Workpackage 2 – Deliverable 4

Report

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

Jo Lebeer & Heleen Neerinckx (Editors)
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Continuous Support Systems and Good Practices towards Inclusion, Activation and Participation of young people with complex and intense support needs

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Part III
Approaches and methods in supporting care & education of children with complex and intensive support needs
Introduction

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

Methods and participants

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

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

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

Results

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

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

Communication, intentionality and capacity to make choices

Juliet Goldbart\(^1\) (Professor of Developmental Disabilities, Manchester Metropolitan University, UK)

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

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

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

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

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

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\(^1\) Juliet Goldbart PhD is professor of Developmental Disabilities and Associate Dean for Research at Manchester Metropolitan University in the UK. A psychologist by background, she has taught speech and language therapy students for over 30 years. Her research interests include communication and complex needs, and appropriate service delivery models for families in the UK and in under-served countries. She has a longstanding involvement with the Indian Institute for Cerebral Palsy, including an evaluation of innovative approaches in establishing disability services in slum areas of Kolkata.

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

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

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

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

Probably the most important thing you will ever learn!

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

Secondary Motivational Impairment

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

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

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

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

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

Key references


Resources

General – 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


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

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

Intensive Interaction: http://www.intensiveinteraction.co.uk/
Augmentative & alternative communication in children who cannot speak

Anna Dal Brun

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

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

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


Enabling interpersonal relations

Sara Nijs

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

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

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2 PhD in Special Needs Psychology & Pedagogy, Catholic University of Leuven, Belgium
in understanding the idiosyncratic signals which may lead to misunderstanding and negation of the person.

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

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

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

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

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


More information
Dealing with problem behaviour

Petra Poppes

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

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

3 Petra Poppes is health care psychologist at the's Heeren Loo Zorggroep in The Netherlands and works as researcher/teacher at the University of Groningen. Petra Poppes has worked as a health care psychologist since 1997 and has specialized in the support of children and adults with a profound intellectual and multiple disability. She has completed her PHD project last year on challenging behaviour in people with PIMD.
consequences of this behaviour for the person with PIMD as ‘not severe’ and the support given to people with PIMD who display a high frequency of challenging behaviour is scarcely aimed specifically at reducing this problem. However, challenging behaviour always influences the ability of people with PIMD to gain experiences and forming relationships with others.

Implications

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

Causes of challenging behaviour

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

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

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

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

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

Case description: Eva

Eva is 27 years old. Eva is described by her parents and staff as a cheerful lady who likes to be around others. According to all those involved Eva enjoys listening to music, playing with soft materials, swimming and being outside (no matter what the weather is like). Eva has a profound intellectual and multiple disability. She has microcephaly, epilepsy (seizures don’t occur because of the medication she is taking) and diabetes. Eva has a visual impairment. She has trouble seeing contrasts. A yellow cup on a white table is difficult to see for her. Colour contrasts are important. There does not appear to be a hearing problem. Eva cannot walk and is in a wheelchair. Eva can hold objects, explores them with her mouth but according to staff she mostly throws the objects on the ground. Staff say it is difficult to capture Eva’s attention and they fear she gets bored.

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

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

Resources

General – film about individualized support program

Links:
www.rug.nl/news-and-events/video/archive/unifocus/0525-unifocuspoppes
www.rug.nl/news-and-events/video/1021-unifocusvandenbosch
Triple –C: restoring life to “normal”

Hans Van Wouwe & Dirk Van de Weerd

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

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

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

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

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4 Special needs psychologist, Carante Care Group for people with intellectual disabilities, ASVZ, Sliedrecht, The Netherlands
The Triple-C values

Figure 1: The Triple C values and how to interrupt the stress circle

Figure 2: The Triple-C support pyramid

References

Contact
Enablin learning, activity and play

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

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

The method "Experience it" recognizes (knows) five principles including:
1. The theory of Experience Planning (by Dr. D. Timmers-Huigens) or development according LACCS (by K. de Geeter and K. Munsterman)
2. Total Communication
3. Basal stimulation (Andreas Fröhlich)
4. Sensory Data Processing
5. Locomotion

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

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

"Experience it" within a framework

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

- personal image
- Perspective
- Main goal

(Work) goals

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

This method is well applicable within the education (system) because it always starts with the basic needs of the child. If this condition is met (answered) the child is open to be able to develop further on his and her own way.
Meanwhile there are written five books and some DVDs have been published about the method 'Experience it'.

Basics “Experience it”  Experience it with crafts  Experience it with care

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

Experience it with practical skills  Experience it with physically oriented activities with  Youtube:
Practical skills  Folding laundry; Baking apple pie; polish shoes
Vita-Motion: robotics to increase passive movement

Objectives Improve wellbeing and QOL and cost reduction

Main activities Development of multi-sensory passive movement experiences

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

More information: www.vita-care.eu
On the move with “force in simplicity”

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

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

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

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

www.cello-zorg.nl [only in Dutch]

Working with music

BIM – experiencing music

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

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

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

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

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

Courses are organized for teachers and educators working with this target group
Music Therapy with Girls with Rett Syndrome

Marina Luisa Rodocanachi Roidi, Kumiko Toshimori, Angelo Colletti and Alessandra Gandini

Rett syndrome: a high complexity disorder
Rett syndrome (RTT) is an X-linked neurodevelopmental disorder. Mutations in the X-linked MACP2 gene can be found in 95% to 97% of individuals with typical RTT. The syndrome is one of the main cause of severe intellectual disability in females, with approximately 1:10,000 females worldwide affected.

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

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

Music therapy in Rett syndrome

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

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

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

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

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

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

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

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

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

*Experience with music therapy at the Don Gnocchi Centre*

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

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

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

Based on our experience, the specific goals for girls with Rett Syndrome are the following:
promoting and supporting relational, emotional and communicative abilities
enhancing better emotional command
promoting relational autonomy and the desire to face the environment
preventing relational, emotional and communicative complications
supporting self-esteem
physical and psychic relaxation

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

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

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

Table function
Patient’s observation and assessment in order to:
- Define a rehabilitation plan,
- Evaluate the time course of the rehabilitation process through qualitative and quantitative items analysis;
- Share data with the rehabilitation team.

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

<table>
<thead>
<tr>
<th>Name</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

#### GENERAL OBSERVATION

<table>
<thead>
<tr>
<th>Feature</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Facial expressions</td>
<td></td>
</tr>
<tr>
<td>Glare mobility</td>
<td></td>
</tr>
<tr>
<td>Stereotypy (yes/no, examples, seriousness)</td>
<td></td>
</tr>
<tr>
<td>Eye contact</td>
<td></td>
</tr>
<tr>
<td>Breathing difficulty (yes/no, examples, seriousness)</td>
<td></td>
</tr>
<tr>
<td>Muscle tone</td>
<td></td>
</tr>
<tr>
<td>Communication aid</td>
<td></td>
</tr>
</tbody>
</table>

#### MUSICAL ACTIVITIES (yes/no, which)

- Songs
- Sound relationships: sound tracing, sound removing, sound dialogue
- Music listening
- Integration with other expressive activities (dancing, drawing...)

**Observations:**
### COLLETTI-TOSHIMORI ASSESSMENT TOOL OF MUSIC THERAPY

<table>
<thead>
<tr>
<th>Name</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

### SONGS AND SOUND DIALOGUE EVALUATION TABLE

#### ACTIVATION
- Interest in instrument/voice
- Communication through eye gaze
- Level of eye exploration
- Level of sound exploration
- Other modalities for exploration (e.g., touch, movement)
- Participation in activities
- Activation level (energetic level)
- Duration of activation
- Inhaling skills
- Inhaling skills with communication aid
- Vocalization

**Integration**

**Functioning level (0-100)**

#### COUNTENANCE
- Memory of musical activities through sessions
- Attention to task
- Ability to stop or change paces during musical activity
- Ability to interact through sound proposals
- Interaction skills with voice
- Variability in the modality of hearing instruments
- Variability in playing sounds
- Rhythm
- Independence
- Autonomy in activating relationships
- Autonomy with communication aids
- Frustration tolerance
- Modifiability after MT session

**Integration**

**Functioning level (0-100)**

### PERSONAL HARMONIZATION

**FUNCTIONING LEVEL (0-100)**

<table>
<thead>
<tr>
<th>Legend</th>
<th>Frequency</th>
<th>Degree of autonomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Never</td>
<td>None</td>
</tr>
<tr>
<td>1</td>
<td>Seldom</td>
<td>With continuous support</td>
</tr>
<tr>
<td>2</td>
<td>Sometimes</td>
<td>With support (sometimes without)</td>
</tr>
<tr>
<td>3</td>
<td>Often</td>
<td>Often without support</td>
</tr>
<tr>
<td>4</td>
<td>Almost always</td>
<td>Almost autonomous</td>
</tr>
<tr>
<td>5</td>
<td>Always</td>
<td>Completely autonomous</td>
</tr>
</tbody>
</table>
**Results**

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

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

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

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

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


**ACKNOWLEDGEMENTS**

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- We thank the Rett's Syndrome team at Don Gnocchi Foundation, Vismara Institute: Francesca Cozzi, Valentina Gestra, Francesca Grange, Elisa Pari, Fabrizia Scotti and we particularly thank Riccardo Rijoff for his contribution to organize observational data and Alessandro Baggia for poster editing and the Girls with Rett syndrome with their families.
III B - Enabling well-being and health

Basal life
Andreas Fröhlich

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

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

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

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

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

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

**Basal support**
The fundamentals of basal support may be summarised as follows:

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

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

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

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

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

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

**Prospects: Basal pedagogical work**
Curiosity, play and exploration are the most important characteristics of childhood. Playing, being
inquisitive and trying out anything and everything are the essential activities for a natural and healthy
development – even if parents often think: ‘That’s enough now!’
This also applies to children with severe and multiple impairments even though they need much more support. Often their physical and intellectual functions are limited or inappropriate to such an extent that they are not able to play, to satisfy their curiosity and to explore in an adequate way. Education and therapy have to provide the necessary assistance and encouragement. We have to make sure that the child can maintain an appropriate position in order to get access to the surrounding objects. We have to present all the relevant objects in the proper light in order to attract the child’s attention to excite his/her curiosity.

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

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

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

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

Your scent.
I know you,
When you are close to me.
Your voice – so far away,
Your face – a soft mist.
I like to feel you,
Your scent tells me that I am safe.
III C - Enabling participation, ethics & society
Participation in education; An integrated approach of care and education
Mia Nijland & Inge Kroes

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

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

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

Mia Nijland & Inge Kroes are special needs psychologist. The founded the Expert Centre for Care and Education, Wijhe, The Netherlands. Mia also works in the “EMB Platform”, which is an experts’ network on people with PIMD.
How should inclusive education be realized? It is not easy for experienced group leaders to achieve purposeful development, let alone an inexperienced teacher who does not know the target group and is not educated or trained to teach these students. Education is characterized by a group-oriented approach; how does it combine with the necessary individual approach of this new group of students? There are also doubts about the feasibility of combining care, therapy and education into one individual programme. The question is how to adapt to specific care and treatment needs in a school environment that is not designed for that purpose.

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

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

**Profiling**

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

The profiling process should not be limited to single momentary information about functioning in sub-areas, such as a sensory-, perception-, focus-, communication- or support profile. These lead to fragmented images instead of a broad integral image, and in education practice they would be more confusing than illuminating. Therefore, these different results and perspectives should be brought together to achieve an integral functional profile. An example of a parent-made video-portfolio is the movie Laura on the Enablin+ DVD.
Action
In order to offer good education to a child with CISN, work has to be done on several levels. First of all, education for children with CISN can only be successful when there is a planned individual education arrangement. Inspiration can be obtained from curriculum and learning trajectories adapted to the target group, which provide useful tools to determine development-oriented goals and learning activities in various domains. Furthermore, it is necessary to create an individually tailored social and communication-rich learning environment, stimulating active involvement and learning processes of the child. Finally, it requires organizational work on an integrated education and care offer.

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

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

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

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

Within a thematic approach, one also takes the calendar age as a base and states that all children of a certain age, including children with CISN, must learn about the same subjects. For example, in the UK, a national curriculum has been developed for all children regardless of their limitations (Tadema,
Curricula of this nature mainly result from the inclusion movement. A widely heard critique is that it is very difficult to find a balance between this thematic approach and the development and learning needs of children with CISN.

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

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

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

*Plancius programme - The Netherlands*

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

Learning trajectories and curricula should not be considered as a strictly linear pattern. This involves the risk that they suggest a normal development. According to Tadema (2007), there is a chance that students will “have to” learn a new step as described in the learning trajectories, without the teacher questioning if it is an appropriate next step for this particular child. The curricula may provide inspiration, but the "learning material" that is selected and the order in which learning steps are taken must be fully tailored to the individual student. Learning is not equal to developing new skills. Also expanding existing skills, needing less support in performing a task, showing more involvement, maintaining skills in regressive conditions ... are forms of learning.

**A stimulating social-communicative learning environment**

Children with CISN learn and develop from interactions with people around them. Active involvement and learning processes are associated with a stimulating social and communicative learning environment (Arthur, 2004; Arthur-Kelly, Bochner, Center & Mok, 2007).

A student with CISN needs a teacher who believes in his (learning) possibilities. If that confidence is not there, one will not be aware of the relatively small developmental challenges that a student makes, and one will be insufficiently stimulating.

Furthermore, a student with CISN will only really develop and be open to learning experiences when there is quality interaction with the teacher. The teacher should, for this purpose, have an open mind attitude and try to systematically discover signals from the person with CISN, try to interpret and respond in a consistent way. Also, the teacher will need to make use of appropriate interactive strategies. This means, for example, changes in the way of communicating (e.g. position, tempo), establishing positive interactions with the person (e.g. confirmations, ratifications, pleasant and enjoyable interactions), use of specific interaction forms (e.g. moving and mirroring of physic, mimic, sounds and language) and stimulating the initiatives of the child itself (Kroes, 2017).
A stimulating social-communicative learning context is also an environment in which the child gets opportunities for input and choices (see Goldbart and Kroes, this manual).

**An integrated and complementary education- and care offer**

Education for children with CISN requires more than working individually based on learning trajectories and classroom adjustments. Due to the complexity of their needs, education for these students will have to be supplemented with a healthcare offering that includes medical care, paramedical treatment and parenting.

Planned thinking through learning trajectories and the expertise to work in a didactically based way on the development of a child is an input from education that is invaluable. From the point of view of healthcare, the centralization of the individual, the art of observing, connecting to the (limited) possibilities of these children, and seeing these possibilities, the knowledge of syndromes, illnesses and medical aspects is a major addition.

Education and care are therefore not separable for these children. There is a need for a multidisciplinary team, with not only a permanent team of teachers, supervisors/childcare workers but also therapists, a remedial educationalist, psychologist, nurse, social worker, even a technical worker for, for example, adaptation of assistive technology. In addition, there must be sufficient flexible personnel; it should be possible to have several staff members attending the same class at certain times. More attention should be given to the education and reception of children with CISN in basic education, training and internal retraining.

Teaching children with CISN also requires a *customized infrastructure*: sufficiently large spaces for wheelchair users; for specific spaces (e.g. self-service area, snooze area); spaces must be accessible, comfortable and maintenance-friendly, etc. There should be *specific tools* available, such as beds, lifts, seat shells, computer adjustments, customized educational material,....

In terms of *education organization*, deviations from the current school system will be necessary. Class groups should be small, 5 to 6 students. One should also let go of school-based approaches to the class time duration. A child with CISN does not live according to an hourly schedule: if at the time of play time the child is aware and alert, why should there be a "forced" break at that moment? Due to their often medically complex problem, a smooth transition from part-time to full-time education and vice versa should be possible without too much administrative hassle.

The question of the *location* of education is secondary. Although a school that is as regular as possible on the basis of social participation opportunities has preference, in principle, every physical learning environment, if the appropriate expertise is applied in a demand-driven way, and the necessary facilities, resources and materials are available, should suffice. This means in the most exceptional situation that a bedridden student goes to school within the day-care area of the living facility where he or she resides.
Furthermore, regional agreements must be made on which schools and care organizations will receive mentioned target group. Examples are given of the “together to school” classes on the Enablin+ DVD and in this manual.

References


Accompanying families

Carlo Riva, Abilità

Dealing with ethical dilemmas and family issues

Mario Mozzanica, Don Gnocchi Foundation

Ethics of care

Video resources for training purposes

Training materials available online

Training support workers to deal with people with complex needs

Source: Department for Education UK.

www.complexneeds.org.uk/ Free online training materials

The Welsh Assembly Government's Routes for Learning materials

Also an excellent free online resource. You can find them separately or within the above resource, at http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/m08p010c.html

Enablin+ Training DVD

With the Enablin+ project we have gathered video samples of some of the mentioned examples of good practice. They are collected on a DVD which accompanies a training manual (a process book) explaining and framing them.

Conclusions

Support systems are often not yet continuous in many countries, for the category of the children who are most in need. Governments are rapidly adapting to the requirements of the UNCPRD, but financing in most partner countries – except perhaps The Netherlands, - falls short. We defined a set of criteria of good practices which is based on quality of life and the objectives of the UNCPRD. The harvest in search of examples of good practices has been rich. People do take various innovative initiatives despite this shortage of resources: towards inclusion, towards more activity, towards involving families as partners, towards a wider range of activities, towards an earlier intervention, towards more education (whereas before it was believed no education was possible, towards sharing knowledge. The nominated examples are far from complete, hence it is important to leave the list open. It is also important to differentiate and take into account that initiatives can be considered “good practice” is they are on the way towards a better quality of life and inclusion criteria. Practical examples are an excellent source of learning. Knowledge is spreading, but true sharing of knowledge and experiences
between parents and professionals, is an issue. Some countries have taken interesting web based sharing initiatives. It is absolutely mandatory to know what kind of approaches work and why.