencing – Developing – Stimulating

Inge Kroes

Children develop in a multitude of relationships. There are relationships with the physical and with the social environment. The physical environment consists of the spaces, objects and events surrounding the child, where the child can see, point out, smell and taste. The social environment consists of the people around the children and their activities. Actions of children focused on the physical environment are embedded in the social environment. Serious motor and mental impairments of children make both types of relationships difficult. Within the care and services for children with severe multiple disabilities, for many years optimal developmental opportunities have been searched for (Nijland, 2006). Their development is “disharmonic”. This means, amongst other things, that development is difficult to predict. It is possible to determine what a child is able to do at a certain time, but it is difficult to indicate how it will develop further. These children develop not only slower, but also differently from “normal” children (van Gemert and Minderaa, 1997).

By analysing observations of interactions during activities, we know how children learn. There are various activities possible if the conditions of interaction are met, such as: initiative (by the child), proximity, predictability, responsiveness together. Providing meaningful learning activities does not mean one has to offer solitary stimuli, but appropriate stimuli, with tailored interaction and taking into account the child's possibilities and limitations. Then there are various activities, such as experiential activities, stimulation and development activities. In fact, you do not have to exclude activities in advance. This provides a perspective for a potential activity offer for children with complex and intensive care needs (CISN), independent of the learning environment.

The perception action system (perception and action) of children with CISN.

The senses do not work well or and may work differently in these children. Having physical and/or intellectual impairments has adverse consequences on the following factors:

1. The perception of ‘learning opportunities’
2. The access to information in the environment
3. The link between perception and action.

The physical abilities of a child determine which learning opportunities are possible in the learning environment. They can lead to limitations in discovering those learning opportunities. The adverse consequences of physical and intellectual impairments thus go beyond sensory and motor impairments. They usually lead to another kind of meaning the environment has for the child and the meaning the

child assigns to itself in the environment. The increasing availability of technological applications may make it possible to change this somewhat (embodied cognition).

An example:

Sanne is in a wheelchair. A few blocks are put on her wheelchair and her carer sits in front of her. Sanne moves slowly, she has low muscle tension and visual impairment. Pretty suddenly Sanne turns her trunk to the left, turning her gaze to the left and she stays in this position for a few seconds until the carer starts talking. The girl turns to the carer again. If we know that 7 seconds before Sanne turned left, something fell on the ground at her left side, we understand why she turned to the left. Her motor constraints hinder her gaze to focus on what she was possibly hearing and to collect information about the event that took place outside her field of view. Her limited action does not provide her with enough information. Her carer could have helped Sanne to further investigate what took place. By talking about the game she disturbed the exploration instead of supporting it. What can you do now as a caretaker to support the child in developing a perception-action system so that the child learns to understand and handle the world?

Experience, Emotional Development and Sensory Development.

In order to arrive at a challenging and balanced learning programme for children with CISN, we (teacher / supervisor / parent) want to find a balance between the experience of effort and relaxation (Heijstek and Makker, 2014). We would like to offer meaningful stimulating activities. For the children, this may be different; there may also be a need for quiet activity. We do not want to increase stress so quickly during the programme or during the activity, that the child does not enjoy it. For an appropriate programme, it is important to pay attention to:

- Predictability (experience organization)
- Proximity (emotional development level)
- Stimuli (meaningful perception)

The degree of proximity required also differs from child to child. If you are familiar with their level of emotional development, you will have an indication of what proximity he or she feels safe with.

What stimuli a child does or does not need to start an activity also differs from child to child. If you know at what level the child perceives the stimuli, you will have some insight into what stimuli the child needs and which ones are just distracting. The alertness level is also very important when it comes to offering incentives.

1. Predictability

The degree of required predictability differs by child and situation. As a support person, you need to understand how the child interprets his experiences, so that you know, for example, how to make an activity which is recognizable to him.

Experience Organization

The theory of experience (Timmer-Huigens, 2005) helps you to estimate what exactly you can expect from a child, and thus how predictable you can make activities for them. This theory maps how a child is organizing his experiences. One of the four ordering types is the most guiding in a particular situation and determines how the support person joins the child in this situation. This increases the possibilities of the child.

The four ordering types are:

1. **Physical-bodily ordering:** In this part the question is central: Is my body safe? This question focuses on the sensory information that comes from within the body or from immediately around. When the answer to the order question is no, the child will try to restore the body's safety. When this element is the most important, it asks you to guide him from close-by, by using a slow pace and offering sensory pleasant experiences.
2. **Associative ordering:** In this section the central question is: is my environment reliable? All actual information from the child's immediate environment about persons, programme components or the layout of the home and room, can be ordered here. When the answer to this question is no, the child will try to restore reliability, such as (compulsive) ordering, continually asking for or blocking changes or transitions. When this is the case, this requires you as a supervisor to offer stability through reliability: clear communication, fixed sequences and a lot of repetition.
3. **Structuring ordering:** in this part the central question is: do I know the coherence of the event? The information that is ordered here is more conceptual. These are the relationships between different facts. As a supervisor you choose to give the child an explanation and responsibility. The child can see an event with a recognizable beginning, flexible middle and recognizable end.
4. **Formative ordering:** Here the central question is: May I be who I am? The essence is to be known as a unique human being. As a supervisor, you offer the person space to be himself by joining his possibilities. Where possible, you offer space, where necessary, give support. You appeal to freedom of choice and problem solving ability in connection with a way that is manageable for the child.

2. Proximity

If the child feels comfortable with his supervisor, he will engage in the activity for longer. If the child does not feel safe during an activity, he cannot focus on what you ask of him. As a supervisor, you must be sensitive to his needs so that he can trust you to be there if he needs you. Confidence arises if the child has experienced that you are also responsive. Because you responded in the right way in situations that caused the child's tension, it turns out that you also benefit from an approach that matches the child's emotional development level. For further explanation see Došen's model in Sappok e.a. (2016).

3. Stimuli

In order to achieve a good activity that lasts for a long time, it is important that there are not too many distracting stimuli. At the same time, the child also needs incentives to get to work and learn. In short, the correct incentives must be present and the distracting absent. Not every perception is also a stimulus. As we know from the introduction of this article, observations must also have a certain meaning. A stimulus is an observation plus the meaning the child imparts to it. Which incentives are important for a child depends on the level of meaningfulness of sensory stimuli.

1. Body/attitude senses: give information about the movements of our body
2. Near-senses: give information about everything that happens to our body (fine motor perception)
3. Far-senses: give information about things being further away (communication).

The following can help to choose the activity that matches the child. In attributing meaning, you can distinguish five levels:

1. **Experience** (attitude and movement). Moving with a wheelchair or armchair. Cradle/swing, (over) stretch. The child experiences the stimuli through other senses passively
2. **Discover**. In particular, the child is mainly concerned with stimuli that he senses by touch and mouthing. Far-senses are used, but passively
3. **Watch and have an overview**. Especially active with visual stimuli. Follows every move and often keeps an eye on everything from a fixed place in space. He may sometimes be very detailed in remembering his surroundings. Far-senses are being used less actively.
4. **Listen**. Especially with auditory stimuli. May give the impression to be dominant. Follows each conversation and often asks what someone has said exactly.
5. **Integration** The child can use all sensory channels in an appropriate manner.

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Watch the videos:

On this DVD:

1, 5, 2, 3, 7, 9, 10, 11, 12

Online:

Reflective questions

- In what way do you recognize the different aspects of ‘the theory of experience’ in your practice?
- What is the value of this theory for practice?
- Considering one child with CISN in your practice (or from a videoclip):
 - Describe in your own words: How do you think she/he conceives or experiences basic stimuli, the environment, interactions and the world?
 - How would you describe her/him as a person?
 - How would you describe her/him in relation to people or space?
 - When does the child feel safe/unsafe? How do you notice that?
 - What’s needed in order to feel or act in a safe way? How can this be stretched?
- Considering the levels of attributing meaning to activities ...
 - What kind of activities match the child’s capabilities and personality?
 - What kind of activities are stressful?
 - What kind of activities are challenging?

Art therapy, a therapeutic approach to artistic activities

Marika Rieth-Socha⁴⁵

Definition

The use of art for therapeutic purposes is both ancestral and at the same time extremely modern. Artistic practice has always been of fundamental importance in the methods of care of many cultures throughout the history of mankind.

Art -therapy

According to the School of Art Therapy in Tours (AFRATAPEM), “art therapy is the exploitation of artistic potential in a humanitarian and therapeutic way”. Art therapy respects the conditions of the official paramedical professions: protocol, strategy, evaluation, ethics ...The art therapist has an original and specific health action in multidisciplinary team care.

Art therapy groups all artistic techniques according to the needs of the therapeutic support. Art therapy, while being generalist is a discipline that can specialise into: music therapy, dance-therapy or within the framework of a specific pathology (autism, cancer etc. ...). The art therapist uses an artistic preferential domain, according to his or her initial artistic training (School of Art, Conservatory) and can then use other artistic forms according to the needs of the therapeutic support and co-therapies (example: Music and painting). Music therapy is considered a specialization of art therapy.



⁴⁵ Art therapist, after studying art & theatre at the Conservatoire of Montpellier (FR), she graduated from the University of Tours Medical Faculty as an art therapist. She was trained in Feuerstein's Mediated Learning Experience, Learning Potential Assessment and Cognitive Instrumental Enrichment. Coordinator of art & culture at Association St. François d'Assise, Réunion Island (FR)

Music therapy

Music therapy is a practice of care, help and support that consists in taking care of people with communication and/or relationship difficulties. There are different techniques of music therapy, adapted to the populations concerned: psychoactive disorders, social or behavioural difficulties, sensory, physical or neurological disorders. Music therapy is based on the close links between the constituent elements of music and the history of the subject. It uses sound and/or musical mediation to open or restore communication and expression within the relationship in the verbal and/or non-verbal register.

- The group is adapted to therapeutic practice
- Practice in accordance with accepted professional standards in music therapy and art therapy.

Therapies offered:

The art and music therapist work with a multidisciplinary team by developing a therapeutic protocol adapted to each user according to the objectives set.

Individual sessions

It involves taking care of one person at a time, to which the art therapist or music therapist offers individual sessions.

Group sessions: art-therapy workshops

- The workshops, where art therapy is practiced in therapeutic groups, are generally in a specific setting, intended to be reassuring and containing for its participants, facilitating their connection.
- These workshops generally take place on the same day (for example every Thursday), at the same time, in the same room, in order to allow participants to identify and integrate within the framework.

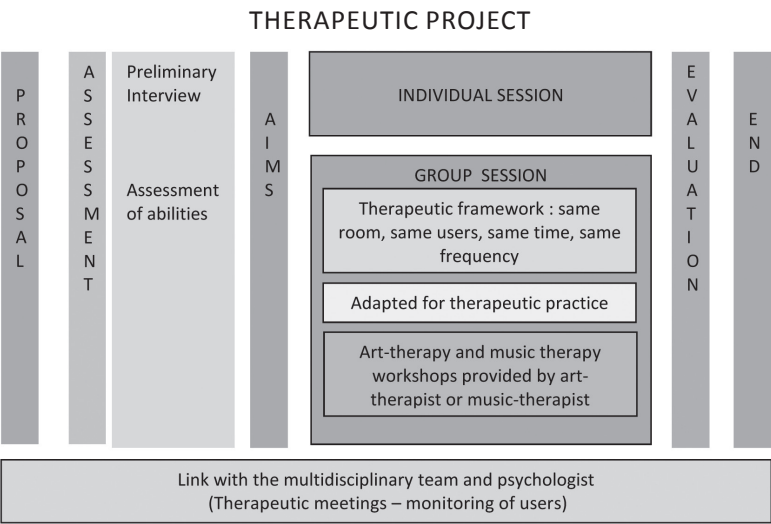


Figure 7 Possible scheme for an art-therapy project

Proposals for art and music therapy.

In France, proposals for art or music therapy are referred by a doctor or the head of a service centre, in agreement with the beneficiaries.

The key to participate is:

- Interest in artistic or musical practice
- Difficulties in expression, communication and relationship
- Lack of self-confidence, lack of assertiveness, low self-esteem

Secondary motives may be:

- Behavioural disorders
- Motor, physical and cognitive disorders
- Lack of investment in a comprehensive support plan
- Spatio-temporal difficulties

Clinical

Art therapy is a clinical practice based on evidence. This discipline is based on protocols established in scientific literature. Through an oriented observation, the art therapist and the music therapist work towards the attainment of individualized therapeutic objectives. The clinical approach and mastery of artistic practice enable the art therapist and music therapist, through their expertise, to build and develop a therapeutic project.

Specificity of a therapeutic approach

The fundamental difference between the objectives pursued in therapeutic and educational, rehabilitative or pedagogical support does not necessarily relate to a specificity of objectives but rather to the modalities of support. Indeed, it is the perspective that the professional will take on the person, and on what he or she brings in a session, which will constitute the specificity of a therapeutic approach.

Artistic mediation combined with our therapeutic approach is our specificity. In addition, the art therapist focuses his or her work on the baseline state and residual abilities of the recipient rather than on the causes of his disorders. The art therapist will not interpret the actions and works of the beneficiary.

Watch the videos:

On this DVD:

9

Additional reflective questions

- Are you familiar with art or music therapy for these children?
- What do you think is the difference between art/music therapy, art/music as a learning activity and art/music as leisure activity? Do we make this distinction for children with CISM? Why or why not?

- How can we include art, artistic or creative activities in daily life and activities of children with CISN?

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Further reading

Stephenson, J. (2006), Music Therapy and the Education of Students with Severe Disabilities, *Education and Training in Developmental Disabilities*, 41(3), 290–299

An optimal learning environment for children and young people with profound intellectual and multiple disabilities: reflection tool for educational practice.

Katrijn Vastmans⁴⁶, Anneleen Penne⁴⁷, Elisabeth Cans, Bea Maes⁴⁸, Annet De Vroey⁴⁹, Lijne Vloeberghs

Everybody has the right to take part in education. This also applies to students with profound intellectual and multiple disabilities (PIMD). Nevertheless, offering high quality education to this target group is a challenge: on the one hand because these students have diverse and complex support and educational needs for which there is no ready-made answer; on the other hand because the knowledge about education and students with PIMD, is limited. These findings were the starting point for practice-oriented scientific research, by the team of the Advanced Bachelor Special Educational Needs, Teacher Education of UCLL and the Department of Special Needs Pedagogy of the University of Leuven (Belgium) that resulted in a digital reflection tool for educational staff. This tool provides an overview of key themes to consider for an optimal learning environment for students with PIMD. Based on literature, an online survey and focus group discussions, educational needs and practice regarding students with PIMD were explored and gathered along the dimensions of a framework for quality education. Rephrased as key questions, they can support teams in reflecting on the education offered. Showing a link between regular education and education for students with PIMD, supports the idea itself of education for children with PIMD. High quality education for this target group includes an individually adapted curriculum, offered in an emotionally safe learning environment, to create openness to learning and learning gains. This results in an increase or an enhancement of the persons quality of life.

The reflective tool has an input, process, context and output section, with about 500 reflective questions.

The input section contains some general information about the kind of difficulties and support needs a child with complex and intensive support has, the importance of its context at home and elsewhere, and reflective questions about the teaching team's previous and current experience with this target group.

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47 Coordinator Multiplus, Expert Centre and training centre for People with profound intellectual and multiple disability, University of Leuven, Belgium

48 Professor of special needs pedagogy, and Dean of the Faculty of Educational Sciences, University of Leuven

49 Director of the Advanced Bachelor of Special Educational Needs, Department of Teacher Education at the University College Leuven-Limburg

The process section has two main parts: part one is a set of indicators and guiding questions on the classroom level; part two has indicators and guiding questions on the school level.

The section about classroom level starts with obtaining an image of the child: it has about 75 questions to gain a fairly thorough and comprehensive idea of who the child is, their functioning, developmental level, activities, preferences, difficulties, etc. Based on this profile, the reader is invited to make a plan and set concrete goals, determine strategies, working methods, evaluation of the goals and reporting ways. The next set of guiding questions refers to the drawing of an individualized education plan, in reference to existing learning trajectories or curricula.

Then the reader is invited to think about the most suitable instruction style regarding interaction and communication: to adopt a sensitive-responsive attitude, to use methods of augmentative and alternative communication (or supported communication), to stimulate choice and control. Then the reader has to think about which resources and materials are going to be used, what would be an optimal learning environment; what kind of grouping (in terms of group size and composition) is going to be used; how much time is going to be assigned to educational activities, and how aspects of physical care are going to be integrated.

Part two of the “process section” deals with questions about school policies and school leadership on various aspects: mind-sets about children with profound and multiple disabilities, the number and qualities of available staff, the supportive school climate for professionalism, partnership with parents and family, and policies, principles and practices regarding inclusive education.

The context section has guiding questions about the school’s context; attitudinal aspects and physical accessibility, infrastructure, population size, educational materials, aspects of safety and aesthetics of rooms and environment; as well as contacts with and involvement of the school’s neighbourhood (based on the concept of a “broad school”).

The output section asks about learning gains, on various aspects: educational and functional learning gains, interaction and participation and quality of life in general.

Reflective questions

The reflective instrument ‘Success indicators for good education of children with PIMD’ has about 500 reflective questions. A brochure⁵⁰ provides more information to work with the reflection tool.

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⁵⁰ For the time being, this brochure is written only in Dutch, but the plan is to make it available in other languages

Dealing with challenging behaviour

Petra Poppes⁵¹

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.

This training is about the Individualized education/support programme for children and adults with profound intellectual and multiple disability (PIMD) (Vlaskamp, Poppes & Zijlstra, 2005; Vlaskamp & Van der Putten, 2009) in combination with movement oriented interventions.

This individualized support or education programme was developed because practice was in need of a working method to best support children and adults with PIMD during the 1980s. They indicated that they were often unsure about the goals they should formulate for children/adults with PIMD: most of the work was done intuitively and practitioners were often unsure about the effects of their efforts. Furthermore the government in the Netherlands wanted more clarification on how their money was spent. Professionals came to the University of Groningen and asked whether they could help. Carla Vlaskamp, Ruud van Wijck and Han Nakken then started research with the aim to develop a programme which allowed professionals to work from a set vision and carry out explicit and planned actions to allow the effects of the support or interventions used to be measured. This resulted in this individualized support and education programme which has been researched on effects extensively and is now the only evidence based programme for people with PIMD in the Netherlands.

51 Petra Poppes works as a health care psychologist at the 's Heeren Loo Zorggroep and as a researcher and teacher at the Department of Special Needs Education and Youth Care of the University of Groningen. She is also involved in a tertiary expertise center on the support of people with a profound intellectual and multiple disability in the Netherlands. This centre of expertise aims to facilitate the implementation of scientific knowledge in practice (<https://expertisecentrumemb.sheerenloo.nl>).

Theoretical premises

- Children with PIMD are capable of building and maintaining **meaningful relationships**, despite the severity of their disabilities.

These relationships are essential:

- to express needs and desires
 - to exert influence over environment
- Children and adults are capable of being co-determiners of what happens with and to them, however dependent they may be on others for all aspects of daily life.

Building and maintaining these highly specialized and supportive relationships is only possible if the support of these children is well planned. Explicit and planned actions as well as goal-oriented evaluations are necessary to give full consideration to the needs of these children. It is also important to work in an interdisciplinary manner to prevent that all professionals work on their own very specific goals with the risk that professionals work on contradictory goals. All ‘stakeholders’ should be involved: parents, direct support professionals, medical staff, supporting staff, therapists and management. Training should contain the basics of theory; be organised preferably on the job (video, team-meetings, and reports) and results should be shared by all.

We start by setting up a personal profile. This process involves taking the child’s life history, his or her abilities and personal characteristics, the feelings and motives that are attributed to them and the quality of his or her relationships with support staff and others. This information is gathered using instruments that are specifically developed for the programme: information based purely on the experience of parents and staff is also included. The role of the knowledge of parents is of great importance in this step of the process. Here the Behaviour Problem Inventory (BPI-PIMD) can be used to signal challenging behaviours.

From the profile, a perspective’ (long-term goal) is formulated. It indicates a desired situation or advisable change in the future. It clarifies what we are aiming for. It can be quite vague but it is meant to set the direction of travel.

All stakeholders (parents and staff) contribute to formulating this perspective and there should be consensus about this.

On the basis of this perspective, one main goal should be defined. On this goal there also must be consensus. Then each discipline formulates their short-term goal. These short-term goals are directed towards achieving the main goal. These short-term goals have a duration of 4 weeks. With each short-term goal the activities to reach the goal are described in detail (how, why and by whom) and the evaluation of the goals takes place every 4 weeks using *Goal Attainment Scale* procedures. Every time a short-term goal is evaluated, this provides new information on the child and this information is used to evaluate the main goal. You will need more than one main goal to reach the perspective. The information that is gathered with the short-term goals can, after a period of one or two years, be used to update the personal profile. This means that the individualized programme is constantly changing. By working

in this manner you give children with PIMD the opportunity to co-determine the amount and content of the support. In this way you can give someone who cannot speak a voice.

More information can be found in the literature and the handbook.

Challenging behaviour should always be addressed in the personal profile and the goals because challenging behaviours hamper the ability the child has to build and maintain relationships with others.

An example

Eva is 27 years old. Her parents and staff describe Eva as a cheerful woman 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 profound intellectual and multiple disabilities. 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 for her to see. Colour contrasts are important. She does not appear to have 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 put 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 gain 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 excited 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 this behaviour. Both parents and staff find it difficult to understand this behaviour and don't know how to reduce or prevent it.

How to proceed?

1. Make a comprehensive profile

Hypothesis: boredom, lack of challenge and variety

2. Choose a perspective and main goal (long term and interdisciplinary):

Perspective: Eva feels safe. Evaluation date:

Main goal: We know the extent to which an increase in activities leads to a decrease of screaming and stereotypical behaviour. Evaluation date:

3. Short term goals for direct support staff:

- Determine when the behaviour takes place.
- Determine which activities Eva likes.
- Choose goals focused on extending activities that give more influence on daily life (e.g. driving wheelchair, wheelchair circuit, time spent in eating, activities to fill voids in the programme)

4. Short term goals for the physiotherapist: Movement oriented interventions, 30 minutes a day, such as: bouncing, swinging, sliding, swimming, cycling (therabike)

5. Evaluation of main goals (with everyone together): it appeared that Eva screams and has stereotypical movements when she is bored; she needs lots of variation and wants to exert influence. By offering Eva many and varied activities in a well-planned manner, the challenging behaviours have been greatly reduced

Watch the videos:

Online:

www.rug.nl/news-and-events/video/archive/unifocus/0525-unifocuspoppes

www.rug.nl/news-and-events/video/1021-unifocusvandenbosch

On this DVD:

2, 5, 11, 12:

Reflective questions:

In general:

- Write down or describe an experience involving challenging behaviour of a child with CISON.
- What in your description are facts?
- What are interpretations? These interpretations are based on what?
- Why is it challenging (to you)?
- How do you put the behaviour in an action-reaction chain? What preceded the behaviour? What were reactions (you, environment, ...)? How did it go on, what happened next?
- How would you describe the behaviour in relation to yourself or others?
- What did the child try to communicate or express?
- How did you feel about this behaviour?

Considering the video clips.

- Why is there so little disruptive or violent behaviour in the examples of video N°s 2, 5, 11 & 12?

More information

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The Expert Centre EMB organizes 1-day training workshops in The Netherlands or abroad, specifically about challenging behaviour in people with PIMD:

<https://expertisecentrumemb.sheerenloo.nl/trainingsaanbod/gedragsproblemen-bij-kinderen-en-volwassenen-met-emb-voor-begeleiders-en-therapeuten> [in Dutch]

Further reading

Vlaskamp, C. & Van der Putten, A. A. J. (2009). Focus on interaction: the effectiveness of an Individualized Support programme for persons with profound intellectual and multiple disabilities. *Research in Developmental Disabilities* 30, 873-883.

Daily life support

Alies Kap⁵² & Jo Lebeer

Supporting a child with very intensive and complex needs can be very intensive for parents and other caregivers, as the name suggests. It can take up all their energy, time and emotions. All daily things which for other, typically developing children or children with less severe disability, may seem “pretty normal”, are not easy for these children, or are not evident at all. Nothing is easy.

We will use the story of Laura, daughter of Alies, to illustrate some of the many issues involved. We do not pretend these are the same for everyone, nor do we intend for this clip to be fully comprehensive. More technical aspects can be found in Pawlyn & Carnaby (2008).

Laura was born as the third child of four, and immediately after birth it became clear that she had serious difficulties. “You have a ‘care-child⁵³”, her mother was told – without giving her a diagnosis, nor telling her that she had multiple disabilities. Laura had difficulties with everything: breathing, moving, eating and later on with speaking and learning. But she did not have difficulties with laughing and being joyful.

Eating

Laura had a lot of trouble drinking from a bottle, she produced excess secretions and was just like a rag doll, with little to no responses.

Children with CISN may have feeding and eating difficulties for various reasons: the muscles of the mouth and tongue may be hypotonic; there might be incoordination of mouth and throat muscles leading to swallowing difficulties. This might cause the child to spit out the food. The child might not manage to eat solid food because of difficulties in chewing. Children may not be able to feed themselves because of difficulties with their manual abilities. There might also be difficulties lower down: reflux is a common problem and might become a reason for food refusal or loss of weight. Feeding usually takes much more time and patience for these children.

Sometimes tube feeding is proposed. For short periods a nasogastric tube can give relief, but if that does not work, a gastrostomy tube feed might be a solution. However, the long term consequence is often that the child loses their ability to eat orally, and getting rid of the gastric tube would then be very difficult. Hence this is not a decision to take lightly.

52 Trained as an MBA financial analyst, mother of four, one of whom having complex and intensive care needs. Works as financial administrator at Foundation ‘t Gerack, an institution for care. Founder of Foundation “Ordinarily Special” which has set up a “Together to School” class for children with CISN in a regular school at Uithuizen (The Netherlands)

53 Care-child is a difficult to translate concept from the Dutch “zorgen-kind”, which has a double meaning: a child needing extra care, and a child which is the cause of sorrow to her parents.

Parents often, with the help of speech therapists or occupational therapists, find individually adapted solutions.

Pain management

Laura may start self-harming when she has too many stimuli to process, or when she is in pain or feeling insecure. This may end up in a downward spiral, from which it is very hard to get her out of. Many people do not recognize her signals and do not see her pain. It takes us a lot of effort to get her back. I'm sure if she did not live with us, and live, for example, in an institution, she would be much more autistic.

Children who cannot speak have difficulty expressing pain. This often is then expressed in difficult behaviour, such as self-harm (but not all self-harming is a sign of pain).

Inclusion: integrating inclusion and education

Two years ago I started a "Together to School" class, with the focus on setting up a small-scale, person-centred, development-oriented class in a mainstream primary school. When you go to school together with your brother, you naturally create an inclusive society. Your child is known by other children, other (regular) children know your (special) child who is just someone else, but also an ordinary child.

Now it's like "Hey Laura!" when she meets children from her school. In the village, this is nice for Laura, but also nice for her mother. At school, we offer as much as possible a one-on-one support so that care is well-organized. You can adapt to the often very intensive care demands and focus on development. But this model also allows interaction with the other children in other classes. I think that all schools should have such a class. All children are entitled to development and education. There are also children from the mainstream primary school (e.g. a child with diabetes) who receive care from the Foundation. A win-win situation! I noticed that Laura made remarkable progress especially in her alertness, I see that she is stimulated by other children in a very natural way. The iPad is brought along and the children will play games together.

This example is an illustration of successful inclusive education, which depends on a number of interrelated fine-tuned factors, which may seem like a natural process, but in fact it is carefully orchestrated. One has to create conditions in order for children to "naturally" meet, and treat the "special" child as ordinarily as possible. This requires careful organisation, in this case one-on-one care, and a good care & education plan. One can see it has a positive effect on development, and on shared attention.

Toileting

Often children with complex and intensive care needs also have difficulties with urinary and faecal continence, because they have absence of sphincter control. Unfortunately this often leads to passive acceptance of permanent incontinence. However, one might be misled by the children's absence of communication or low level of intelligence. It does not necessarily mean that these children need to stay in nappies throughout their lives. Patiently pursuing toilet training might be worthwhile. One has to learn to pick up little signs of awareness. And even if there is no awareness, some "time conditioning" might also become successful in the

long run. One of the methods which has shown some success in intellectually low-functioning children is the response restriction method (Van Oorsouw et al, 2009), which uses behavioural conditioning techniques

Health problems

Laura is a very vulnerable girl and we have already had many hospitalizations. This is very difficult for her because she needs a safe environment. When she has pain or she is surrounded by unfamiliar people, that sense of safety completely vanishes. During all these hospitalizations, many things have gone wrong due to the fact that a lot of “narrow-minded” healthcare is provided. What I mean by this is that she is often observed and treated only for the cause of her admission. The rest of her multiple impairments are not taken into consideration.

Health problems may be manyfold and may interfere substantially with development and learning: e.g. problems with recurrent lung infections, epilepsy, mouth- and tooth problems, reflux and gastrointestinal problems. The challenge is to continue to see the child as a whole person, with idiosyncrasies, and particular needs. Parents and caregivers need to inform medical staff about the “whole person’s needs”, and careful lines of communication need to be established. It helps if one medical person monitors the whole. This can be a general practitioner. Parents know their child’s needs and therefore are crucial informants and need to be taken seriously.

Organising care: dealing with “the world of care” and organizing personal support & care

Laura brought us into contact with a whole new world, the world of care. You have to deal with many different agencies, who always work from the principle “our organization first”, rather than being “child first”. One has to adapt to appointments, rules and systems.

What I have seen over the years is that it is difficult as a parent to get the right care at the right time. Often it’s “yes but ...” and that they cannot offer it as an organization because of planning, financing, protocol, etc.

A “personal budget”⁵⁴ is just a tool that you can use flexibly in your own way, but it incurs a lot of employer & management skills.

We wrote a support plan for Laura to ensure good care for her, to have the same way of working, to share experiences, like a communication passport. In this we explain how we interact with Laura’s body language and sounds.

Having a personal budget for your child’s home-care means that you have an extra person in your family at home for a large part of the week. We therefore plan the same people at regular times, because this is good for Laura, but also for us and the other children.

Consistent with the UN Convention and the right to participate in society as a full citizen, the organization of institutional care is moving from an institution-oriented principle towards a “person & family-governed” principle. As one can see from Laura’s

⁵⁴ In the Netherlands every family with a child with disability is entitled to a personal budget, which is governed by the family (and closely monitored by the social service administration), and which permits the family to choose people to support the child in daily life, in order to ensure activity and participation

experience, this transition is taking place with some resistance. A personal budget allows families to choose their own way, and it facilitates inclusion and inclusive education, provided the budget is high enough. But it also is more challenging to organize. Personal assistance is certainly not yet generalized in European countries.

Intensity of care

It is extremely intensive to take care of your child, day after day, year after year. Day and night. Even when you come home from a beautiful U2 concert, you see your child awake with a squeaky pump and full nappies. Then you just get back to work in the middle of the night. You always have to have someone to take care of your child or have to be ready to do it yourself. You cannot skip this.

Holidays, birthdays and trips are fun, but also mean a lot of extra, intensive preparation. But this allows you to stay at the party yourself.

Laura is a very vulnerable girl, it's a challenge to keep everything in balance for her. When this is the case, she is an open, sweet, happy, lovely girl. We cuddle a lot and we mirror a lot. She enjoys little things like the wind in her hair. This also taught me to look at things differently and enjoy the little things differently and to keep things in perspective.

When Laura is ill, you often feel powerless, especially when there is no improvement. In addition to sadness, we are also busy ensuring we get the right care for her.

Parents as partners in therapeutic decisions

Parents are still not always actively involved in decisions about treatment and care. It is so valuable to take up care aspects together and listen carefully to each other. The right to treatment is also becoming an issue. Children with multiple and serious disabilities are sometimes not offered any more treatment because doctors believe that this prolongs their unbearable suffering. Even in such cases, it is just so important to make agreements together.

Taking care of oneself as a caregiver

Because the child's sleep is often disturbed, parents' sleep is also disturbed. This might take a toll and lead to exhaustion. When care is permanent, day and night, and multifaceted, it is important that parents find a way to hand over care for a while. In some countries, short term respite care houses exist. Preventing burn-out is important, not only for parents, but also for care staff. There is no higher staff turnover rate than in institutions caring for people with complex and intensive care needs. To prevent burn-out, a good support network is needed, and besides good organisation, also inspirational meetings and a sense of meaning. This reminds of Antonovsky's findings about salutogenesis (how to keep healthy despite appalling risk factors) (Aho e.a., 2017)

Enriching experience

We have four special children. I would not want to be without her. She gives added value to my life. Through her I entered the "care world" and I have been able to use my talents within it. The "To school Together Classroom" is a very good example. Through her I fight for better care and well-being for her and other children

Throughout the daily, very intensive care tasks of parents, it is important to remain aware of a deeper experience of meaning, otherwise people just don't endure the hardships. Hardships may then become sources of enrichment and joy. Professionals who only see deficiencies may have become blind to see this process.

Watch the videos:

On this DVD:

3, 7, 1, 2

Online:

Daily care <https://youtu.be/v65H1N0VzLU>

Feeding: https://youtu.be/_nqDaeuP-IY

Various daily life difficulties (sleep, feeding, etc.): www.reseau-lucioles.org
(only in French)

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About Enablin+ project

What is ENABLIN+?

The ENABLIN+ project is a European partnership within the Leonardo Life Long Learning Programme. The project's aim is to develop a system of interdisciplinary in-service vocational training, where professionals and parents of various backgrounds learn together, with the aim of enhancing quality of life of the children with very complex and intensive support needs. ENABLIN+ develops a series of on-the-job training modules to improve inclusion, communication, behaviour management, activation and learning, support for daily life care

Objectives

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

Activities

WORKPACKAGE 1

Who are they? Needs of people with complex dependency needs. 1st Conference in Antwerp, research report and articles

WORKPACKAGE 2

Good practices of continuous support systems for activity and participation. 2nd Conference in Varna, research report and articles

WORKPACKAGE 3

Interdisciplinary In-service training development. 3rd conference in Wijhe (NL), leading to a "quality of life training" curriculum, training handbook and training manual + DVD

WORKPACKAGE 4

Pilot various formats of in-service training modules in the partner countries + evaluate their efficacy, feasibility, content and modalities; 4th meeting in Cluj-Napoca (RO).

WORKPACKAGE 5

International conference & train-the-trainer workshops Milan, to ensure multiplier effects









WORKPACKAGE 6

Dissemination & Valorisation. Newsletters, website, publications, participation in international and national conferences.

WORKPACKAGE 7

Quality assurance, evaluation & reporting. 6th partner meeting and dissemination conference in Évora (PT).

Partners

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Education and Culture DG

Lifelong Learning Programme

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