

Using a common language together with parents in early childhood intervention

Pre-print

Authors

Manfred Pretis, Prof. Dr. Affiliation: Medical School Hamburg office@sinn-evaluation.at	Rozita Petrinska Labudovicj Education for ALL, Skopje
--	--

Abstract

This paper within the Erasmus+ projects www.icf-inclusion.net, www.icf-plan.eu, www.icf-implement.net addresses the use of the ICF in early childhood intervention. Using easy read, this paper explains to professionals how the ICF is used and how it could help to focus on a common language, observations, meaningful participation goals, and a new understanding of developmental difficulties.

Key words: Cooperation with parents, Easy Read, ICF, Participation

0. EASY READ as a starting point

This text is written for parents. It helps to better cooperate with professionals in the “team around the family”. We use simple words and build a good relationship between parents and professionals in early childhood intervention. This can be seen as one of the most important aspects of family support processes. The following text avoids difficult expressions, uses simple sentences, and provides an answer to the question: which benefits can parents and children with developmental difficulties have when using ICF as a common language together with professionals?

1. What is the International Classification of Functioning, Disability, and Health (ICF)

The ICF is a book which was published in 2001 by the World Health Organization (WHO, 2001). It is translated into many languages. Even a parent-friendly version (www.icf-school.eu) is available. The main goal of this book consists of creating a common language when parents or other guardians communicate and exchange with professionals about the developmental situation of their child. This is very important, as usually parents are faced with a lot of contacts with medical doctors, physiotherapists, speech therapists, special educators, social workers, or other professionals. Together with the parents, all these

professionals create the “team around the family”. Even though most of the professionals are highly trained in their field, it might be very difficult for the parents to understand always what these professionals talk about. Sometimes parents experience difficulties in understanding medical language with all those Greek and Latin words. Some parents also might face challenges when talking about scientific findings, names of muscles, or even when talking about different legal entitlements. Because of this, WHO decided to create a common language which could be understood by all the involved persons. This does not only refer to children with developmental difficulties but to all persons. Many parents know that WHO also uses other description systems: they might know the International Classification of Diseases (ICD 10) or the Diagnostical Statistical Manual of Mental Disorders (DSM V). However, these two books mainly describe what a child with a health situation **cannot** do: these two books mostly describe symptoms.

However, these two books are not able to describe what a child or person with a health situation or a diagnosis is able **to do in meaningful situations**. In addition, they do not mention what a person wishes to do. Because of this, WHO created a book where the whole situation of a person with a health concern (this also means children with developmental difficulties) can be described from various points of view. So, the parents can talk about the situation of their child in their parental language (Pretis et al., 2020): the medical doctor can join this conversation with his or her expertise, and they both understand because they use the same categories.

2. How does this work?

The ICF describes what a child (despite his/her health concern) is able to do. The ICF uses different categories to do so.

The first refers to the **individuality** of the child: what Simon (6 years) likes or dislikes, but also to what was Simon’s individual (hi)story from pregnancy till now.

The second group of terms refers to the **environment** of the child. This can be the home, the kindergarten, or the village. Peers in the neighbourhood, toys, books, technical aids, a physiotherapist could be assessed as facilitators or as barriers towards the development of Simon. This is important: the ICF understands developmental difficulties as an exchange between the child and his/her environment. The child is never seen as a single “stigmatised” patient, but as an active “agent” in different social situations, be it at home with the parents,

the grandparents, the siblings, at the nursery, the kindergarten, the school, the playground, the supermarket, and so on. If there are barriers, it is important to reduce them.

The third category refers to the **health concern or the health situation**. This might be about the diagnosis or concerns/wishes of the parents. For many parents and professionals, the diagnosis is important: but children and families are more than only a “diagnosis”. Suzan is more than “Down syndrome”, Terezie is more than “spina bifida”, and Pavel is more than “cystic fibrosis”: because every child is always seen as an individual with his or her resources and strengths in diverse environments.

The fourth group refers to the **body (structure)**. These are the anatomical parts of each human. Mainly medical doctors feel responsible about this aspect. Sometimes children need surgery or even prostheses.

The fifth group refers to what this body can do. This is called “**body functions**” and refers to breathing, controlling the movements, hearing, seeing, being awake. Therapists and medical doctors usually perform examinations and interventions. Sometimes children have to take medication to ameliorate, substitute, or recover some functions.

The sixth and most important aspect is “**participation and activities**” in meaningful situations. Early childhood intervention is mainly understood as meaningful support for children and their parents (including siblings, grandparents...). Participation means that a child is able to do all those activities which other children without health problems are typically doing. If there are developmental difficulties, we also ask ourselves which kind of support a child needs to be able to do this in the best possible way.

Talking about participation in early childhood intervention also gives the children a “say”: Professionals together with the parents try to understand which goal the child itself wishes to reach. Focusing on participation means focusing on the activities of the child: so, it is not about physiotherapy, but it is about James: *he is 6 months old with a suspected hypotonia, and he lifts his head at home when his mother supports him*. Why he does so? We suppose that he wishes to observe and look at toys or family members around him and participate, the ICF, therefore, helps to create meaningful goals and activities in the real life situation of a family.

3. Why to use ICF?

For the parents talking with professionals is sometimes challenging. Parents might have difficulties understanding used terms, they even might be shy to ask important questions.

Using a common language therefore helps parents to better understand, what professionals are saying and make goals more transparent and meaningful for the whole family. Pretis and Brandt (2017) report that parents feel much more like an expert within the “team around the family” if all members use ICF. As said before, for the ICF the environment is important: if parents and professionals think of supportive or hindering environments they also increase inclusive thinking and acting (Pretis, 2017), rather than the child as a “patient”.

Parents communicate on an equal base with professionals. This also refers to all documents: they should be written in a way that parents are able to understand these “stories” about their child in their family situation.

4. How can parents use the ICF in the “team around the family”?

First, parents need some basic information about the words and categories used by the ICF. Usually, this is easy if we use words which parents typically use: “sleep” instead of “sleep function”, “watch” instead of “visual perception”, or “toys, or computers” instead of “material surrounding”. There are also different tools (like pictures or mobiles) to explain the important 6 groups of observations in the ICF:

- 1) the child’s individuality,
- 2) the child’s meaningful environments,
- 3) the health concern of the parents or the diagnosis by a medical doctor,
- 4) the body (structural) issues of the child (mainly described by medical doctors),
- 5) all the (body) functions - what the child can do with his or her body and,
- 6) participation in terms of meaningful activities.

Usually, parents do not show big difficulties to understand these six groups. However, professionals can also guide the discussion by asking relevant questions (Table 1):

Table 1: Exemplary ICF-based questions

Child’s individuality	What is the name, age of your child? What are his/her preferences, personal history etc? Also, the child is always addressed by his/her name (in all documents).
Child’s environment	How is the material situation at home? Are there any aids to help the child: does Simon need glasses, orthopedic devices, etc.? Who is important for Lidia at home? What do these important persons, including professionals, think about the developmental difficulty of Peter? How do you consider your surroundings, transport situation, financial situation, legal situation, etc. for Arzu?
Health concern and body	What does the doctor say, or which diagnosis are mentioned?

issues	
The same refers to body structures. The main question will refer to possible descriptions by medical doctor	Are all the organs of Liz okay? How tall is Jitka? Did Robin had a surgery of his heart?
Body functions About body functions, parents are easily able to answer questions like	How does the child sleep, how does the child eat, how is the digestion functioning, which kind of things the child remembers, how long could be the child's attention to games, how the child moves, whether a child is able to see and hear, and so on. Usually, parents as experts of their daily life are able to answer these questions from their perspectives.

Activities and participation sometimes might be a little bit challenging for parents as there is a possibility to confound categories and aspects. In Table 2, helpful guiding questions can be found when speaking to parents.

Table 2: Helpful questions to address „participation and activities“

About learning	How does Richard learn? How does he listen and watch things in school? How is Rebecca learning concepts like colors in the kindergarten? Which complex tasks can Can perform at home or in the kindergarten? How can Mehmet follow rituals in the nursery?
About (daily life) tasks	Which complex tasks can Michael perform at home or in the kindergarten? How can Mehmet follow rituals in the play group? How does Isa cope with distress at home?
About communication	How is Aleksandra communicating in the kindergarten, e.g., by signs, pointing to something, or using vocalization?
About moving around	How does Felix moves around at home? How is Isabel reaching or grabbing things during the sessions? How is Sarah moving from here to there when she wants something?
About self-care	How is Ada eating, showing her need towards toileting and dressing or undressing herself in the Center?
About interacting with others	How is Ronaldo interacting with you as the parents, with the siblings, with the grandparents, with the kindergarten teacher?
About what is important in life attending kindergarten, play,...)	How does Katerina play in the kindergarten?
About social life of the family	How does Chan participate in social life e.g., visiting a church, the mosque, the synagogue, family parties, sport events and, so on?

These structured questions focus on the **HOW** (see: www.icf-inclusion.net) and NOT on “which problems do you perceive as parents or professionals”. This is a second important aspect besides using a common language: The ICF invites professionals and parents firstly to **observe** what a child is doing: *Jane (2 years old) lifts her head when supported by her mother at home. Ahmed (3 years old) expresses his needs in kindergarten by pointing at things. Dance (5 years old) draws circles in kindergarten, when the teacher directs her arm.* This is important as many professionals and parents often use direct or indirect assessments: “*My child is not able to walk (Jane)*”, *My child is not able to talk (Ahmed)*, *My child has difficulties in drawing (Dance)*. Therefore, reports in early childhood intervention tend to be very negative: professionals and parents rather focus on what a child is not able to do. However, each child is different and each child has strengths and abilities. Jane, Dance, and Ahmed try to **participate** and be **active** in their relevant environments. The ICF celebrates abilities by differentiating between observations and assessments. No child is totally disabled: usually, each child is also able to do a lot of things. We have to observe and describe them.

However, the ICF does minimize worries of parents. In a second process, the ICF will invite professionals and parents to assess what we observed: *Do Janes, Ahmet and Dance’s activities represent age typical participation?* Sometimes in early childhood intervention children might show participation restriction. Often these restrictions are the reason why early childhood intervention is performed.

Jane shows participation restrictions in her mobility as 2-year-old girls usually control their movement and walk, sit, grab things... Ahmed shows participation restrictions in communication as 3-year-old boys typically communicate through words.

Based on such an assessment, it is also possible to talk about participation and treatment goals:

Within 6 months, Jane reaches toys at home by grabbing them with one hand and supporting her balance with the other arm.

Within 6 months, Ahmed expresses his need in the kindergarten using picture cards.

It is noteworthy that children might have difficulties expressing their own wishes and goals. Specifically in early childhood intervention, goals will be discussed and set with parents and professionals. However, Swiss experience shows (www.icf-school.eu) that from age 6 also children might be actively involved in talking about their own wishes and goals concerning kindergarten or school.

5. The impact of using the ICF together with parents in the team around the family.

As Pretis and Brandt (2017) could show, using the ICF as a common language in early childhood intervention increases the self-efficacy of parents. They feel respected both as experts of the daily life of their child and as a full team member as they use the same language. The ICF increases the cooperation, as parents fully understand what professionals are talking about. The ICF also increases the focus on meaningful goals and the possibility to evaluate them.

6. How to start this process towards using ICF as a common language in the team around the family?

If an early childhood intervention center decides to use the ICF, usually implementation and training processes take place (www.icf-plan.eu). It is important: that parents are always a part of the “team around the family”. We highly recommend that parents themselves take part in the ICF training together with the professionals. Only then, a meaningful use of the ICF is guaranteed.

Last, but not least: What is the ICF not? The ICF is not a system of diagnosis or a system of stigmatisation and not a numeric coding system in early intervention using codes and numbers to describe children. No family wants to be a list of codes and numbers but families want to communicate on equal bases in the team around the family.

What is the ICF? It is a common language that helps increase understanding for all team members in early childhood intervention and hopefully increases the meaningfulness of support.

7. References

- Pretis, M. (2017). “Let us be prepared, but wait and see” The use of ICF-CY in early childhood intervention and paediatric social care in Germany and neighbouring countries. In Castro, S. & Palikara, O. (Eds.) *An Emerging Approach for Education and Care: Implementing a Worldwide Classification of Functioning and Disability*. London: Routledge
- Pretis, M., & Brandt, J. (2017). ICF gemeinsam mit Eltern. In. Gebhard, Sohns. Seidel, Möller-Dreischer. (Hrsg.), Kongressband VIFF-Symposium 2017. (ICF together with parents)
- Pretis, M. (2020). Teilhabeziele planen, formulieren und bewerten. München: Reinhardt. (Planning participation goals)
- Pretis, M., Kopp-Sixt, S., Harden, E., & Schpock, E. (2020). ICF version for parents. So that they can communicate on equal level and in a common language with the professionals. Skopje: Education for all.
- WHO (2001). ICF. International Classification of Functioning, Disability and Health. New York: WHO.