

## Challenges for Parents of Children with Disabilities during the COVID-19 Pandemic

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### Abstract

Parents of children with disabilities are under more pressure than typical children. Moreover, the pandemic has brought additional challenges to those already in the families of children with special needs. The present study investigated what were the most important challenges these parents faced (emotional, educational, time management, financial, recovery-related challenges), but also the fact that they became teachers for children with SEN, or even took over certain responsibilities from therapists so as not to stagnate the recovery of their children. Many of them have experienced episodes of depression and anxiety.

**Keywords:** challenges, kids with disability, parents, COVID-19, depression, anxiety.

### Introduction

Families comprised of a child with disabilities, endure far more challenges than families with typical children. Besides the ordinary responsibilities of a typical family, additional challenges incur for a family with a disabled child: those regarding child diagnosis, the recovery process, the child's ability to make a progress, the financial responsibilities generated by the recovery therapies, the time availability for development of such therapies, and also the increased need to supervise a child with disabilities. Additionally to all of these, the parent of a child with disabilities goes through increased emotional challenges. All these facts put extra pressure on the parents with such children.

The emotional stress encountered within disabled children's families is proven by countless scientific studies. For example, mothers of children with neuromotor impairments, with mental and chronic illnesses, have a higher stress degree as compared to mothers of children with psychological disorders (Feizi et al, 2014).

Parents of children suffering from autism spectrum disorder (ASD) are exposed to a higher stress risk, as compared to parents of children with other developmental disabilities or of children with normal development (Estes et al, 2013). Whereas, when we discuss of multiple disabilities (a complex disability encountered in cerebral palsy), the task of caring for a child with complex disabilities at home, can prove overwhelming for the family. Providing such a level of care has an impact both on the physical health and the psychic health of parents with children having chronic disabilities (Raina et al, 2005). Moreover, a different study highlights the fact that the caregivers of children with neurodevelopmental disorders and behavioral disturbances score a higher number of health and psychosocial issues. (Lach et al, 2009).

The coronavirus pandemic disturbed everybody's lives. However, several persons have been impacted more severely by the current situation. Among those, we can list the children with disabilities and with other special needs, together with their parents/ caregivers.

The starter of the coronavirus pandemic, in March 2020, brought along additional challenges within families with disabled children. The state of emergency period, as well as the interval following the two-month lockdown, put the parents of special children through unprecedented situations, which demanded for their energy, resources on all levels, for their time, and emotional balance.

“Among all the other children, the kids with special needs find it very difficult to stay confined in closed spaces, in the absence of social exposure, which often leads to frustration, nervousness, or aggressive behavior. Subsequently, their parents are having a rough time. Before the pandemic, the caregiving and recovery of disabled children used to be divided between parents, schools, and recovery centers. However, nowadays, during the pandemic, most parents remained almost alone alongside their children. During such times, it gets ever-more important to support the children with special needs, along with their parents, those who take care of them”, Eric Falt, UNESCO Executive.

The pandemic also had specific implications for disabled children and children with SEN, concerning the support granted for their learning, structure, routines, and behavior. There were several organizations abroad, such as Scope and the National Society for the Prevention of Cruelty to Children (NSPCC) which provided resources for parents (Scope, 2020; NSPCC, 2020). Moreover, the additional support and activities granted outside the school system – which contribute to children's welfare, grant social engagement, a helpful routine, acting as an additional resource for parents – have also been impaired by the pandemic and the state of emergency.

The routine disconnection caused by the pandemic can prove extremely negative for children with SEN (Lee, 2020) and might exacerbate behavioral issues. A lack of structure has negative effects on the social and emotional development of disabled children, as it exacerbates mental health issues (Patel, 2020). A negative impact has also been identified in autistic children, due to the loss of social contact generated by school closure (Pellicano and collab. 2020).

Moreover, children with special educational needs have been severely impaired by school closure (O'Connor Bones and al, 2020). The study presents how parents of children with SEN – both those attending regular schools and those attending special schools – were the most susceptible to incur difficulties in all areas of home-schooling.

As a continuation of these studies and ideas, we intended to discover which were the challenges incurred by parents of children with disabilities, from Romania, during the pandemic.

## **Research Methodology**

### **Research Objective**

The current research has as objective the discovery of the main challenges that the parents of children with disabilities incurred during the coronavirus pandemic.

### **Research Hypothesis**

1. We consider that the parents of children with disabilities faced various challenges during the coronavirus pandemic (educational, time management-related, psychological, child recovery program-related, financial).
2. We presume that fears faced by the parents of disabled children were in connection with the children becoming ill, the stagnation in child recovery, losing the already existing achievements, the impact of socialization absence.
3. We consider that certain parents of children with disabilities undertook some of the tasks/responsibilities from therapists to continue the recovery program for their disabled children.
4. We presume that several parents of children with disabilities experienced depression and anxiety episodes during the pandemic.

### **The Sample**

The questionnaire was published according to groups of special children's parents, it was delivered to the support-teachers who distributed it to parents with SEN children (the ones they were working with), whereas the latter filled it in online. There were replies from 66 parents having children with the following disabilities:

- Autism (30 children)
- Cerebral palsy – various types: spastic tetraplegia, spastic diplegia, hemiplegia (21 children)
- Down syndrome (4 children)
- Neuropsychomotor developmental delay (4 children)
- Mental retardation (4 children)
- One child with hypoacusis
- One child with Spina Bifida
- One child with blindness

Over 50% of the children present multiple disabilities. Next to the main diagnosis some children also suffer from:

- ADHD
- Epilepsy
- Speech delay

64 of the children have ages between 2 and 18. However, there were also four parents of young adults with severe mental retardation, all of them being over the age of 18.

57.1 % of the children, whose parents answered the questionnaire, are attending school, whereas 42.9% are not (either due to their age or to their disability). Out of those attending school, 66.7% are following the courses of a regular school, whereas the rest of them are attending special schools, according to their needs.

### **Research Methodology**

I opted for survey-type research, which included an opinion-gathering type questionnaire, as means to collect the qualitative information required for the current study. The forwarded questionnaire was the mixed type, designed to include both open and closed questions, questions with multiple answer variants, Likert-scale type questions. This was intended to collect the

required data and to find out as many as possible of the fears, dreads, and challenges that the parents with disabled children were faced with during the coronavirus pandemic.

The questionnaire includes 28 questions grouped accordingly to the types of questions: questions about parents' challenges and fears, questions regarding therapies, the impact of therapy absence on children, questions concerning the parents who undertook several responsibilities from therapists, and questions that intended to discover the emotional state of parents as a result of all these challenges.

#### Closed Questions:

- 3 closed questions with a dichotomous-type answer (Yes/No). These were the questions related to school attendance, the type of school, and wheater or not they had continued with online therapy.

- 10 questions with answer-variants, where they had the option to check multiple answers (*At the start of the pandemic, which were your biggest fears? What type of challenges did you face, as parents of a child with special needs? What was the impact of the therapies/treatments' absence on your child? If you answered with YES, what therapy types were you able to implement online? If you answered with NO, what prevented you from implementing them online? Were you able to undertake a part of the practices therapists were doing with your child? If you undertook some of the therapists' practices, what exactly were you successful in practicing with your child? Which were the educational challenges (for those having children at school)? From an emotional point of view, which challenges did you face by being the parent of a special child? What do you consider that your child missed the most during the pandemic?*)

- 1 question with multiple answers (they had the option to check only one answer among them) (*What motivated you to get through such difficult moments?*)

- 2 scale-closed questions (Likert scale) 4 variants each: Never, Sometimes, Many Times (*During these pandemic times, did you go through depression and anxiety episodes? Did you experience moments when you felt you could not move forward?*)

- 2 scale-closed questions (Likert scale), 4 variants each: Not at all, A little, Pretty much, Very much (*How much does the fact that people around wore masks influence the communication with your child? Did your child adapt to the new hygiene regulations (washing hands frequently, wearing a mask, social distancing)?*)

I used closed questions due to the ease of recording all the answers, the speed, and ease of processing results (statistics), as well as to help the subjects choose the appropriate answer more easily.

#### Open Questions

Besides the two questions that helped me find out children's disability type and age, I used 8 more open questions, to *find out parents' fears during pandemic times* (others than those listed in the questionnaire), *what type of challenges did they face during the pandemic, effects of therapy absence on special children, what therapies were possible to follow online, what responsibilities the parents undertook from therapists, what educational challenges they faced (others than those already mentioned), what motivated them to go on each time they felt at their wits' end*. I have also used open questions as they allowed me to acquire rich information on the approached topics. They supplemented the information gathered through the predetermined answers, furthermore, there was no suggestibility risk from the researcher, due to the answers provided.

The questionnaire was designed to balance the closed questions, the ones with predetermined answers, which parents were able to answer easily and fast, by checking one or several answers,

with the open questions that gave parents the possibility to fill in their own experience. This was impossible to cover through the predetermined answers. The intention was to design it so that the answers to the open questions completed the ones given to the closed questions. Thus, the answer-giving process was intended to be an easy one, so that parents should not abandon filling in the questionnaire along the way.

### Work Procedure

The questionnaire was delivered online to several parents of children with disabilities. All participants received the indication to get through the questionnaire individually. There is a paragraph at the beginning of the questionnaire, which explains to parents the purpose of this research.

### Quantitative and Qualitative Analysis of Data

The answers coming from all 66 parents to this opinion-gathering questionnaire, which was self-managed, gave us several types of information, all required for the current research.

Concerning the fears of parents with disabled children, I have presented them in Table No. 1.

**Table No. 1** Fears of parents with disabled children, during the pandemic

No .	Fears that Parents Faced during the Pandemic	Percentage
1	Fear that child's recovery will be impaired	82,8%
2	Fear that they will find it difficult to preserve their emotional balance	50%
3	Fear that the child might become ill	43,8%
4	Fear they will get through financial issues	23,4%
5	Fear the pandemic will result into a major setback	7,5%
6	Fear they will lose their job	6%
7	Fear they will get ill (and they will not be able to take care of their children anymore)	6%
8	Fear they will not be able to manage all responsibilities and will not be able to supervise the child	1,5%

The top challenges that parents faced during the pandemic, is as follows:

**Table No. 2** The top challenges that parents faced during the pandemic

No .	Challenges Incurred by Parents	Percentage
1	Emotional challenges	<b>71,9%</b>
2	Challenges connected to the absence of socialization	<b>68,8%</b>
3	Challenges connected to the absence of treatments and therapies	<b>57,8%</b>
4	Educational challenges	<b>46,9%</b>

5	Financial challenges	<b>45,3%</b>
6	Time-related challenges	<b>34,4%</b>
7	Challenge to adapt to an increase in the family members' number	<b>1,5%</b>
8	Challenge to acquire the necessary means, as a single parent who did not want to expose the child to crowded areas	<b>1,5%</b>

**Table No. 3** Percentage of children that attend/ do not attend school

	Children attending school	<b>51,7%</b>
	Children not attending school	<b>48,3%</b>

Here are the main educational challenges mentioned by their parents. We specify that these percentages come from the total number of parents that have children who attend the school.

**Table No. 4** Educational challenges incurred by parents during the pandemic

No.	Educational Challenges	Percentage from the respondents to this question
1	The feeling they have transformed into a teacher/ professor	<b>61,8%</b>
2	They had to help their child with homework	<b>47,1%</b>
3	They had to remain alongside the child during classes and explain what was delivered	<b>47,1%</b>
4	They had to explain the homework to their child	<b>47,1%</b>
5	They had to supervise the child during classes, besides having to work from home	<b>3%</b>
6	Children with hypoacusis required permanent assistance during classes because the teacher was wearing a mask	<b>3%</b>
7	They had to adapt school materials to children's needs and explain to them so that they won't experience a setback	<b>1,5%</b>
8	They felt incapable as the kid was not willing to cooperate with his/her parents, as it used to be during kindergarten	<b>1,5%</b>
9	They had to put in countless efforts so that the child with SEN can adapt to online school (they made a projection of the laptop screen on the TV)	<b>1,5%</b>
10	They had to purchase a second laptop and reorganize rooms, for their two children that attended online school simultaneously	<b>1,5%</b>

During the pandemic, especially during the state of emergency, children with disabilities were lacking the therapies they were accustomed to. Here is what the parents believe to be the impact of therapy absence on their children.



**Table No. 5** Impact of therapy absence on children with disabilities

No.	Impact of Therapy Absence on Children with Disabilities	Percentage
1	The child was more nervous	<b>51,7%</b>
2	I noticed a regress	<b>48,3%</b>
3	They experienced losing a part of the achievements	<b>39,7%</b>
4	Others (getting fat, changed poise, became shut down, didn't want to go to school or outside anymore)	<b>12,1%</b>

During the pandemic, some therapists – when it comes to the respective therapies that allowed this – tried to deliver them online. Out of the 66 subjects being questioned for this study, 69.4% DID NOT undergo online therapy. Only 30.6% succeeded with that.

**Table No. 6** The number of children who underwent online therapy

1	DID NOT undergo online therapy	<b>69,4%</b>
2	Underwent online therapy	<b>30,6%</b>

Among the online delivered therapies, parents declared attending the following: speech therapy, speech disorder therapy, ABA therapy, occupational therapy, attention stimulation, ergotherapy, cognitive stimulation, psychotherapy, behavioral therapy.

Reasons that did NOT make online therapy possible

**Table No. 7** Reasons that prevented children from undergoing online therapy

1	Lack of attention from the child	<b>60%</b>
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2	The respective therapy type requires physical presence	<b>52%</b>
3	Financial reasons	<b>20%</b>
2	Lack of time on parent's behalf	<b>2%</b>

Some of the parents whose children were not able to follow through with online therapies (either because of the child's lack of attention or interest, or because the therapy required the child being physically present, or because of financial reasons) tried to undertake some of the therapist's responsibilities and to support by themselves the recovery process.

**Table No. 8** The parent undertakes responsibilities from the therapist

No.	The Parent Undertakes Responsibilities from the Therapist	Percentage
1	They undertook responsibilities and did as much as they were able to	<b>65,1%</b>
2	They almost transformed themselves into therapists	<b>28,6%</b>
3	They were not able to undertake any responsibility	<b>17,5%</b>

Parents declared what they were able to do for their children, in the absence of therapies, and to replace the latter: *motor stimulation (kinesiotherapy), speech therapy, ABA therapy, occupational therapy, information building, training for exams.*

The pandemic period was a difficult one for everybody, however, we wanted to find out if the families of children with disabilities experienced it as such. Within Table No. 5 I have presented the top of emotional challenges that parents of disabled children had to face.

**Table No. 5** Emotional challenges for parents with disabled children

No.	Emotional Challenges	Percentage
1	Fear that the little one might regress and they will find it very difficult to compensate for that which they lost	<b>66,7%</b>

2	Fear that the absence of socialization will result in a regress	<b>58,7%</b>
3	Fear that the absence of therapies might lead to loss of achievements	<b>57,1%</b>
4	Fear that they might not be able to go along with all responsibilities (job, homework, recovery)	<b>42,9%</b>
5	Financial fears	<b>33,3%</b>

As we wanted to find out which were the consequences of such educational and emotional challenges, as well as those related to the undertaking of responsibilities from therapists, we directly asked the parents if they had experienced depression and anxiety episodes.

**Table No. 6** Parents faced depression and anxiety episodes

No.	<b>Depression and Anxiety Episodes for Parents</b>	Percentage
1	Sometimes	<b>60,9%</b>
2	Several times	<b>20,3%</b>
3	Never	<b>14,1%</b>
4	Always	<b>4,7%</b>

We went even further, with the desire to find out if there were any critical moments during the pandemic when parents of disabled children might have felt overwhelmed by all the previously listed challenges.

**Table No. 7** Were there any moments when they felt overwhelmed

No.	They went through moments when they felt they were not capable to go on	Percentage
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1	Sometimes	<b>54,7%</b>
2	Many times	<b>26,6%</b>
3	Never	<b>18,8%</b>
4	Always	<b>0%</b>

Since the challenges extended over a longer time, and this type of trial was an unprecedented one in people's lives, we wanted also to find out what exactly motivated the parents to keep going on and overcome the crisis moments.

**Table No. 8** Reasons that helped parents keep going on

No.	Reasons that Helped Parents Keep Going On	Percentage
1	The love for their child	<b>61,3%</b>
2	Just one moment for myself to help me recharge my batteries	<b>8,1%</b>
3	Friends	<b>3,2%</b>
4	The shame of admitting that they were no longer capable	<b>1,6%</b>
5	Their way of being, of facing issues, a permanent adaptation	<b>1,6%</b>
6	Personal therapy	<b>1,6%</b>

## Conclusions

In about more than 50% of the cases of the aforementioned 66 parents, we dealt with children with complex deficiencies, which required special care even before the pandemic. Over 50% of the children used to attend either a regular school or a special school.

**We hereby restate the hypothesis that generated this research:**

### **Research Hypothesis**

1. We consider that parents of children with disabilities faced various challenges during the coronavirus pandemic (educational, time management-related, psychological, child recovery program-related, financial).
2. We presume that fears faced by the parents of disabled children were in connection with the children becoming ill, the stagnation in child recovery, losing the already existing achievements, the impact of absence of socialization.
3. We consider that certain parents of children with disabilities undertook some of the tasks/responsibilities from therapists to continue the recovery program for their disabled children.
4. We presume that several parents of children with disabilities experienced depression and anxiety episodes during the pandemic.

**Following the analysis on data collected from the 66 parents, we believe that hypothesis No. 1, 2, 4 do check-up. Hypothesis No. 3 is only partially confirmed.**

1. We consider that parents of children with disabilities faced various challenges during the coronavirus pandemic (educational, time management-related, psychological, child recovery program-related, financial).

From the analyzed data, it follows that **the biggest fears** of parents having disabled children are:

- Fear that the child's recovery shall be impaired 82,8%
- Fear that they will find it hard to preserve their emotional balance 50%
- Fear of their child becoming ill 43,8%
- Fear they will encounter financial issues 23, 4%

Whereas, **the top of the challenges** looks as follows:

- Emotional challenges 71,9%
- Challenges related to the absence of socialization 68,8%
- Challenges related to the absence of treatments and therapies 57,8%
- Educational challenges 46,9%
- Financial challenges 45,3%
- Time management-related challenges 34,4%

Those over 50% (51,7%) parents with children that used to attend school (either regular or special) experienced the following **additional challenges**: they felt they were transformed into teachers, they explained the lessons to their children, they supervised children during classes, they did homework alongside their children.

Only 30% of the children continued with **online** therapies (speech therapy, speech disorder therapy, ABA therapy, occupational therapy, attention stimulation, ergotherapy, cognitive stimulation, psychotherapy, behavioral therapy). The main reasons that the rest of almost 70% DID NOT undergo online therapy, were the child's lack of attention, or the requirement to undergo the respective therapy face to face. **Living under these circumstances**, for fear that the little ones might forget all achievements, might regress or stagnate in their disability recovery process, certain parents tried to proceed with the recovery work for their children, by themselves, as follows:

- They undertook responsibilities, by doing what they were capable of 65.1%
- They almost transformed themselves into therapists 28.6%
- For both the above situations, the parents implemented: *speech therapy, ABA therapy, occupational therapy, information building, training for exams.*
- However, **17.5% WERE NOT able to undertake any responsibilities**, thus they could not continue with a recovery at home.

Among **the emotional challenges**, here are the most important ones:

- Fear of regress, stagnation, loss of achievements 67.7%
- Fear of not being able to face responsibilities (including homework, job, housekeeping, recovery) 42.9%.

This period was extremely demanding for parents of children with disabilities, **60.9%** said they experienced depression and anxiety episodes **sometimes**, **54.7%** went through moments when they thought they would not be able to go on. **61.3%** declared they were motivated to get through such crisis moments due to **the love for their children**.

In *The Life During COVID-19: A Guide for Parents of Children with Disabilities*, created by UNESCO New Delphi, the specialists recommend parents with disabled children to attend to their special children, to their entire family, however, not to forget about their wellbeing and happiness. Those who have such children under their care (parents, grandparents) should benefit from personal relaxation times (listening to music, reading a book, or practicing recreational physical exercises). Whereas, whenever they feel overwhelmed by negative thoughts, UNESCO recommends the respective parents to go see a psychologist.

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