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Is Security Above All? Questions of Equal Access to Early Childhood Intervention during COVID-19 Pandemic

There are several reasons for examining the access to early childhood intervention at the earliest possible age during the COVID-19 pandemic. The consequences of the lack of early and widespread access to quality services are well documented, delays might cause irreparable damage, which could lead to challenges in long-term social integration. The article introduces the findings of an online survey exploring how the COVID-19 pandemic affected expectant women and those giving birth, as well as their experiences of the health care system and early intervention services in Hungary. To illustrate how measures in focus access to early intervention can be introduced under such circumstances, we describe a good practice in the field of services.

Our data shows that even though less medical examinations were cancelled or postponed than expected, these as well as early intervention mostly took place in the private sector. The majority of mothers faced a high level of stress and anxiety – especially during the restrictions. While depression among mothers did not rise significantly, the feeling of loneliness doubled. 27% turned to a specialist for support – mostly to a psychologist, and an unexpectedly high rate of parents contacted a specialist on parent-infant relationships.

Keywords: early childhood intervention, access to services, COVID-19, pandemic, mental health of mothers, innovation

INTRODUCTION

There are several reasons for examining the access to early childhood intervention at the earliest possible age during the COVID-19 pandemic. The consequences of the lack of early and widespread access to quality services are well documented, delays might cause irreparable damage, which could lead to challenges in long-term social integration (Soriano, 2005). Furthermore, some services for children already enrolled in early childhood intervention were also suspended during the lockdowns, reaction and adaptation to the sudden crisis depended on how services modified their operation (Ramos, 2021). In our article, we wish to add knowledge to what already has been observed internationally (Liu et al. 2022, Perez et al., 2022, Venta et al., 2021) by being the first to examine the changes, processes in early childhood intervention and their short-term effects in Hungary. We consider these issues highly relevant as children and their families were in increased need of adequate services.

This paper introduces the findings of an online national survey exploring the effects of COVID on the lives of families expecting or giving birth. To illustrate how adequate measures that hold the child's right to access to early intervention in focus can be introduced, we describe a good practice in the field of services in the second part of the paper.

RESEARCH METHODOLOGY

Our research aimed to examine how the COVID-19 pandemic affected expectant women and those giving birth. In our research, we collected data about the sociodemographic situation of the family, about the mother's social relationships, mood and experiences/concerns related to the coronavirus, and about the experiences of the health care system through an online survey. [The detailed presentation of the research is available Czeizel et al. 2022.]

The online survey ended with an open question about any experiences the mothers wished to share. We advertised the survey through our social media channels of the Institute of Psychology of the University of Pécs and the Early Intervention Centre Budapest in July 2022.

The sample

We received 496 responses to the survey from all over Hungary, 99% from mothers – thus we shall formulate our observation about the mothers. The youngest respondent was 22, the oldest 48, their average age was 33. Most respondents were married (93.3%) and all of them had a partner (only one person said that they did not live in the same household). Most of the respondents live in Budapest or smaller towns, every fifth person in larger cities, and every fifth in villages.

Two thirds of the respondents have a higher degree of education, another 23% have passed A-levels. Only 12 people do not have at least the A-level exam. This means the respondents have a higher level of education than average Hungarian women. Most of the mothers do not work but are taking care of their small child. 15% are employed, while 3 respondents are actively looking for employment. The majority of respondents have more than one child (56.9%) – 30% have two, 10% have three, and 13 women have four or five children.

The average age of the children involved in the research is 18 months, so the pregnancies took place during the lockdown of the first and second wave of the COVID pandemic. The youngest baby is two months old, the oldest is 44 months at the time of research.

In 213 cases, the respondents (or a professional) noticed some form of a delay in the early development of the child, that needed early intervention in 84 cases: in 79 cases the children received the intervention, in 5 cases they did not.

RESEARCH QUESTIONS

Due to the measures introduced during the pandemic, several public and health services became temporarily unavailable, resulting in high risk to expectant mothers and those with small children as they could not meet their doctor, nurse or those working in early intervention in person. We were curious to see whether due to restrictions, certain medical checkups had been postponed or canceled, and whether giving birth had been different to the prior expectations of the mothers – for example, because their partner or doula had not been allowed to accompany them. To examine this, we asked questions about their visits and contact with various

stakeholders of the health sector. We were also curious to see if the recognition of differences in development, subsequent reactions, diagnosis, and access to early intervention had also been delayed. We used the definition of the European Agency for Development in Special Needs Education (2005), where Early Childhood Intervention is a “composite of services/provision for very young children and their families, provided at their request at a certain time in a child’s life, covering any action undertaken when a child needs special support to:

- ensure and enhance her/his personal development,
- strengthen the family’s own competences, and
- promote the social inclusion of the family and the child.” (p.18)

The mental health of the mothers is an obvious risk factor in the early child development philosophy. Social interaction decreased both within the family and their wider social network, possibly resulting in further problems, isolation, and anxiety. We asked questions related to the anxiety the mothers experienced during their pregnancy, giving birth, puerperal period and then about the development of the child, their mental problems and supportive factors during the COVID-19 pandemic. We wanted to know if people in their informal network as well as professional helpers were available, or the mothers had to face their problems on their own. We investigated the unmet expectations about giving birth, as the exclusion of the partners or doulas during the birthing due to restrictions can affect the mental health of the mother in a negative way. We also analyzed whether the child had contact with extended family or other children (for example in the playground, play room or other activities in the community).

In the pandemic situation, organizations could speedily re-organize their services for the children and families by moving most activities to the online space. We describe the innovative measures introduced in a case study in a later chapter.

FINDINGS

EARLY CHILDHOOD INTERVENTION DURING THE COVID-19 PANDEMIC

Prenatal care

Most compulsory examinations did take place, only 2% reported missing a blood test, 4% an ultrasound. The highest rate was those having missed the mandatory dental checkup (25%). In contrast with our expectations, 80% of the fathers could be present at giving birth. Only 4% of the mothers had planned to give birth with a chosen doula, but only one third could really benefit from their assistance. A bit more than a quarter of mothers (27%) claimed that their experience in giving birth was adequate, even though not completely according to their expectations.

Screening and problem detection

The mandatory and timely meetings with the family health nurse and family pediatrician, required by law, are vital in recognizing the need for early intervention. We explored how these meetings took place during the lockdowns. Responses show that it was only in a few cases that these meetings did not take place at all – only 1-5% of respondents said that they did not meet their family health nurse or pediatrician ever. The examinations during the first six weeks after birth and those in the 12th month almost all materialized, examinations of the 9th and 15th month were the ones that were missed by some – but even this remained under 5%. The meetings with the family health nurse were more likely to be held online, while meetings with the pediatrician mostly took place in person.

Access to early intervention services

In almost half of the cases the pediatrician or another health professional identified some health problem or signs of developmental delay. In these cases we explored the 'child's pathway' in the system of early intervention.

In most cases, parents noticed the problem first (64%), followed by their pediatrician (24%). The rate of family members and other professionals, presumably due to limited contact, is very low (1-2%).

Parents usually contacted their pediatrician (34%) or a specialized doctor (32%) first. The private sector scores unexpectedly high – 20%. 5% of the respondents first accessed early intervention in NICU, 4% in an early development support service.

At last, most families received help from the health sector: 20% from their pediatrician, 37% from a specialized doctor. Early development service in the private sector was sought in a fifth of the cases, in early development support centers 7% and the public educational sector further 3%.

At the time of the survey, one third (35%) of these children were receiving some form of intervention, almost two thirds did no longer need it, and only five respondents said that they did not access early intervention although their child would have needed it.

In about half of these cases parents pay for early intervention services or specialists in the private sector. Only one third of the children receive intervention completely funded by the state, and another third use both sectors.

COVID-19 TRAUMAS, MENTAL HEALTH OF MOTHERS

COVID in the family

We asked respondents about serious COVID infections and death due to COVID within their family. These traumas can have an obvious effect on the mental health of the mother and the whole family. 13% reported the death of a loved one, one fifth

hospitalization due to COVID. In five cases the mother herself, in seven cases the small child needed hospital care.

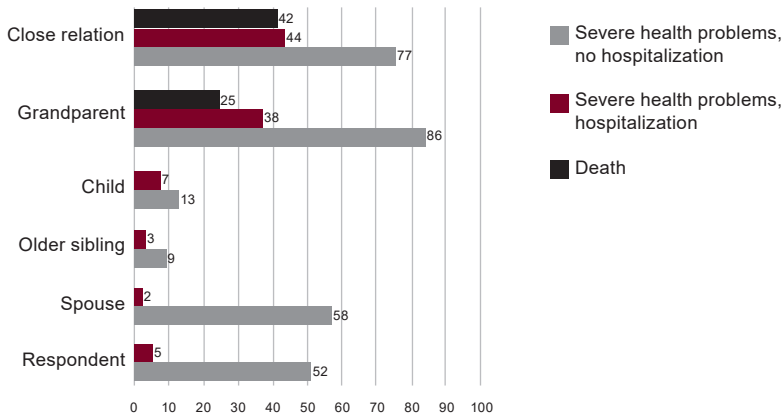


FIGURE 1 SEVERE COVID CONDITION IN THE FAMILY (PEOPLE)

Mental health

At the time of the survey, so in the relatively safe era after the pandemic, when most restrictions had been lifted, the mental health of mothers was satisfactory: they were much less anxious, nervous or tense and were less likely to lose control of their anxiety.

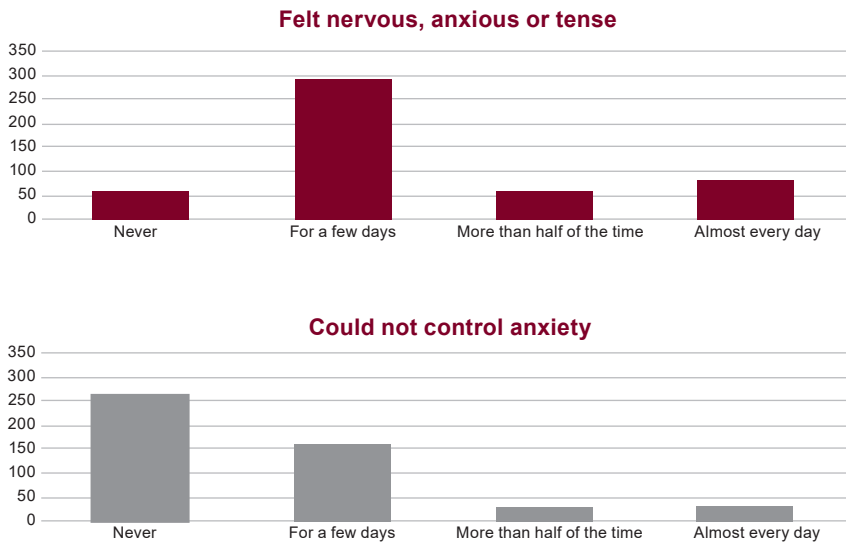


FIGURE 2 HOW OFTEN HAVE YOU FELT THE FOLLOWING IN THE PAST TWO WEEKS...? (PERSON)

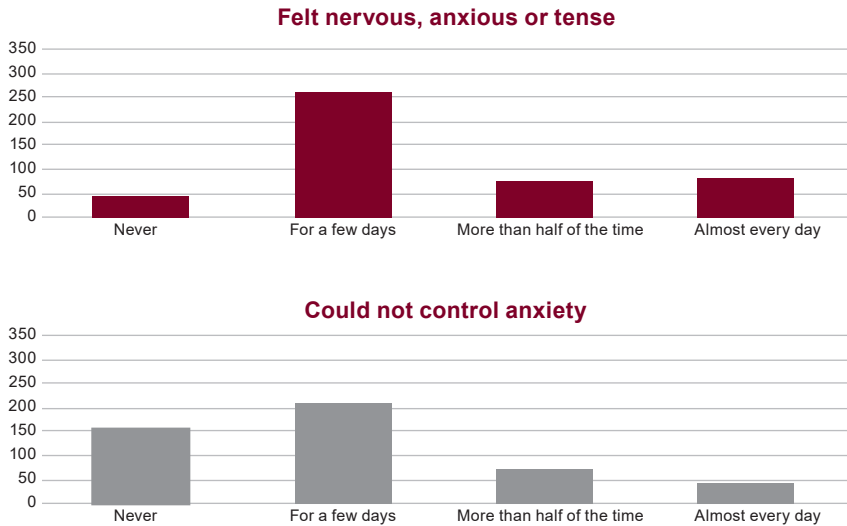


FIGURE 3 THINKING BACK TO THE TIME OF RESTRICTIONS DURING THE COVID-19 PANDEMIC, HOW OFTEN DID YOU FEEL THE FOLLOWING? (PERSON)

Naturally, mothers felt anxious about the pandemic and its direct health consequences: 75% feared that their family member, 70% that their child would get infected. 60% feared that their child would not get adequate health care. 54% expressed fear due to separation, 37% to the lack of support. 32% reported fears about the financial situation of the family.

At the time of the survey, 4.8% reported feeling depressed all the time or most of the time, while 6.8% reported being just lonely. During the lockdown a bit more of the women experienced depression (6.4%), while the rate of those feeling lonely all the time or most of the time doubled (12%).

27% sought help from a specialist, most of them from a psychologist or psychiatrist, but many turned to a breastfeeding consultant, an integrated parent-infant consultant or a perinatal consultant.

THE EXPERIENCES OF THE MOTHERS

To our surprise, almost a third of all respondents (31%) shared experiences connected to their pregnancy or birthing during the COVID-19 pandemic, in many cases at quite some length. Some of the respondents were obviously in a very emotional state when sharing their stories, intensely re-living the difficulties, traumas of the COVID era.

About one third of the responses (54 cases) talked about anxiety or stress in a general way, others retold specific difficulties that led to anxiety and stress.

“My first child was born in the same public hospital, under the supervision of excellent professionals (obstetrician and immunologist) two years before my second child, under the COVID pandemic. There was a huge difference between the two

pregnancies and birthgivings. My first birth experience, even though it ended with an emergency caesarian, brought great joy to me and I felt very fit afterwards. I found out I was pregnant with my second child just when the COVID pandemic hit Hungary. I was anxious from the very beginning. Are services going to be like they were before, what if I catch the virus? We did not visit any of our family or friends in person. My older child stopped going to the nursery. I did not feel at ease while giving birth, and now, one year later I still cannot look back on it as a positive experience. It was a very difficult time.”

Most respondents reported loneliness, isolation (34 people), for example not being able to receive visitors in the hospital or being placed in single rooms. The former was especially difficult for those who had to stay in hospital for several weeks, even months due to a risk in the pregnancy or premature birth, and could only keep in touch with their loved ones through the phone or the hospital window. The latter was mostly mentioned by mothers with their first child, who would have welcomed advice from a more experienced woman while in the hospital.

“I did not enjoy being pregnant from the 26th week on, when we found out that something was wrong, but no one knew exactly what. I had to stay in the hospital for a month, where no one was allowed to visit me, I could not go anywhere, I had to wear a mask all day, even in the hospital room. After my son was born, it gradually became better as I started to get good news and it turned out that he was all right.”

23 women complained about feeling isolated in the puerperal weeks following their stay in the hospital, and 21 women about the lack of help. 8 women spoke about their baby being easily scared when seeing a stranger, which they connected to isolation.

“The first few weeks, even months, were really difficult after my daughter was born. I was always worried that someone would bring the virus home. We had to wear masks when seeing our family. My daughter only met our extended family much later. At first we only allowed the grandparents to visit. Let alone our friends. For a long time, we did not even take her to the playground or the grocery store. Only my husband went to such places. I only took the baby for walks outdoors. Before giving birth, I was afraid what would happen if I tested positive, which hospital would be open, what would happen to us, how we would be treated. Before my due date, we did not meet anyone for a month, my husband did not even work for two weeks. Fortunately, he could be with me when giving birth, but the possibility of having to give birth on my own terrified me.”

“I felt completely abandoned, I did not receive support from the family health nurse, even though I would have needed it. My child even today does not accept strangers, we struggle with getting him in a group setting. I am afraid to sign him up to the creche. I am afraid of how I will be able to finance all the basic things he needs. He needs early intervention, which is an emotional as well as a financial burden on us. We lost most of our relatives during the pandemic.”

Several respondents wrote about not meeting family members for months for fear of infecting the baby. 16 mothers mentioned sadness over having to miss out on community activities, playgroups for the children.

“It was much easier to be at home by myself during the restrictions before and during the pregnancy than with the baby. I struggled with postnatal depression, but that was not connected to the pandemic. I was more anxious about the infection when I was pregnant, after giving birth less so. Then it was my husband who became more afraid. I was feeling really low when he asked me not to go anywhere (to baby clubs, activities, visit friends) with the baby, while there were many people infected. I was afraid of losing my mind, and also that the social skills of my baby would suffer if she does not see anyone but her depressed mother the whole day.”

Regarding prenatal care and early intervention, 23 mothers reported on having difficulty accessing the necessary medical examinations or not being able to access them all, or having to turn to the private sector instead of the public health care system.

“The absence of a family health nurse caused a lot of difficulties during my pregnancy.”

“Prenatal care really sucked: there were no doctors, I did not get referrals, there were no examinations. Only those things worked that we paid for on the private market.”

“We were worried. The health care system was in ruins. I was told to wait for five weeks with the first ultrasound in two different hospitals. So we went for all the checkups in the private sector, which was quite difficult financially. Because of the uncertainty about which hospitals, which wards would be open as well as the ban on visitors, we decided to give birth at home. It was the best decision!”

Several people wrote that even though they were able to get in contact with the family health nurse and their pediatrician, this took place through the phone or email, and they did not feel that the other person could assess the state of their child accurately this way.

“Doctors were uncertain, nurses sometimes acted horribly with mothers, saying they could get infected. The rules in the hospitals were changing all the time, everything was unstable. The checkups after I gave birth did not take place when they were supposed to (the examination of the baby’s hip etc). Our pediatrician did not see the baby for a long time, and I do not think diagnosing such a small child through the phone can be accurate, as parents might not recognize all relevant symptoms.”

18 mothers talked about the general state of the health care system as a source of worry, 12 about the constantly changing COVID protocols (which hospital is going to be open? are partners allowed to be there when giving birth? will they have to wear a mask?). 11 women spoke about the difficulty of having to wear a mask throughout their lengthy stay in the hospital or during giving birth. 8 wrote about the hardship of not being allowed to give birth with their partner, while seven missed their partner at

the medical examinations while pregnant. 11 women told stories of being forced into the private sector to access adequate services for prenatal care as well as for giving birth, which often caused further financial difficulties.

*“It is horrible that my own doctor cannot be present when I give birth, even more so during COVID! ... **Giving birth in a mask is torture!**”*

“I missed having a chosen doctor or midwife. It was disturbing to receive contradictory information about being vaccinated during pregnancy, as well as the constantly changing protocols regarding the presence of the father at birth or the rules regarding visitors. Often my family health nurse and gynecologist did not know what applied at that moment. I got COVID when I was seven-weeks pregnant, nobody had any information or experience about the possible consequences to the pregnancy or the development of the baby. Hospital staff were clearly overworked, there were not enough of them. I gave birth at the same time with two other women, and there was only one doctor and one midwife on duty. I did not feel safe, I did not see how they could manage all three of us should there be a complication somewhere.”

“I went with private doctors throughout my pregnancy, all the examinations and tests were done on the private market, and I gave birth in a private hospital. We are fortunate as we can afford this. I was terrified that if one of us (me or my partner) tested positive when the time came, I would be forced to give birth in a public hospital, alone. Fortunately, we both tested negative, and the father of my baby could stay with us for the three days that we had to stay in the hospital.”

INNOVATIVE SOLUTIONS ON THE FIELD

To illustrate how adequate measures can hold the child’s right to access to early intervention in focus, we describe the good practice introduced by the Early Intervention Centre Budapest. The organization speedily re-organized its services for the children and families already enrolled, moving most of these to the online space.

The Early Intervention Centre Budapest operated with its “normal schedule” until March 16th, 2020, when, following the 3/2020. (III.14.) EMMI decree of the Ministry, switched to “online teaching”. Its staff developed new, innovative methods to enable the smooth continuation of their work with creativity and great speed.

As a result, therapy and intervention could continue online for the 210 families already enrolled in the daily intervention activities – 80% of the families agreed to work online. Families of the children attending the special education kindergarten for children with severe and multiple disability received social and medical counselling on top of educational activities. Complex diagnostic evaluation of the children, carried out via online questionnaires and home-made videos (recorded using specific guidelines), was done after several consultations with the family, based on the cooperation of several experts, resulting in families receiving immediate intervention despite the lockdown. The Centre continued to work online until the end of May

2020, and then went back to normal operation, with some restrictive measures while keeping some of the new practices developed.

Professionals supporting the families were in constant communication with them even during the lockdown. Not all types of intervention could be held online – group activities as well as individual manual therapy were canceled. Instead, families received individual counseling. During regular times, intervention usually takes place once or twice a week. With online teaching intervention took various forms, often exceeding the formerly 45-minute-long classes.

The following solutions were used online:

- The parent records videos about the child using the guidelines provided, shares these with the professional, who analyzes what is seen and then, in a previously agreed time, calls the family, offers intervention tips and writes a memo for the parent;
- The child is to be observed during the online counseling, while the professional discusses with the parent, they can also give instructions. This way the family can try various positions, physical exercises, developmental tasks, games and communication situations. They can observe the child together and interpret together what they are doing;
- Older children can recognize their teacher during the online video call, can pay attention to the games introduced, follow instruction, so can be taught online;
- Professionals assemble personalized tasks to be used at home by parents, for example tips for games and intervention, gymnastic exercises, everyday items to be used as a training field, tales, personalized rhymes, daily and weekly schedule cards;
- Professionals provide tips on how the child can play alone, discuss the creation of space, about what toys to use and how to place them, which household items can be used as tools of development;
- In case of a chaotic daily routine: counseling, analysis of sleeping and eating diary, reacting to it;
- Eating therapy: suggesting positions, tips on sensitizing, possibilities of play, collecting specific eating experiences and advice;
- Support in getting a place in the right creche or kindergarten;
- Supporting the mental wellbeing of parents – “how are they? how do they cope?”. Availability of more consultation for parents. Involvement of psychologist, psychiatrist if needed;
- If the child has already used alternative or augmentative communication, supporting them to take further steps;
- Regular individual counseling regarding the use of medical aids;
- Lending of equipment to be used at home: specialized games, communicators, equipment to help develop mobility, medical aids;
- For autistic children: support with setting up of a daily routine in their home, sending pictures or producing printable pictures of the photos sent by parents, discussing or writing down their use, reacting to parents' observation;
- Discussing about behavioral challenges at home, preparation of the report using the STAR-modell, analyzing the report, reacting to it;

- Discussing specific events thoroughly, for example learning of the independent use of a spoon, the steps of potty training, the use of flow charts;
- Continuous and intense collection, development of online training materials, sending these to families, writing down tips of games; assembling of images to be used in intervention; digitalization of already existing collections of exercises; recording of videos; assembling of thematic photo collections; analysis of tales; collecting of verified and useful links and articles.

Most tools developed for online use are sustainable and have been in use ever since. Materials for intervention that have been collected, produced and neatly arranged are still available for all staff on an internal platform, and can be used to supplement personal meetings. Online consultations are still available, parents can often find the time easier in this setting. If staff or a child is quarantined but otherwise well, lessons are not missed but rather held online. This allows for the continuity of service, which has become more stable than earlier.

CONCLUSIONS

Our data of the national survey shows that less medical examinations were cancelled or postponed than could be expected. The rate of these happening during the pandemic corresponds to the result experienced in the Hungarian representative sample. The data on the basic conditions of childbirth do not differ significantly from the data measured in the Kohorsz'18 birth cohort study (Veroszta et al. 2021, Veroszta et al. 2022). However, medical care and early intervention mostly took place in the private sector. This corresponds to the data measured by KSH (Lengyel 2022), according to which the number of private medical care increased dynamically, and in 2021 private births increased by 46%.

Overall, the results of the survey suggest that early childhood intervention was more or less working during the pandemic, less examinations were canceled than could be expected. However, these responses are somewhat different when the mothers freely share their experiences, telling of many of these checkups taking place in the private sector, as well as the increased stress caused by the uncertainty of the public health care system. The quantitative data already reflected the growing use of the private sector in early intervention. This was reinforced by the final comments, where parents could also share their concern about having to consult with medical experts through the phone or via email only, and how they did not find this satisfactory.

The majority of mothers faced a high level of stress and anxiety – especially during the restrictions. On top of their health-related problems, many experienced isolation, lack of help and the fear of financial difficulties. While depression among mothers did not rise significantly, the feeling of loneliness doubled. 27% turned to a specialist for support – mostly to a psychologist, and an unexpectedly high rate of parents contacted a specialist on parent-infant relationships (- this could also be explained by the high level of education of respondents). The comments reflected on the causes of anxiety in detail: isolation, being locked inside, missing the support of friends and family.

We can conclude that the various stakeholders of early intervention made significant effort to facilitate access to their services. More research involving national data from services would be needed to be able to state this with assurance. It would be very useful for the various actors to share their innovative ways of working and protocols in order to allow others to learn from these. In the last chapter of our study, we shared the experiences of the Early Intervention Centre Budapest – as a first step in the dialogue sharing good practice.

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