

Family-centred, Routine-based Practice of Early Childhood Intervention Provided in Natural Environment in Hungary.

Assessment Country Report of Piloting the
Family-centred Practices.



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In the ECI Agora pilot program starting in September 2019, we provided nearly 200 families with our services under the Agora concept. In the three pilot institutions, a total of 18 professionals – physiotherapists, special educators, and conductors – provided care for the families. The therapists participating in the pilot consulted with other professionals (psychologist, district nurse) based on family needs. The changes in children's development were followed by pediatric neurologists during the pilot, following the protocol of the Gézengűz Foundation. Between September 2019 and March 2020, professionals provided care more than 800 times according to the Agora concept to the families who participated in the pilot study.

To measure the effectiveness of the pilot, we asked 50 families to participate. A very high proportion of them (88%) completed the online questionnaire issued in May 2020, which examined changes in the pilot period in several areas.

As a result of the COVID-19 pandemic started in the first quarter of 2020 in Hungary, personal care was suspended due to the epidemiological situation. Therapists continued to support families in the form of remote consultations, and consultation between professionals and supervision of pilot organizations took place online as well. The majority of the families participating in the pilot were open to using various digital platforms to conduct video consultations and continue the pilot. However, in some cases, families were, unfortunately, unable to continue the pilot, partly for technical reasons and partly due to negative environmental factors. Despite the difficulties, we were also able to keep in touch with them by providing telephone consultation, to partially maintain the continuity of their support.

The epidemiological situation has been a challenge of uncertainty for both families and professionals. The pandemic required immediate adaptation in the face of sudden changes in living conditions, changed possibilities and responsibilities on the part of everyone. The majority of families accepted the teleconsultation option offered or any support that contributed to their child's condition. In the case of families who received care in one of the pilot institutions before the pandemic, the transition to online care was rather smooth, since the professionals had worked closely together with the family previously, too: they focused on the home life and everyday implementation during the development of the intervention plan. However, for families who joined us during the COVID-19 epidemic, it was difficult to begin working together without meeting in person, as the children and the professionals could not yet experience the presence of each other.

For some families, the main difficulty was that in many cases one, two or even more siblings were at home at the same time in addition to the child in need of care, so everyday routines had to be constantly adapted to the home environment and family dynamics. As a result of 'social distancing,' mothers were left alone; the possibilities of the support network have narrowed, as could be seen on ECOMAP. The father became only one 'personal' supporter, who had to do the their everyday jobs as well. The grandparents, extended family, friends, caregivers could only help the mother in the online space, who was burdened with even more tasks with the siblings who stayed at home, too. Perhaps as a consequence of this, professionals reported that families approached them with several questions that fell outside their field of expertise and competence. An additional challenge for the professionals was that during the video consultations they could only support the family through verbal and therapy practice dummy presentations, they could not lend a helping hand in different functional situations.

However, despite the difficulties, everyone tried to adapt to the new situation to the maximum, which eventually resulted in positive insights as well. Families were very enthusiastic about sharing home-made videos of the exercises and their success with professionals. Parents who previously did not trust themselves enough and looked at professionals as problem-solvers during care, now in this emergency they became active participants in their child's development, which, as a positive change, significantly increased their competence as parents. The achieved goals and successes were a joy for the whole family.

1 | How the pilot implemented the routine and family-centered approach?

1.1 | Work in natural surrounding (e.g. at the home of the family)

The therapists and families participating in the pilot mostly thought it was a positive experience to have care, counseling, and coaching in a natural-family home environment, even in the online space.

By virtually entering the daily lives of the families, the caregivers got an insight into the everyday life situations and real difficulties of the participants in the pilot, as well as the families' own space and environment (for example, what kind of home equipment they have, how exactly the meals take place, family rituals, etc.).

The continuous remote consultation in a natural environment created an opportunity to find solutions to the issues that arise from week to week in line with the daily life of the family. In addition to the positives, both families and professionals reported initial high levels of stress.

At first, it was unusual for families to let an outsider into their lives. Therapists also had to adapt to the expectations of the pilot and the possibilities.

1.2 | Used tools (e.g. ECOMAP, routine based interview)

We received very different feedback on the tools used. Many of the therapists saw the RBI as a good starting point, providing them with a kind of guideline during the conversation. However, several commented that the long-term use of this form of RBI could not be imagined: it was found to be too structured, it was more difficult to interpret the listed routines in the case of babies, focusing on nursery, kindergarten, school-age children. The recording of the RBI took too long, so it was not really practical for everyday use. Families found the recording of RBI too time consuming and exhausting, but in many cases, the satisfaction scale at the end of the routine meant positive feedback and confirmation for them.

We quote some of the feedback below:

'Completing the questionnaire wasn't that easy. There were some things I had to think about, but after we were done with it, I was really faced with what activities, things that are harder to do (dressing, talking, bathing ...) I got a lot of useful advice on these, which I accepted. it helped me a lot, we improved a lot, we learned to talk with hand signals, I gave my son more space to get dressed, he learned how to signal pee or poop into the nappy and so on...' (From a mother)

Clearly, tabulating and prioritizing goals was the most useful tool for families. This is because setting smaller goals and constantly reviewing/monitoring them helped them to have more rational expectations for their child's development. Thus, the development achieved was more spectacular, which had a positive effect on the mood and dynamics of the whole family. However, based on parental feedback, we would point out that the pre-determined number of goals was too structured, which stated that we should set 6 goals. Rather, it triggered a compliance constraint on them.

Overall, the ECOMAP helped families raise awareness of their relationships, visualized by those who have a positive impact on the family, and who is a source of tension for them. By realistically reviewing their real situation, they helped assess their resources so they could more easily take advantage of the opportunities available to them.

'Once it was done, I noticed what hidden sources of stress I have that make our already difficult family life even more difficult, which in itself was interesting to me!' (From a mother)

However, therapists found ECOMAP less useful and usable for their own work.

1.3 | Work with family members beside the child with the disability

In summary, the pilot helped deepen the relationship between the caregiver and the family. During the virtual and personal family visits, limited family resources became more visible, so the whole family became more involved. Although in our experience, a higher proportion of mothers attended the meetings, the roles of other family members also emerged during the conversations.

1.4 | Positive findings (what went smoothly, which attitudes of professionals and families changed)

According to the care providers, the main positive outcome of the pilot was that they were able to gain insight into the everyday life of the families, thus gaining new insights with which they could help to interpret and identify the current difficulties of the families. As a result of these effects, spectacular changes began in the life of the families.

'Setting up the order of the problems and scoring the difficulty, I feel, encouraged me, as a therapist, to be purposeful enough. I monitored and evaluated the changes every month. It also set a direction for the conversations and the therapeutic process.' (From a physical therapist)

'Involving professionals from other fields, reviewing the agenda were not new elements in the care model; at the same time, home care and resource mapping was a positive novelty for both parties.' (From a physical therapist)

Families felt that as a result of the pilot, they became more competent in caring for and help the development of their own child. Learning about the family's daily routine has made it easier to incorporate individual intervention plans into everyday activities. For families, prioritizing goals helped formulate appropriate milestones, thereby reducing excessive expectations for both children and themselves, resulting in less sense of failure. By articulating the current steps and goals that are available, families have had more sense of achievement.

'In the pilot project, I liked that the important focal points corresponding to the pace of development became visible, tailored to my child's personality. This, in a written form, regularly discussed and ranked, was a great help to us, parents, as to what we should pay more attention to in our daily routine, we were given many suggestions for solutions, and we were also encouraged to find a solution according to our lifestyle.' (From a mother)

1.5 | Challenges for the future (what was difficult and needs more knowledge, experience)

Therapists identified the lack of expertise outside their field as their main difficulty. They would need more experience and continuous cooperation with other fields and institutions to provide full, comprehensive assistance to families, as in many cases problems of a psychological or social nature arose. One of the conclusions was based on the feedback from the experts that O.T. (occupational therapy) is a shortage occupation in Hungary.

Some families described it as a difficulty that they initially received the caregiver a little distrustfully in their own home, and according to their feedback, the development of a proper relationship of trust between the family and the therapist is also important for effective collaboration.

2 | What is a correlation between the changes in pilots and changes in families answers of the same pilots (how the particular movement towards new concept changed the perception of "family-centered practice")

Overall, the families were open and happy with the opportunity, finding it helpful to be able to see their own system, their difficulties from the outside, and this helped them solve the problems more effectively. In addition to increasing the sense of competence, the intervention integrated into everyday activities also meant greater responsibility for families. During the pilot, care in a home environment was compared to that experienced in district nursing care. The families' reports revealed that some elements of the concept, such as the discussion of everyday activities and situations for home therapeutic purposes, had already been part of the care.

'We felt that it was more focused on personality, that our child's daily life and way of life also came to the forefront, so we, as parents, were able to pay attention to what factors we need to pay attention to.' (From a mother)

3 | What will follow after the implementation of pilots?

3.1 | How the pilots done can be supportive for spreading of the concept further (e.g. to legislation, to authorities, stakeholders, parent organizations) as an argument for a change of ECI system in your country)

Initial discomfort and confusion due to the unusual situation of care in the home environment also appeared in families and therapists alike. Proper preparation, training, and coaching for professionals could help to communicate more effectively and deal with initial difficulties, thus helping to deepen the relationship. Namely, based on the feedback received, it was easier to work in a natural environment in the relationship of trust between the therapist and the family, which resulted in more open communication, honesty, and liberation on the part of the children. Consideration should be given to formulating the RBI into a structured set of questions according to a care algorithm, dividing it into subunits, since, as mentioned, therapists and families both have found the recording of the RBI long and tedious, and it turned out to be difficult to apply to children of certain ages.

Based on the feedback, ECOMAP drew attention to the importance of the visual representation of social relationships, while the goal table (precise setting and prioritization of goals) helped to form the point of view, thus the families could set realistic goals and expectations. This made positive perceptions easier and gave them more opportunities to experience joy. The everyday application and incorporation into therapeutic care can further help families function effectively and experience success.

Proposals of the providers participating in the pilot for the future: launching parental forums, supporting parental initiatives. To expand the approach in the framework of our co-operations with the various national interest representation organizations (e.g. Hand in Hand Foundation) with national scope, to incorporate it into the communication as a professional policy aspect. However, parents cannot imagine confirming their positive feelings and feedback with numbers, and without numbers as a proof, it is difficult to imagine gaining supporters.

3.2 | How your partner organization as a future ECI AGORA CENTER will deepen the understanding of the routine and family-oriented concept among the providers and families - what further education you plan, what other activities you plan after finishing Agora project?

On the one hand, all institutions can promote the Agora pilot experience at the local level with lectures, workshops, and experience sharing. In the future, we would aim to launch a postgraduate course in which we would introduce the concept of the ECI Agora project to professionals working in early childhood intervention. Our long-term plan is to develop a module that can be connected to the university education of professionals and can be included in the curriculum as an ECI training material.



Project partners



EASPD, Eurllyaid and partners from Central and Eastern European countries: Hungary, Slovakia, Bulgaria, Poland, Romania. The ECI Agora project, supported by The Velux Foundations, aims to support the development of adequate ECI systems at a local and national level.



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