

Remote parent-implemented intervention for young children on the autism spectrum during the COVID-19 home confinement period in Geneva, Switzerland: the experience of parents and therapists.

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Abstract

In the spring of 2020, autism intervention programs in Geneva, Switzerland, were forced to close during a state-mandated home confinement period, in the response to the beginning of the COVID-19 pandemic. Therapists from three programs were asked to move early, intensive intervention sessions to an online video-conferencing format, providing primarily remote parent-implemented intervention sessions over a two-month period. In this study, we assessed the participation and satisfaction of 45 families from diverse cultural and socio-economic backgrounds, with 43 young children on the autism spectrum, and 5 toddlers who were suspected of having autism, as they experienced intervention services via telehealth for the first time. We provided questionnaires, to both the parents and the therapists working with them. Parents, regardless of socio-economic status or cultural background, were highly motivated and engaged to learn the intervention strategies, with most families reporting high levels of satisfaction with the intensive, remote parent coaching model. The majority of parents reported that they progressed more in their interaction skills with their child with the daily remote coaching sessions, compared to services they received prior to the pandemic. Additionally, parents reported a positive experience with a much higher frequency of coaching sessions than has previously been studied. In our monitoring of child developmental progress, we observed a pattern of continued significant improvement across domains, without any stagnation of progress during the telehealth period. Our findings support previous studies that have demonstrated the benefits of telehealth services for young families with children on the autism spectrum, and go further to demonstrate high levels of satisfaction and motivation with caregivers from diverse cultural and socio-economic backgrounds, when provided with a high frequency of remote parent-implemented intervention.

Introduction

In response to the spread of the COVID-19 pandemic, recommendations for social distancing made it difficult for many families of young children on the autism spectrum to access in-person early intervention services.^{1,2} The preschool years represent a critical developmental period where children who receive evidenced-based, behavioural and developmental intervention, can make significant gains in language, cognitive functioning and adaptive skills.^{3,4} Faced with home confinement orders and cancelled programs, many caregivers and professionals looked for alternative ways to maintain intensive early intervention instruction, in an effort to avoid the potentially detrimental effects of a prolonged interruption of services.^{5,6} For many families, remote parent coaching via video-conference was offered as an alternative to in-person intervention sessions.

Parent-implemented intervention, where a parent or caregiver is coached to use techniques that promote learning and engagement with their child, is widely considered a valid and essential part of early intervention in autism.^{3,7-9} The feasibility and efficacy of coaching parents remotely via telehealth has also been supported in the literature, and is considered a cost-effective way to increase access to high quality intervention services.^{2,10,11} As with in-person parent coaching, studies on remote delivery have reported overall parent satisfaction and positive experience with online sessions. However, most research of in-person and remotely-delivered parent-implemented intervention for autism, prior to COVID-19, had studied caregivers who had the time and resources to volunteer, often leading to samples of married, college-educated mothers, who were not employed outside of the home.^{2,12,13} Less is known about how working parents, fathers, families with lower socioeconomic status, or families from diverse cultural backgrounds experience these services.¹⁴⁻¹⁶ This is important, as it means that the majority of caregivers, who could potentially benefit from in-person or remote coaching, are not well represented in the parent-implemented intervention literature.¹⁷ Researchers have begun to turn their attention to understanding how high-quality, evidenced-based practices, proven to work in clinical autism research settings, can be adapted to work in real-world community settings.^{14-16,18} The COVID-19 stay-at-home orders created a situation where families, from all walks of life, would have the chance to participate in telehealth autism intervention programs, allowing us to measure the feasibility of providing these services to caregivers from a wider demographic.

The lack of access to daily, in-person early autism intervention programs may also have led to a higher dosage or frequency of parent coaching sessions than has previously been studied. Most research to date on parent-implemented intervention, both in-person and via telehealth, has measured the effects of one to three hours of coaching per week.^{8,10,19,20} This dosage appears to be relatively arbitrary, possibly based on the research funding available to provide the services, or an estimation of how often caregivers would agree to take part in the sessions, or perhaps an assumption that parents need more time between coaching sessions to practice and consolidate what they've learned.^{8,20} Theoretically, the sooner a caregiver learns to implement the early intervention techniques effectively, the sooner the child would benefit from the treatment being implemented as intended.^{8,20} Recent studies have suggested that there may indeed be a potential advantage of offering parent coaching more intensively up front, finding that caregivers seem to be willing and motivated to participate in more frequent sessions, and do not necessarily experience an increase in stress associated with the increase in coaching dosage.^{8,20,21} In order to begin to define an optimal frequency for parent implemented intervention sessions, one where the caregiver manages to acquire the intervention skills quickly, while still maintaining a high level of overall satisfaction, there needs to be a better understanding of how families of young autistic children and the professionals working with them experience a higher frequency of coaching sessions.

In this article, we will discuss how three community-based programs in Geneva, Switzerland moved their intensive, early autism intervention services to a telehealth platform, providing daily, parent-implemented or direct intervention via videoconference, during Switzerland's first Covid-19 state-mandated home confinement period. We measured the engagement and satisfaction of a diverse group of caregivers, and that of the professionals working with them, as they experienced intensive, parent-implemented intervention via telehealth for the first time.

Methods

Context of Covid-19 home confinement in Switzerland

On the 16th of March, 2020, in response to the initial outbreak of the COVID-19 pandemic, the Swiss Federal Office of Public Health ordered a nationwide closure of all non-medical services as an emergency measure to prevent the spread of the infectious disease. Schools and childcare centres were closed, and people were asked to work from home. This period lasted for nearly 2 months, with the gradual reopening of services, including our intervention centres, starting April 27th, 2020 and the schools starting May 11th, 2020 (figure 1). Given the uncertainty about the COVID-19 situation at the time, families were given the option to continue sessions via videoconference through to the end of May. By June 8th, 2020 most of the restrictions had been lifted, and despite the country having subsequent social distancing measures, the schools and our centres have remained open to date.

Participants

Children: All 48 children enrolled in three autism intensive intervention programs at the time of the COVID-19 stay-at-home orders, were offered remote services (table 1). These participants are part of an already established longitudinal study on the developmental trajectories of young autistic children.²² Forty-three of the children had received a clinical diagnosis of Autism Spectrum Disorder (ASD) according to the DSM-5²³ and confirmed using a full-battery evaluation. Five of the toddlers were suspected of having autism, but did not have a confirmed diagnosis (see table 1 for clinical characteristics of participants).

Caregivers: The 45 families (three families with two participating siblings each) in the three centres came from diverse socioeconomic status levels, with 69% of children being from low-to mid-income households, of which 38% were considered low-income as indexed by the cost-of-living standards in Switzerland (table 1). Educational attainment was also varied, with 39% having completed secondary school or less, of which 6% had only elementary school or less, and 61% had post-secondary education. Five children came from single-parent households. Families came from various ethnic backgrounds, representing Geneva's diverse population, with parents listing 27 different countries of origin, and 15 different languages spoken at home (see table S1). All families provided their written consent for the study, in accordance with protocols approved by the institutional review board of the University of Geneva.

Intervention received prior to home confinement: Three programs

- 1) Centre for Early Intervention in Autism (Centre d'Intervention Précoce en Autisme / CIPA): Thirty children aged between 24 and 54 months, were receiving 20 hours a week of in-centre, daily, therapist-delivered intervention services, using the Early Start Denver Model (ESDM).²⁴ ESDM is an evidenced-based, Naturalistic, Developmental Behavioural Intervention (NDBI) for young children on the autism spectrum.³ In addition, parents were initially provided with 12-hours of once-a-week in-

person parent coaching sessions using the Parent-Implemented Early Start Denver Model or P-ESDM, and subsequently continue to meet with their child's lead therapist on a regular basis, individualised to meet the family's support needs.²⁵ P-ESDM is an effective parent coaching intervention aimed at helping caregivers to use ESDM techniques to embed social-communicative learning opportunities for their child into daily routines. The CIPA program is subsidised by state, private foundation and federal disability insurance funds, and available to children living in the State of Geneva. Children typically remain in the CIPA for two years.

- 2) The Boussole Program: Five young children, aged between 8 and 24 months (admitted prior to 18 months), suspected of having autism, were receiving 8 hours a week of in-home and in-centre, therapist-delivered ESDM intervention²⁴ and 2 hours of P-ESDM coaching. The Boussole is subsidised by private foundation and insurance funds.
- 3) The CIPA Inclusion Program (CIPA-I): Thirteen children aged between 4.7 and 6.6 years were receiving between 13 to 24 hours per week of individual in-school support and intervention services. These children had all completed the CIPA program prior to starting school, with seven in their first year at school, and six in their second year. The CIPA-I program is funded by Geneva's Department of Public Education.

Telehealth intervention during Covid-19 home confinement

Each child's program was individualised for remote delivery, taking into account new parameters such as the parents' availability to take part in video-conference sessions, their level of access to technology, and the child's behavioural profile, including the child's likelihood to attend to, and interact with, a therapist online. Based on these parameters, the families were offered two 1-hour sessions a day, Monday to Friday, of either: 1) Remote Parent-Implemented Intervention, where the therapist offers parent coaching using P-ESDM,²⁵ or 2) Remote Direct Intervention between child and therapist, where the therapists work on the children's learning objectives using ESDM strategies, proposing interactive activities like singing songs, discussing topics and playing turn taking games. When appropriate, the therapists also proposed screen-shared activities that targeted pre-academic and cognitive learning objectives, such as matching and sequencing.

Table 1. Description of the sample of children (n = 48) and their families (n = 45) included in the study

Measures		CIPA (n = 30)	Boussole (n = 5)	CIPA-I (n = 13)	All intervention centers (n = 48)
Age at the onset of the confinement period <i>Mean (SD)</i>		3.39 (±0.79)	1.34 (±0.49)	5.67 (±0.63)	3.79 (±1.49)
Sex (female/male)		3 / 27	3 / 2	1 / 12	7 / 41
Intervention duration prior to the confinement period (in years)					
	<i>Mean (SD)</i>	1.07 (±0.51)	0.33 (±0.26)	3.24 (±0.71)	1.58 (±1.78)
	<i>Range (min-max)</i>	0.08 - 1.74	0.04 - 0.59	2.37 - 4.51	0.04 - 4.51
Age at diagnosis/start of the intervention <i>Mean (SD)</i>		2.41 (±0.44)	1.13 (±0.37) ^f	2.50 (±0.40)	2.30 (±0.58)
ADOS-CSS at diagnosis <i>Mean (SD)</i>		7.83 (±1.91)	-*	8.15 (±1.46)	7.93 (±1.77)
Mullen Early Learning Scales Developmental Quotient (MSEL DQ) at diagnosis <i>Mean (SD)</i>		60.8 (±18.4)	70.8 (±14.1)	60.8 (±15.9)	61.6 (±17.3)
VABS-II Adaptive Behavior Composite at diagnosis <i>Mean (SD)</i>		78.7 (±10.00)	77.8 (±8.85)	81.8 (±7.07)	79.5 (±9.13)
Household organization					
	One parent/two parents	3 / 28	1 / 4	2 / 11	6 / 45
Parent's ethnicity					
	European	17 (56%)	2 (40%)	4 (31%)	23 (48%)
	Admixed American	2 (7%)	-	2 (15%)	4 (8%)
	African	3 (10%)	1 (20%)	1 (8%)	5 (11%)
	Asian	4 (13%)	2 (40%)	3 (23%)	9 (19%)
	Asian+European	2 (7%)	-	1 (8%)	3 (6%)
	Admixed American+European	2 (7%)	-	2 (15%)	4 (8%)
Parents' education (higher of the two when applicable)					
	Elementary school	2 (7%)	0 (0%)	1 (20%)	3 (6%)
	High school	10 (33%)	5 (38%)	1 (20%)	16 (33%)
	Post secondary	18 (60%)	8 (62%)	3 (60%)	29 (61%)
Household income at diagnosis**					
	Low income (<60k CHF)	8 (27%)	4 (80%)	6 (46%)	18 (38%)
	Mid income (60-140k CHF)	13 (43%)	-	2 (15%)	15 (31%)
	High income (> 140k CHF)	9 (30%)	1 (20%)	5 (39%)	15 (31%)

Notes: * Children in this group were not administered ADOS (young age /lack of motor autonomy)

** Source: Swiss Federal Statistics Office-SFSO, Statistics on Income and Living Conditions SILC-2018, version 07.10.2019.

Therapist participation and training

All 45 early intervention therapists working in the three programs at the time of the closures participated in the study. All professionals providing the telehealth interventions were licensed psychologists aged between 25 and 38 and had a minimum of a master's degree. The therapists were trained in the use in of the ESDM approach, meeting fidelity in clinical practice on the ESDM Fidelity Rating System.²⁴ Within the team, 15 credentialed ESDM therapists supervised the children's programs, and the programs were overseen by an ESDM certified trainer. Following the home confinement orders, all therapists participated in a one-day, emergency, informal training on providing telehealth services. Less experienced therapists were encouraged to remotely observe other therapists' sessions. The majority of sessions were recorded for supervision purposes and reviewed via screen sharing during weekly team clinic meetings, which were also held via videoconferencing.

Materials

The video-conferencing sessions took place using ZOOM software (Zoom Video Communications, Inc., Version 4.4; <https://zoom.us/>). Parents were asked to set up their computer, smartphone or tablet

in a place with few distractions, where the therapist would be able to have a clear view of a play area or of the child's work area. Prior to the first session, each lead therapist contacted the child's parents to explain how the video conferencing would work and helped them to install the ZOOM software. They discussed materials to have available such as toys, felt markers and paper, and other items that they might use during the sessions. For parents who did not have access to these materials, the therapists arranged a toy-lending program. Each family had a copy of the book *An Early Start for Your Child with Autism: Using Everyday Activities to Help Kids Connect, Communicate, and Learn*,²⁶ in French, English or translated version. When appropriate, the therapists also suggested videos, website links and ideas for activities in line with each child's intervention objectives.

Measures

Parent and therapist satisfaction questionnaires: Satisfaction questionnaires were sent via e-mail to both parents and therapists after the first video-conference intervention session, at 3 weeks, and after their final online session. Parents and therapists responded to questions on a Likert seven-point scale ranging from "Strongly Disagree" to "Strongly Agree" and multiple-choice questions. They were also given the opportunity to leave written comments pertaining to their experience with the telehealth services.

The Early Start Denver Model Curriculum Checklist for Young Children with Autism (ESDM-CC): The children in the Boussole and the CIPA are evaluated using the ESDM-CC²⁷ prior to starting in the programs, and then every 12 weeks of their intervention program.⁸ This evaluation helps parents and interventionists decide which learning targets they will prioritize in the child's treatment plan over the following three-month period. The ESDM-CC evaluates areas of expected child development at 4 levels: 9-18 months, 18-24 months; 24-36 months and 36 to 48 months, covering domains such as communication, social skills, motor skills and cognition.²⁴ We looked specifically at domains that span all four levels: receptive and expressive language, social skills (including joint attention in level 2), and play. Skills are evaluated as being "A" (acquired, consistent, and generalised); "P" (Partial or emerging); "N" (child is unable or unwilling to perform the skill); or "X" (no opportunity or not tested). For the purpose of this study, we considered a child's current developmental age range to be where the majority (50% or more) of the skill items were rated as an "A". If the highest level had an equal number of acquired and not-yet acquired skills, the child was considered between two levels for that skill (i.e., 1 / 2), and were converted into numerical levels for the purpose of the statistical analyses ($1 / 2 = 1.5$; $2 / 3 = 2.5$, etc.). For this study, the ESDM-CC was used to monitor developmental progress in the children's learning objectives, in light of the drastic change to our service delivery model. To compare with the magnitude of progress during in-person intervention sessions, we included an additional measure that comprises the ESDM-CC performed 3 months prior to the one preceding home-confinement. We considered three time points: T1 - ESDM-CC three months before the Pre-Confinement ESDM-CC; T2 - Pre-Confinement ESDM-CC; T3 - Post-Confinement ESDM-CC.

Statistical Analyses

We used the Mann Whitney test to examine group differences in program satisfaction, as the measures did not follow a normal distribution (Shapiro-Wilk test). We compared the parents' and therapists' overall experience and satisfaction with the remote intervention, as well as the change in satisfaction between the first day and following three weeks of treatment. To illustrate child developmental progress, we used the Wilcoxon matched-pairs signed-ranks test to compare the global and subdomain scores of the ESDM-CC between the three time points, as the measures were not normally distributed. Statistical analyses were conducted using GraphPad Prism v.8 and SPSS v.25 software: (<https://www.ibm.com/analytics/spss-statistics-software>). All results in our study were considered significant at the p value of 0.05. The False Discovery Rate (FDR) was controlled using Benjamini-Hochberg procedure.²⁸

Results

Program participation

All 48 children and their 45 families, as well as the 45 therapists of the CIPA, Boussole and CIPA-I programs, participated in the remote sessions during the confinement period (figure 1, table 2). Thirty-four of the 35 children from the CIPA and Boussole programs received Remote Parent-Implemented Intervention, of which 11 also had some sessions of Remote Direct Intervention. One older child in the CIPA (3 years, 9 months), and all 13 of the children in the CIPA-I program received only Remote Direct Intervention, although their parents were often in the background. Therapists adapted the length of sessions to the needs and availability of the families, with sessions lasting between 30 and 90 minutes.

The total period where remote sessions were offered spanned a period of 2 months, with a seven-workday break over the Easter holiday (figure 1). Within the main confinement period, when all families were receiving telehealth services, there were 19 days when services were provided for the families in the CIPA and Boussole (between March 20th and April 27th, 2020) and 29 days for the CIPA-I (between March 20th and May 11th, 2020). During this period, children in the CIPA received between 4.47 and 13.7 sessions per week (mean of 8.75 (± 1.93)) of primarily parent implemented intervention coaching sessions, for an average of 7.3 (± 2.2) hours per week. The children in the CIPA-I received between 3.97 and 8.28 (mean of 7.06 (± 1.08)) sessions of direct intervention per week, for an average of 5.41 (± 0.92) hours per week (table 2).

Thirty-four families, including 56 individual parents, participated in the parent-implemented intervention sessions. Twenty-seven percent of the parent coaching sessions were done with fathers, 54% with mothers, 14% with both mother and father present, and 2 % with a childcare provider (table 2). Fifty-nine percent of the families used a computer, 24% a tablet, while 16% participated via smartphone and 1 family did not have access to a wi-fi connection, and was coached via landline telephone.

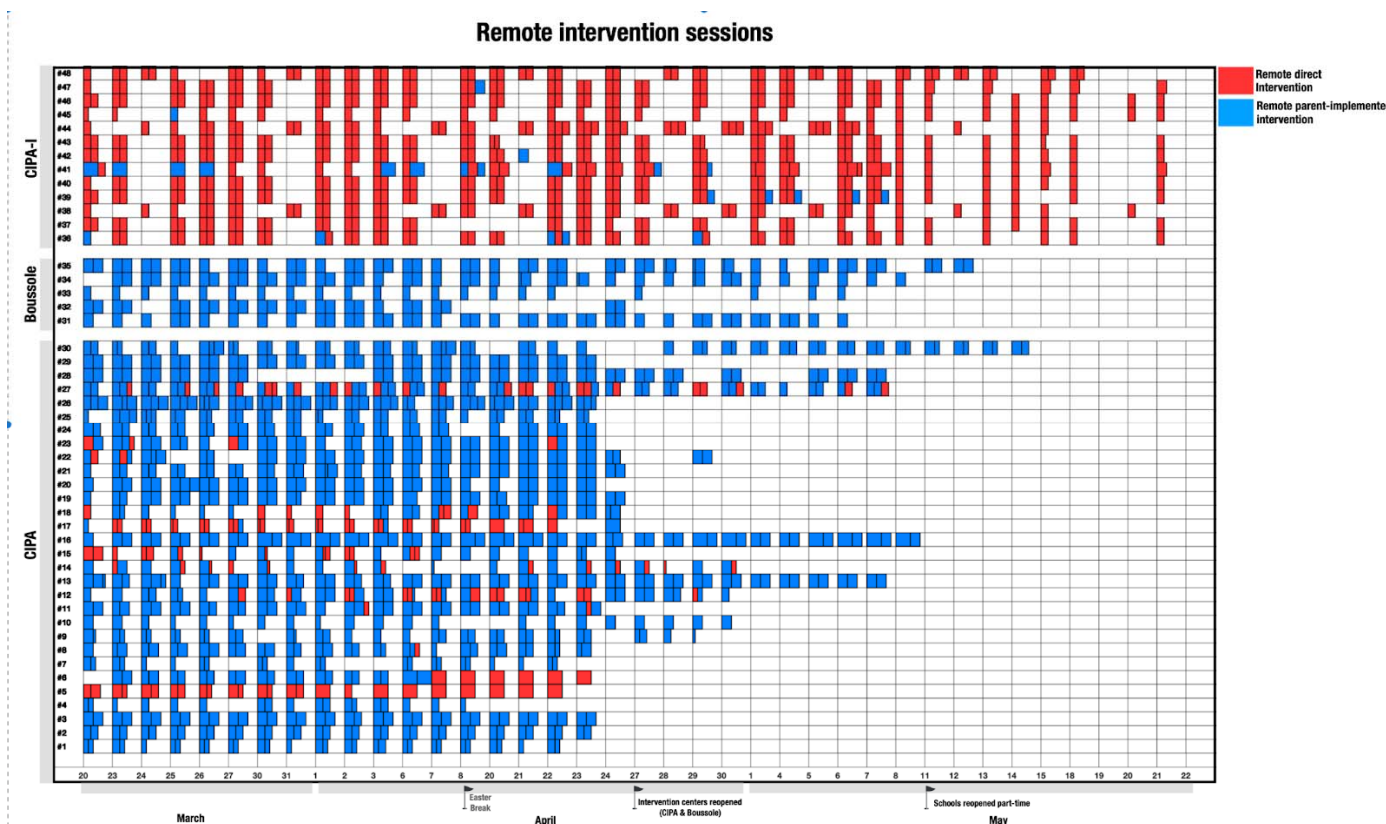


Figure 1. Remote therapy sessions distribution across three centres (y axis: CIPA, n = 30; Boussole, n = 5; CIPA-I, n = 13) for the two-month confinement period (timeline: x axis). Remote intervention sessions started on March 20th and lasted until May 22nd. On April 27th, intervention centres re-opened and families were given a choice to start in-person therapy or to continue remote sessions. Schools re-opened part-time on May 11th and remote sessions in CIPA-I continued being offered until May 22nd. Each row represents sessions for one child. Individual sessions are depicted in coloured rectangles (blue = parent implemented intervention and red = remote direct intervention). Session duration (30-60 -90 minutes) is proportional to the width of the rectangles.

Table 2. Description of the remote intervention sessions

Measures	CIPA (n = 30)		Boussole (n = 5)		CIPA-I (n = 13)		All three centers (n = 48)	
	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)
Total number of sessions over the entire period	39.6 (±11.0)	18 - 68	36.4 (±12.8)	21 - 51	46.8 (±6.03)	30 - 53	39.7 (±11.1)	18 - 68
Total intervention time (in hours)	31.3 (±12.1)	12.3 - 63.8	34.4 (±13.5)	15.8 - 48.3	35.9 (±5.27)	22 - 44	32.9 (±10.8)	12.3 - 63.8
Average frequency of sessions per week during main confinement period *	8.75 (±1.93)	4.47 - 13.7	7.05 (±1.61)	4.47 - 8.42	7.06 (±1.08)	3.97 - 8.28	8.12 (±1.87)	3.97 - 13.7
Average intervention time (in hours) per week during main confinement period *	7.3 (±2.2)	3.22 - 11.1	6.75 (±2)	3.36 - 8.16	5.41 (±0.92)	2.89 - 6.72	6.73 (±2.06)	2.89 - 11.1
Type of remote sessions:								
Parent Implemented	32.3 (±13.9)	0 - 58	36.4 (±12.8)	21 - 51	1.85 (±3.29)	0 - 11	24.5 (±18.2)	0 - 58
Direct Intervention	4.87 (±8.62)	0 - 30	-	-	45.0 (±6.68)	29 - 53	15.2 (±19.9)	0 - 53
Parent Implemented interventions conducted with (in percent):								
Mothers	52.4 (±37.4)	0 - 100	66.2 (±29.5)	25 - 96	-	-	53.9 (±36.8)	0 - 100
Fathers	26.4 (±33.2)	0 - 100	25.2 (±31.4)	0 - 70	-	-	27.2 (±33.4)	0 - 100
Both parents	13.5 (±23.2)	0 - 100	7.80 (±9.55)	0 - 24	-	-	13.9 (±23.5)	0 - 100
Other caregivers (e.g. nannies)	2.08 (±7.92)	0 - 44	0.80 (±1.79)	0 - 4	-	-	2.14 (±8.03)	0 - 44

Note : * Confinement period for all children in CIPA and Boussole programs: March 20th to 27.04; for CIPA-I: March 20th to May 11th, 2020.

Parent and Therapist Satisfaction Questionnaires

Forty-two out of 45 families and all 45 therapists filled out all 3 time-points of the satisfaction questionnaires. The questionnaire was filled out by the parent(s) who participated in the coaching or were present during the direct intervention sessions. We divided the questionnaire responses into the following three areas of interest (figures 2-5):

1) Experience and satisfaction with videoconferencing format at week 3: Parents reported general satisfaction with the online format, with 88% saying they felt comfortable with the use of technology and their role in the telehealth intervention, and only 9% reporting technical difficulties. While 29% did think it was harder to understand the therapist via Zoom than in person, nearly all parents (90%) felt motivated to try and apply new techniques with their child following a remote session, and 89% felt the sessions were useful and helped the child progress (figure 2). At the end of the home confinement period, we asked parents what they found most challenging with the intense telehealth delivery model, and 50.3% said that the hardest thing was controlling the home environment around them during the sessions, such as siblings and other distractions, and 33% felt the most difficult part of the video conferencing sessions was managing their own child's behaviours. Ten percent said the biggest challenge was not having enough toys and materials, while only 7% said the most difficult thing was using the video-conferencing technology. Only one parent described feeling that it was difficult to play with their child while being observed via video-conference, while the rest of the parents did not report this as a difficulty (figure 3, A1).

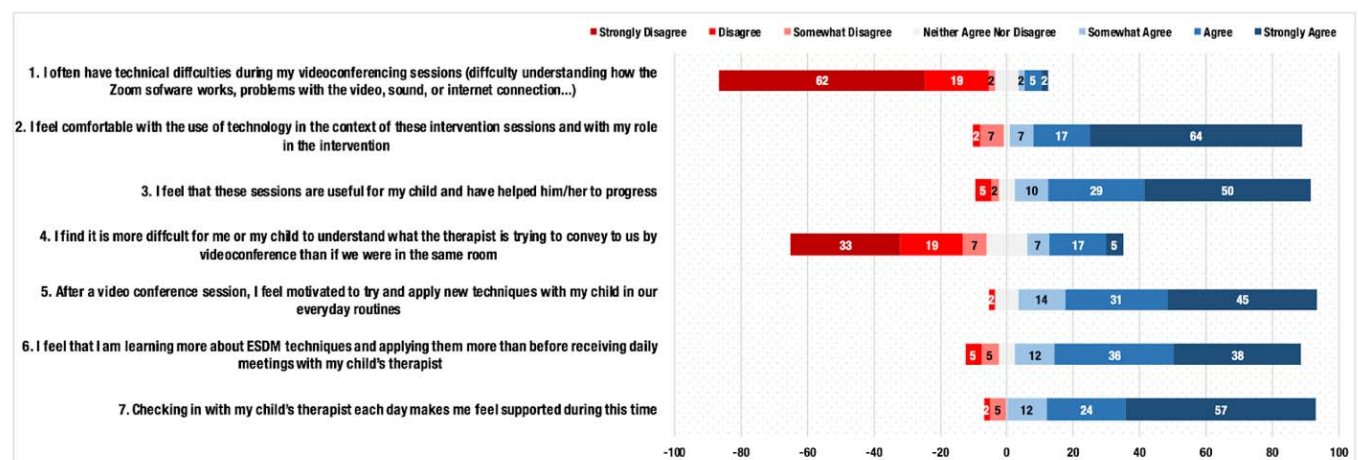


Figure 2. Parents' satisfaction with the remote intervention delivery was assessed at week 3. Questions were assessed on a 7-point Likert scale (Strongly Disagree-Strongly agree). The percentages of categories of responses are represented on the figure with the exception of the neutral response "Neither agree nor disagree" (point "4" on the Likert scale).

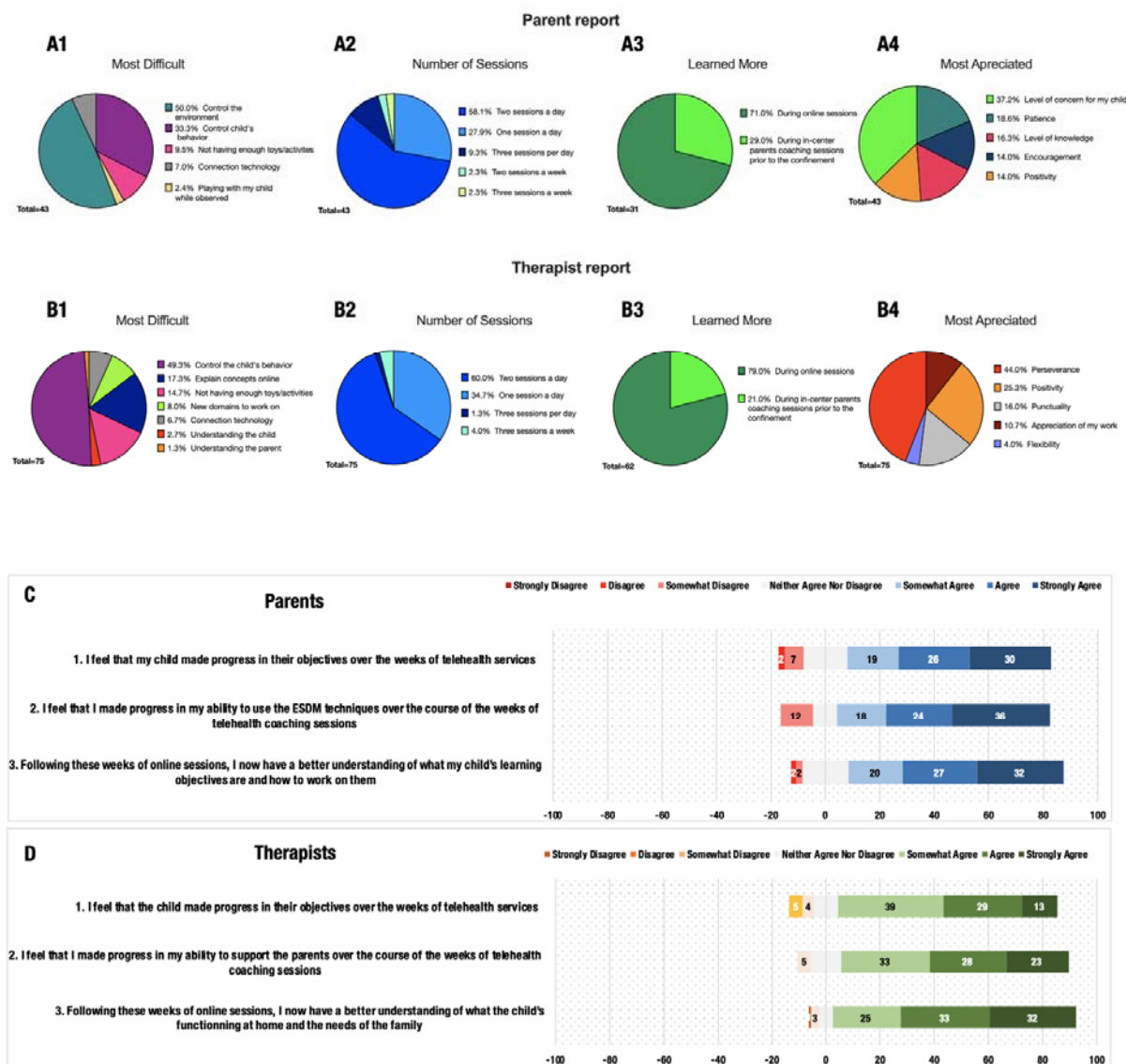


Figure 3. Satisfaction questionnaire administered following the final remote session. Panels A and B illustrate multiple choice question answers for parents and therapists respectively. The percentage of responses is denoted on the figure except for neutral responses (point “4” on the Likert scale): C Responses of the parents (n = 47); D therapists (n =45).

2) Parent experience of increased dosage (frequency of sessions): Nearly all parents (93%) felt that checking in daily with their child’s therapists made them feel supported in their efforts, and 86% felt that they learned more about ESDM techniques and were applying them more than before receiving the daily meetings with their child’s therapist (figure 3). Likewise, 84% of parents felt that they made progress in their ability to use the intervention techniques and 79% felt that the weeks of online daily sessions helped them to have a better understanding of their child’s learning objectives and how to work on them. Following the period of remote delivery, we asked the parents and therapists what for them would be the ideal frequency of the remote sessions. To our surprise, 58% of parents and 60% of therapists felt that 2 sessions a day was the ideal frequency, while 28% of parents and 35% of therapists felt that one-session a day would have been better. None of the parents or therapists said they preferred the typical rate of 1x a

week, however, 2 families and 3 therapists said they would have preferred only 2-3 sessions per week (figure 3, panels A2 & B2).

We tested the relationship between the parent-reported satisfaction and the income level. As previously described families were divided into three groups based on their annual income (table 1). Overall, we do not find significant differences between the three groups of parents with regards to their assessment of therapy sessions. All three groups considered sessions were very useful and helped the child progress, though we notice less variance in the low-income group (figure 4, B). All three-group reported high motivation to try and test new things learned during remote sessions and they highly valued the possibility to have daily check-ins with the therapists of their child. Mid-income families reported less technical issues compared to both low-income ($U = 70.5$; $p = 0.07$) and high-income families ($U = 48$; $p = 0.04$) however, this last comparison did not withhold after the Benjamini-Hochberg procedure for FDR control.

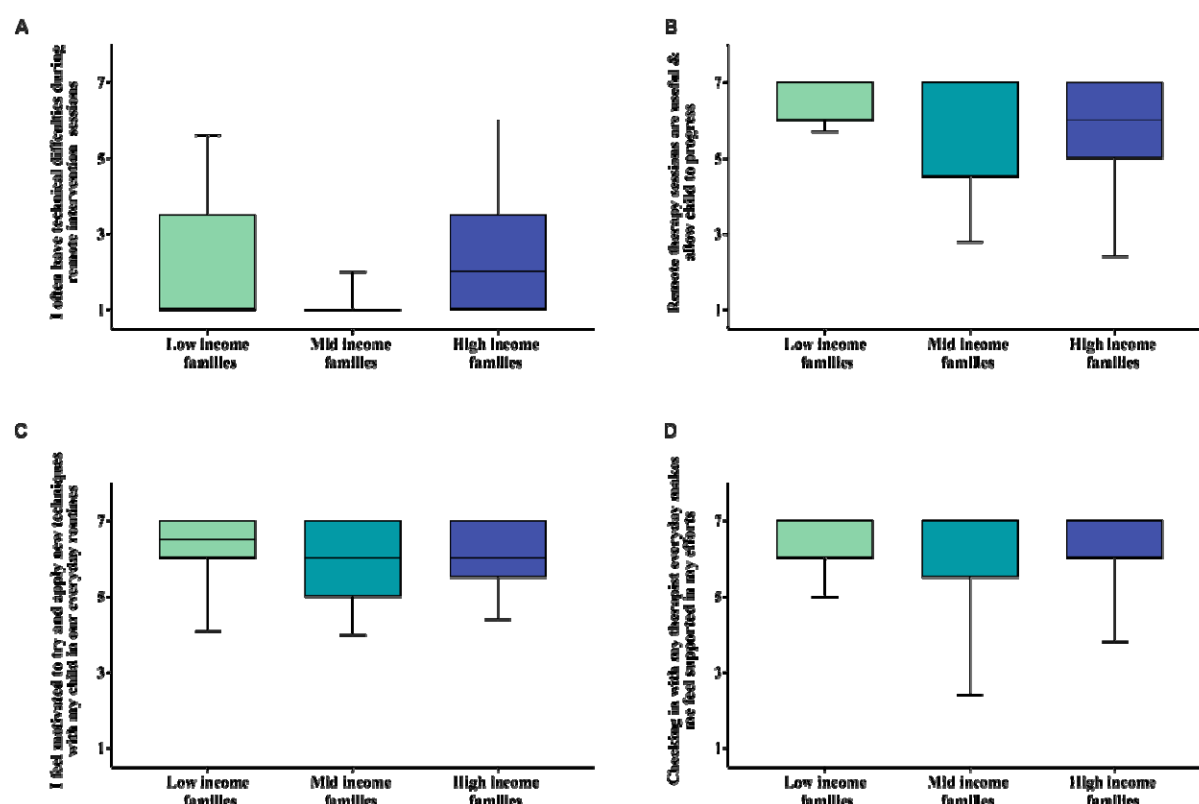


Figure 4. Comparison of parents' perception of remote sessions across three income groups defined according to the Swiss Federal Statistics Office guidelines: A: technology issues during remote sessions, B: perception of remote intervention usefulness; C: parents' motivation to try new techniques; D: perceived importance of daily checking in with the therapists of their child.

3) Comparison of parent and therapist satisfaction and perceptions Overall, the therapists tended to be more hesitant about the switch to an intensive telehealth service delivery model than the parents. In our assessment of parents' comfort level with the new format, we found significant group differences between parents and therapists, with therapists perceiving the parents as less comfortable with the format than the parents actually were, both at Week 1 ($U = 649$; $p = 0.004$, $d = 0.6$) and Week 3 ($U = 986$; $p = 0.001$, $d = 0.6$) (figure 5). No significant change in perception of parents' comfort level was observed in parents or

therapists between Week 1 and Week 3. Similarly, parents tended to perceive the therapists as more comfortable in using the telehealth format than the therapists actually reported feeling. We found group differences both at the initial measure ($U = 339$; $p < 0.001$, $d = 1.4$) and at the second time point ($U = 963$; $p < 0.001$, $d = 0.6$), where therapists reported feeling less comfortable with the new format than the parents perceived them to be. Therapists showed a significantly lower estimation of their own comfort with the service delivery format at Week 3 compared to Week 1 ($U = 1023$; $p < 0.001$, $d = 0.7$). We also found group differences for how useful the parents and therapists felt the daily sessions were. Parents perceived the sessions as being more useful for them and their child than the therapists did, both at the initial measuring time point ($U = 687$; $p = 0.012$, $d = 0.5$) and at Week 3 ($U = 1145$; $p = 0.029$, $d = 0.4$). However, the difference at Week 3 did not hold statistical significance after the Benjamini-Hochberg correction for multiple comparison. When we asked both parents and therapists whether they felt it was important to continue early intervention services remotely during the Covid-19 home confinement period, we detected group differences at Week 1, with therapists having a slightly lower estimation of the importance to continue intervention during this period ($U = 778$; $p = 0.020$, $d = 0.4$). However, by the third week, both groups strongly agreed that it was important to continue the services remotely.

In the final questionnaire, we asked parents which characteristic they liked most about the therapist working with them. Thirty-seven percent of parents reported that the therapists “level of concern for my child” was what they appreciated the most, with the others noting it was the therapist’s “patience” (19%), “level of knowledge” (16%), “encouragement” (14%), and positivity (14%) that made the difference (figure 3, A3). Likewise, when the therapists were asked what characteristic, they most appreciated in the parents, 44% answered that it was the parents’ “perseverance”, while others felt it was the parents’ “positivity” (25%), “punctuality” (16%) and “flexibility” (4%) that they liked most. Eleven percent of therapists noted that the characteristic they most appreciated in the parents was how much the parents seemed to appreciate their (the therapists’) work (figure 3, B3).

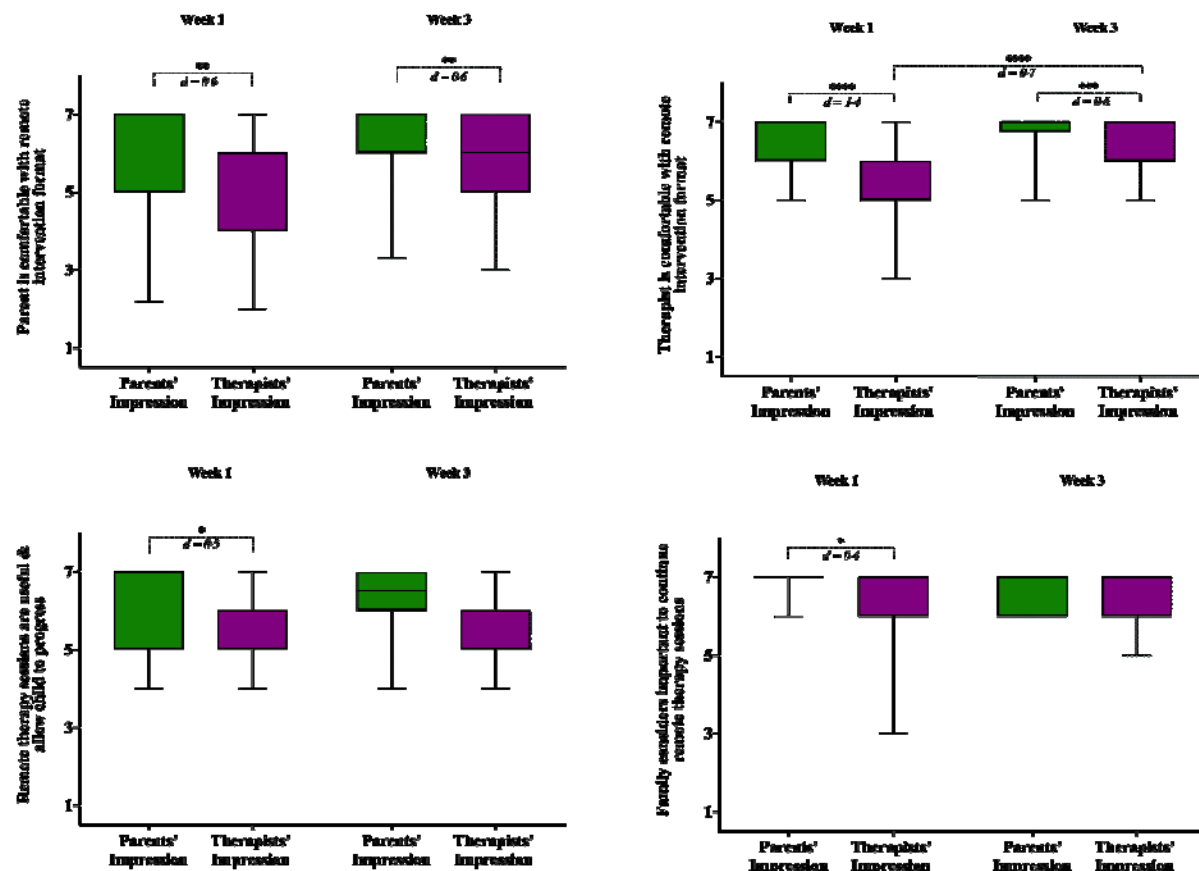


Figure 5. Week 1 and Week 3 comparison of change in parents' and therapists' impressions with regards to: parental comfort with the new, remote format of intervention (upper left); therapists' comfort with the remote format of intervention (upper right); perception of remote intervention usefulness (lower left) and family perception of importance to continue the online intervention format (lower right). The effect size is expressed using Cohen's d and significance level are defined as follows: * $p < 0.05$, ** $p < 0.01$, *** $p \leq 0.001$, **** $p \leq 0.0001$.

Monitoring progress during telehealth services using the ESDM Curriculum Checklist

We aimed to measure the magnitude of change across different developmental domains assessed by the ESDM-CC following the intervention received during home-confinement. We compared the ESDM-CC global and subdomain scores between three time points (T1 - ESDM-CC three months before the Pre-Confinement ESDM-CC; T2 - Pre-Confinement ESDM-CC; T3 - Post-Confinement ESDM-CC) using Wilcoxon matched-pairs signed rank test. As depicted in figure 6, in all domains but expressive language we observed a pattern of continued significant improvement between all ESDM-CC evaluations, without any stagnation of progress related to the confinement period (between T2 and T3). For expressive language, the improvement observed between T2 and T3 did not reach significance level ($p=0.06$) (see Figure 5). Global scores showed significant change post (T3) compared to prior confinement (T2); $Z = -2.71$, $p = 0.007$, $r = 0.36$, slightly higher change was observed in a period preceding the confinement ($Z = -3.04$, $p = 0.002$, $r = 0.41$). However, the change observed in three out of four assessed domains, namely Receptive Communication, Social Skills and Play was higher during the Confinement Period (T2-T3) ($Z = -3.03$, $p = 0.002$, $r = 0.40$, $Z = -3.07$, $p = 0.002$, $r = 0.41$, $Z = -3.45$, $p = 0.001$, $r = 0.46$ respectively) compared to the pre-confinement change T1-T2 ($Z = -2.82$, $p = 0.005$, $r = 0.38$, $Z = -2.81$, $p = 0.005$, $r =$

0.38, $Z = -2.94$, $p = 0.003$, $r = 0.39$ respectively). This global effect might be driven by a lesser change evidenced in the domain of the Expressive Communication during T2-T3 ($Z = -1.38$, $p = 0.17$, $r = 0.18$) compared to the pre-confinement period ($Z = -3.60$, $p < 0.001$, $r = 0.47$).

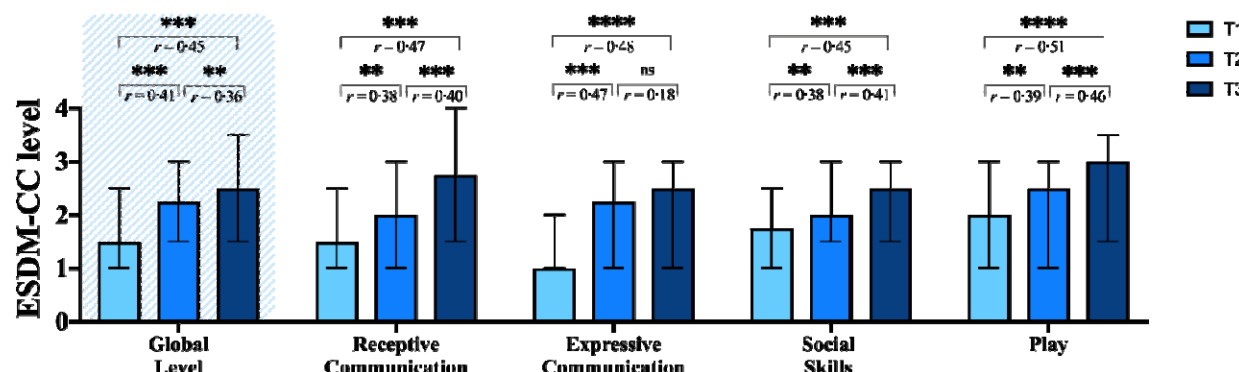


Figure 6. Bar plots depicting the change in ESDM curriculum checklist (ESDM-CC) levels at 3 time points: T1- ESDM-CC 3 months before Pre-Confinement ESDMCC, T2-Pre-Confinement ESDM-CC, T3 Post-Confinement ESDM-CC. The magnitude of change is expressed in effect size $r = Z/\sqrt{N}$ (Rozenthal, 1991) and significance level are denoted as follows: ** $p < 0.01$, *** $p \leq 0.001$, **** $p \leq 0.0001$.

Discussion

Measuring experience of remote parent-implemented and direct intervention across a diverse population of families with children on the autism spectrum

The current study supports previous research that has shown that providing autism intervention services, and more specifically parent coaching via videoconference, is not only clinically feasible, but that parents report high levels of satisfaction with the online format.^{2,8,9,12,13,20} The unprecedented circumstances of a global pandemic and subsequent home-confinement orders meant that all of the families in the current study switched to receiving remote services, and we did not have to rely on recruitment of volunteers. Unlike the majority of studies on parent implemented intervention (both in-person or via telehealth) prior to Covid-19, our sample included comparable numbers of low, mid and high income families, as well as parents with lower educational attainment, working parents, fathers, single parents and families representing many different ethnicities and cultural groups.^{8,10,13,17} This gave us a realistic picture of how these telehealth services could work in our community setting, demonstrating that nearly all of the families, regardless of their socio-economic situation or cultural background, were highly motivated to learn tools to help their child, and appreciative of the regular support they received via videoconference. As Stahmer and her colleagues found in a 2019 study on improving access to autism services,¹⁵ families with lower socioeconomic status, in the current study, faced potential barriers, such as a smaller living space to work with their child, less toys and materials available, or a lack of a computer and dependable internet connection. Despite these obstacles, we found no significant difference in their participation (many participated by smart phone or borrowed a tablet), in their satisfaction, or in how important or useful they found the sessions. In fact, these families tended to be more unanimously positive about the support they received, when compared to mid- and high-income families. Our findings suggest that caregivers from diverse cultural backgrounds, and in varying socio-economic situations, are just as motivated and engaged in their child's programs as the families who have been, until recently, more represented in the literature. However, for telehealth parent-implemented intervention be more inclusive

of traditionally underserved children,¹⁵ programs should provide access to a computer, internet connection, toys and therapy supplies as needed.

Parent-Implemented Intervention via telehealth for families living in proximity to service providers

Prior to Covid-19, autism-related telehealth services were often considered for people living in remote areas, where in-person meetings with a specialist were limited^{2,19}. The current study found that having the option to provide services online can be equally helpful for families who live in close proximity to specialized centres, making it easier, for example, for a working parent to join an online consultation over their break, or for a parent to have a coaching session while their younger child naps at home. This also had important implications for separated parents who share custody of their child, allowing them to hear the same information without being physically in the same room. The need for more accessible service provision was emphasized in de Nocker and Toolan's 2021 systematic review of telehealth intervention for autism¹⁰, where they suggest that in order to reach more families, and in particular underserved communities, we need to be open to more flexible telehealth solutions.^{10,29-31} Video-conferencing consultations have shown to reduce commute and waiting room time, and allow the professional to work in the natural context of the home, albeit virtually, instead of a clinic setting.^{9,32} In the current study, both parents and therapists brought up the benefits of having frequent "in-home visits", describing how working on skills in the environment, where they typically take place, allowed them to better understand the strategies. For example, some parents were able to prop up the computer on the lunch table to get help with their child's feeding skills, or show the professional challenging behaviours that tend to happen in the home. Our programs had always provided in-home visits, however, only at an average rate of 1x a month, due to travel time and the parents' comfort level with professionals coming into their home. This finding supports what other authors have described as the importance of working on real-life situations and daily routines in their natural context.^{8,12,20,32,33} Future research should consider studying a combination of providing both in-person and remote services - a 'hybrid' model combining the benefits of the in-person therapeutic connection and hands-on coaching of clinic work, with the flexibility and reduced costs of telehealth consultations.

Parent experience of a high dosage of parent-implemented intervention

The Covid-19 home confinement period also prompted us to provide far more frequent parent coaching sessions than usual, in an effort to compensate for the cancelled therapist-delivered intervention sessions. Although this was a very unique situation where parents were 'stuck' at home, most of them did have to continue to work remotely, while also managing their children. We were impressed by the level of engagement in the videoconferencing sessions, with nearly all families agreeing that it was important to continue intervention sessions remotely, and reporting that daily meetings with the therapist supported their intervention efforts.

Despite interacting via a screen, parents felt they learned more with the daily delivery format when compared to the weekly, in-centre coaching sessions they had received prior to the pandemic. This could be a result of the special circumstance, with an increase of interactions with their child during the stay-at-home period, however, it lends support for idea that a higher frequency of parent coaching sessions is indeed feasible, with the potentially positive effect of the parent acquiring and applying the skills sooner with their child.^{8,19} Indeed, a goal of parent-implemented intervention is to help caregivers acquire intervention strategies, in an effort to improve and increase parent-child interactions, and ultimately encourage child developmental change.^{8,34} The idea of a higher dosage of parent coaching was explored in

a recent study by Rogers and her colleagues⁸, where they compared one-session-a-week parent coaching with an enhanced program that involved two coaching sessions per week, demonstrating that caregivers, who received the additional session, found the intervention techniques easier to implement, and made significantly greater gains in interaction skills with their child. Likewise, a 2014 randomized controlled study demonstrated significantly greater improvements in child outcome when the parent coaching was offered 2 to 3 times a week, compared to once-a-week group parent training.²⁰ In the scope of the current study, given that it was unplanned, we were not able to measure parent acquisition of skills, however, the majority of parents did report feeling more confident in their ability to use the intervention tools, and more motivated to apply the techniques with their child, following the daily coaching sessions. We were also not able to complete formal pre- and post-testing to measure child outcome, however, through analysis of our regular, quarterly monitoring of child developmental progress using the ESDM-CC, we observed a pattern of continued significant improvement across all developmental domains (except expressive language, where improvements were considerable but did not reach significance level), without any stagnation of progress during the confinement period. Although these findings do not allow us to draw conclusions on the efficacy of intensive parent-implemented intervention, they do suggest that we should consider new forms of parent coaching, other than the once-a-week meeting, such as offering more frequent sessions at the beginning of treatment, when the parents are first learning the techniques, and checking-in more often thereafter, to support ongoing implementation.

Comparison of parent and therapist perceptions

Satisfaction questionnaires revealed that parents tended to perceive the therapists as being more comfortable in using the telehealth format than the therapists actually were, and inversely, we found significant group differences showing that the therapists tended to perceive parents as being less at ease with the telehealth services than parents reported being. These findings suggest that professionals may underestimate the readiness of families to participate in online parent coaching, and may themselves come across as more confident in an intervention session than they actually feel. In our final questionnaire, we asked parents which characteristic they appreciated most about the therapist working with them. In-line with other studies looking at parent satisfaction with autism services,^{21,35} most parents reported that the therapist's "level of concern for their child" was important to them. When asked the same question about the parents, therapists reported appreciating the parent's "perseverance" as well as their "positivity", and for a few therapists, "how much the parent seemed to appreciate them". When the parents were asked what the therapist could have done differently to improve the sessions (open ended question), the parents unanimously noted that the sessions had gone as well as they could have, and tended to be very positive. When we asked the therapists, they came back with a lot of constructive ideas, such as varying the time of the sessions to be able to work on the child's meal-time skills and finding effective ways to occupy the child while they discussed with the parents.

Limitations and future clinical considerations

The main limitation of this study was also what made it possible - the unexpected circumstance of supporting families during home-confinement orders. It was not possible to randomise groups or complete formal measures of child and parent outcome, and our satisfaction questionnaires needed to be created very quickly. This was a period of great uncertainty, and relative solidarity, where parents seemed open to try new modes of communication and were motivated to keep a sense of continuity for their child's program, all of which may have impacted their level of participation and satisfaction. It should also be noted that the parents in our study had all met or worked with their therapists in-person prior to being asked to meet online, which may have increased their willingness to take part in the new approach.^{1,30} This study did not examine whether a family without previous experience in early intervention would have the same level of engagement with the remote delivery of services. In considering ideal sessions frequency, the current study did not compare parent experience between

varying durations of sessions (30 vs 60 vs 90 minutes), which would be important to take into account in future research.

The COVID-19 pandemic disrupted our intervention program for children on the autism spectrum, forcing us to re-think our service provision model and giving us the chance to experience very frequent interactions with the families. It reminded us of the importance of parent-partnership, which is often neglected in clinical treatment settings where parents aren't present during intervention sessions. Therapists and families *felt that* they had a stronger bond and more common goals following the weeks of daily meetings. It helped us to imagine a future of clinical practice where telehealth services would allow an increased frequency of interaction with parents, with more emphasis on parent coaching in the 'virtual' home environment, potentially opening up services to far more children in our community.

Research Ethics Committee Approval

The relevant ethics committee regulating all work performed at the Faculty of Medicine of the Geneva University is the Commission Cantonale d'Ethique de la Recherche sur l'être humain; Regional Research Ethics Committee (CCER), Geneva, Switzerland. The CCER approved the current project (n° PB_2016-01880) on April 20, 2020. The methods used in the present study were performed in full accordance with the relevant guidelines and regulations of Geneva University.

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Measures	CIPA (n = 30)	Boussole (n = 5)	CIPA-I (n = 13)	All intervention centers (n = 48)
Age at the onset of the confinement period <i>Mean (SD)</i>	3·39 (±0·79)	1·34 (±0·49)	5·67 (±0·63)	3·79 (±1·49)
Sex (female/male)	3 / 27	3 / 2	1 / 12	7 / 41
Intervention duration prior to the confinement period (in years)				
<i>Mean (SD)</i>	1·07 (±0·51)	0·33 (±0·26)	3·24 (±0·71)	1·58 (±1·78)
<i>Range (min-max)</i>	0·08 - 1·74	0·04 - 0·59	2·37 - 4·51	0·04 - 4·51
Age at diagnosis/ [#] start of the intervention <i>Mean (SD)</i>	2·41 (±0·44)	1·13 (±0·37) [#]	2·50 (±0·40)	2·30 (±0·58)
ADOS-CSS at diagnosis <i>Mean (SD)</i>	7·83 (±1·91)	-*	8·15 (±1·46)	7·93 (±1·77)
Mullen Early Learning Scales Developmental Quotient (MSEL DQ) at diagnosis <i>Mean (SD)</i>	60·8 (±18·4)	70·8 (±14·1)	60·8 (±15·9)	61·6 (±17·3)
VABS-II Adaptive Behavior Composite at diagnosis <i>Mean (SD)</i>	78·7 (±10·00)	77·8 (±8·85)	81·8 (±7·07)	79·5 (±9·13)
Household organization				
One parent/two parents	3 / 28	1 / 4	2 / 11	6 / 45
Parent's ethnicity				
European	17 (56%)	2(40%)	4 (31%)	23 (48%)
Admixed American	2(7%)	-	2 (15%)	4 (8%)
African	3(10%)	1(20%)	1 (8%)	5 (11%)
Asian	4(13%)	2(40%)	3 (23%)	9 (19%)
Asian+European	2(7%)	-	1 (8%)	3 (6%)
Admixed American+European	2(7%)	-	2 (15%)	4 (8%)
Parents' education (higher of the two when applicable)				
Elementary school	2 (7%)	0 (0%)	1 (20%)	3 (6%)
High school	10 (33%)	5(38%)	1 (20%)	16 (33%)
Post secondary	18 (60%)	8 (62%)	3 (60%)	29 (61%)
Household income at diagnosis**				
Low income (<60k CHF)	8 (27%)	4 (80%)	6 (46%)	18 (38%)
Mid income (60-140k CHF)	13 (43%)	-	2 (15%)	15 (31%)
High income (> 140k CHF)	9 (30%)	1 (20%)	5 (39%)	15 (31%)

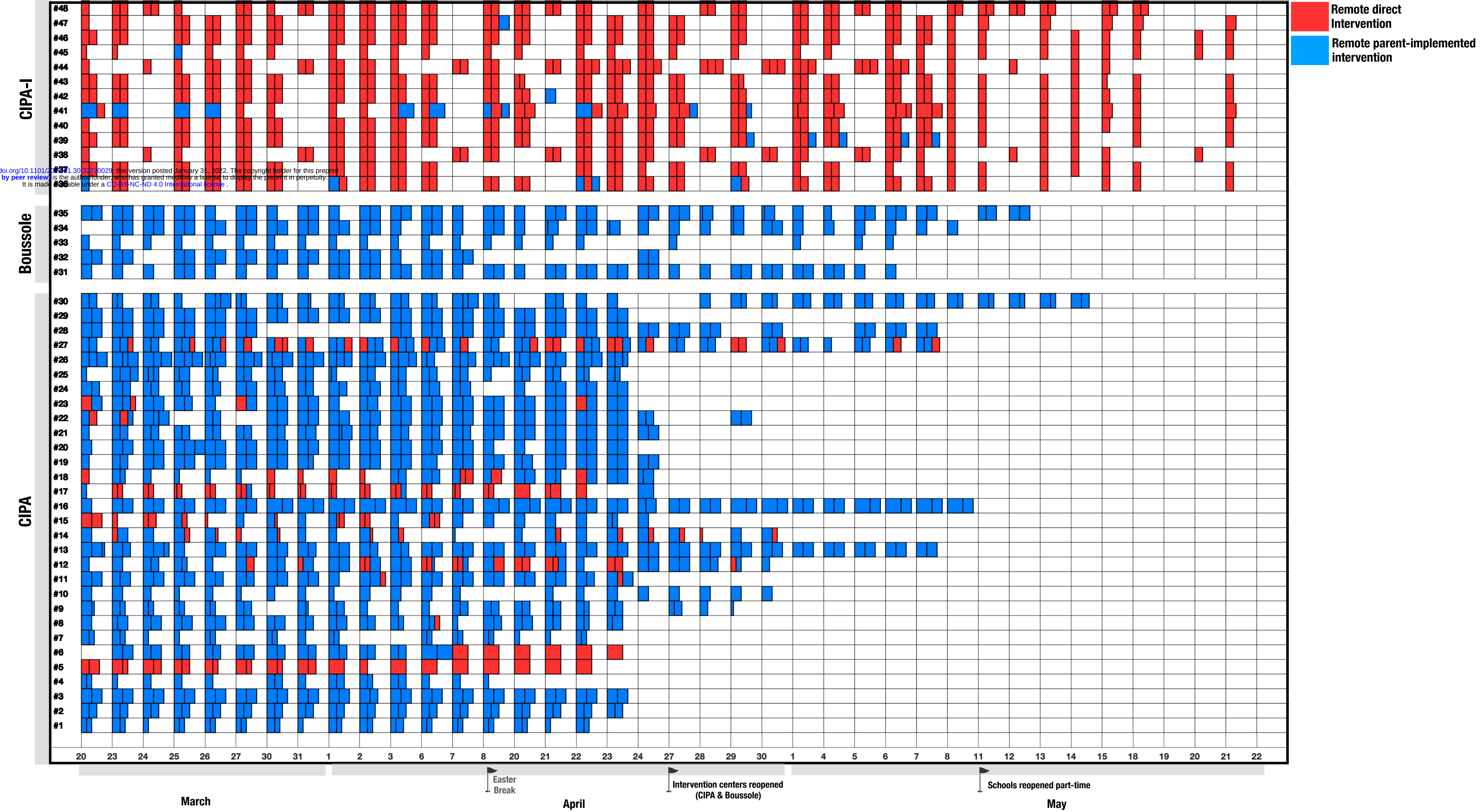
Notes: * Children in this group were not administered ADOS (young age /lack of motor autonomy)

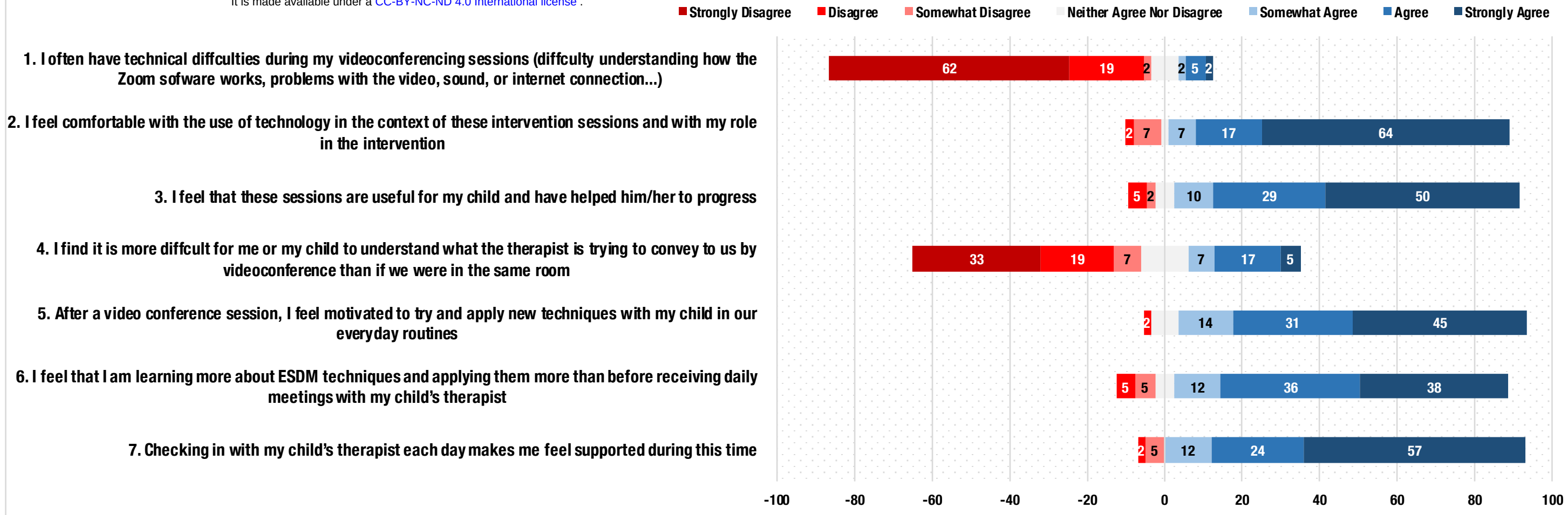
** Source: Swiss Federal Statistics Office-SFSO, Statistics on Income and Living Conditions SILC-2018, version 07.10.2019.

Measures		CIPA (n = 30)		Boussole (n = 5)		CIPA-I (n = 13)		All three centers (n = 48)	
		Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)
Total number of sessions over the entire period		39.6 (±11.0)	18 - 68	36.4 (±12.8)	21 - 51	46.8 (±6.03)	30 - 53	39.7 (±11.1)	18 - 68
Total intervention time (in hours)		31.3 (±12.1)	12.3 - 63.8	34.4 (±13.5)	15.8 - 48.3	35.9 (±5.27)	22 - 44	32.9 (±10.8)	12.3 - 63.8
Average frequency of sessions per week during main confinement period *		8.75 (±1.93)	4.47 - 13.7	7.05 (±1.61)	4.47 - 8.42	7.06 (±1.08)	3.97 - 8.28	8.12(±1.87)	3.97 - 13.7
Average intervention time (in hours) per week during main confinement period *		7.3 (±2.2)	3.22 - 11.1	6.75 (±2)	3.36 - 8.16	5.41 (±0.92)	2.89 - 6.72	6.73 (±2.06)	2.89 - 11.1
Type of remote sessions:					-				
	Parent Implemented	32.3 (±13.9)	0 - 58	36.4 (±12.8)	21 - 51	1.85 (±3.29)	0 - 11	24.5 (±18.2)	0 - 58
	Direct Intervention	4.87 (±8.62)	0 - 30	-	-	45.0 (±6.68)	29 - 53	15.2 (±19.9)	0 - 53
Parent Implemented interventions conducted with (in percent):									
	Mothers	52.4 (±37.4)	0 - 100	66.2 (±29.5)	25 - 96	-	-	53.9 (±36.8)	0 - 100
	Fathers	26.4 (±33.2)	0 - 100	25.2 (±31.4)	0 - 70	-	-	27.2 (±33.4)	0 - 100
	Both parents	13.5 (±23.2)	0 - 100	7.80 (±9.55)	0 - 24	-	-	13.9 (±23.5)	0 - 100
	Other caregivers (e.g. nannies)	2.08 (±7.92)	0 - 44	0.80 (±1.79)	0 - 4	-	-	2.14 (±8.03)	0 - 44

Note : * Confinement period for all children in CIPA and Boussole programs: March 20th to 27.04; for CIPA-1: March 20th to May 11th, 2020.

Remote intervention sessions

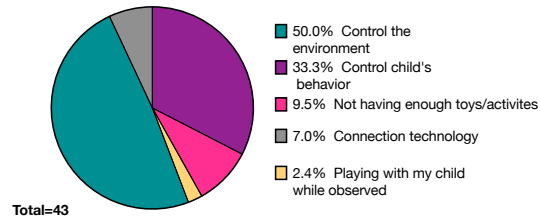




Parent report

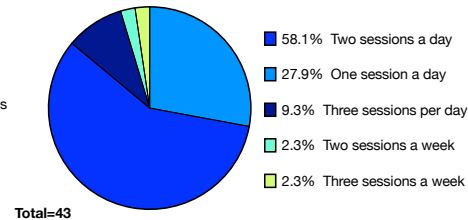
A1

Most Difficult



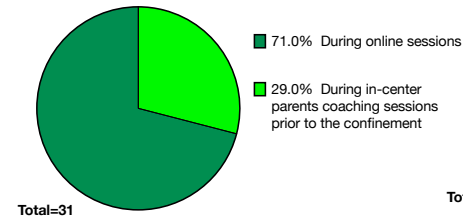
A2

Number of Sessions



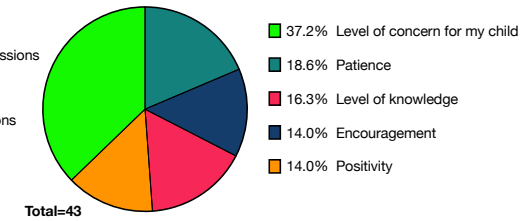
A3

Learned More



A4

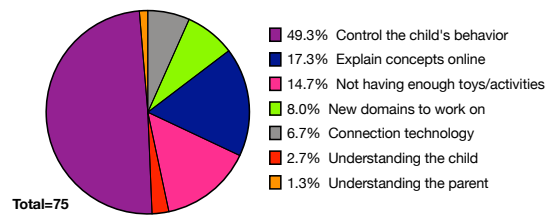
Most Appreciated



Therapist report

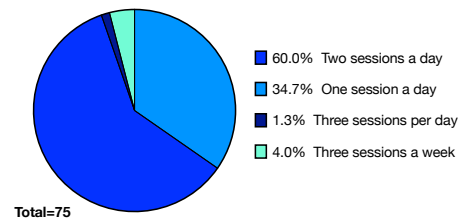
B1

Most Difficult



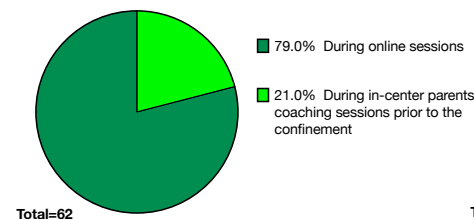
B2

Number of Sessions



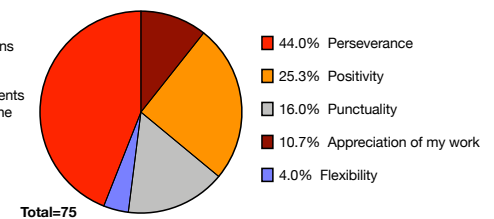
B3

Learned More



B4

Most Appreciated

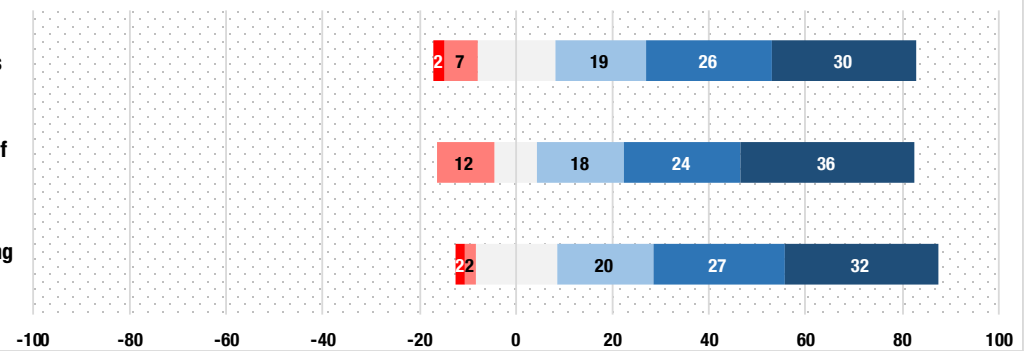


C

Parents

Strongly Disagree Disagree Somewhat Disagree Neither Agree Nor Disagree Somewhat Agree Agree Strongly Agree

1. I feel that my child made progress in their objectives over the weeks of telehealth services
2. I feel that I made progress in my ability to use the ESDM techniques over the course of the weeks of telehealth coaching sessions
3. Following these weeks of online sessions, I now have a better understanding of what my child's learning objectives are and how to work on them

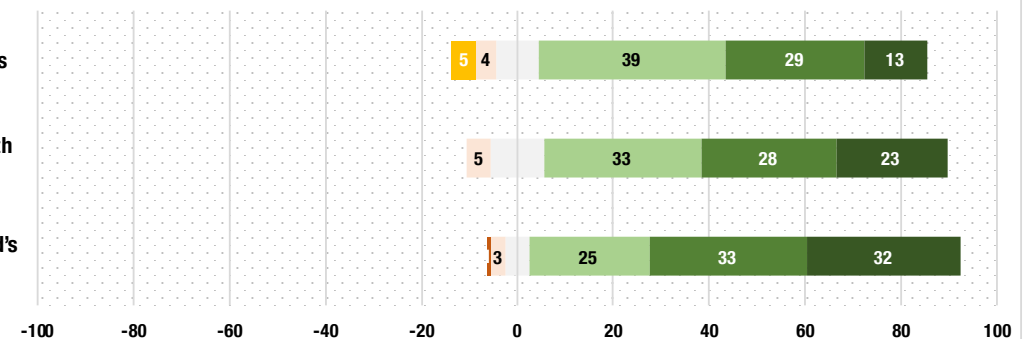


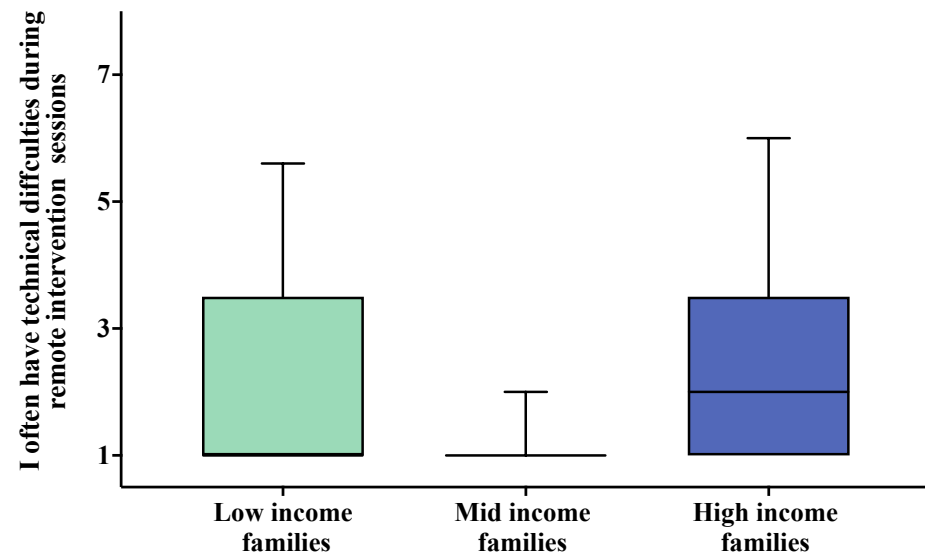
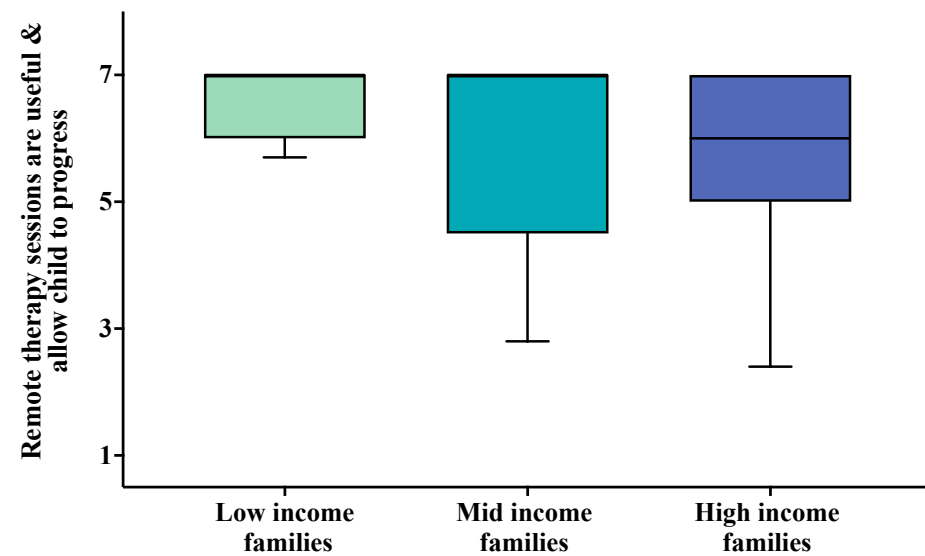
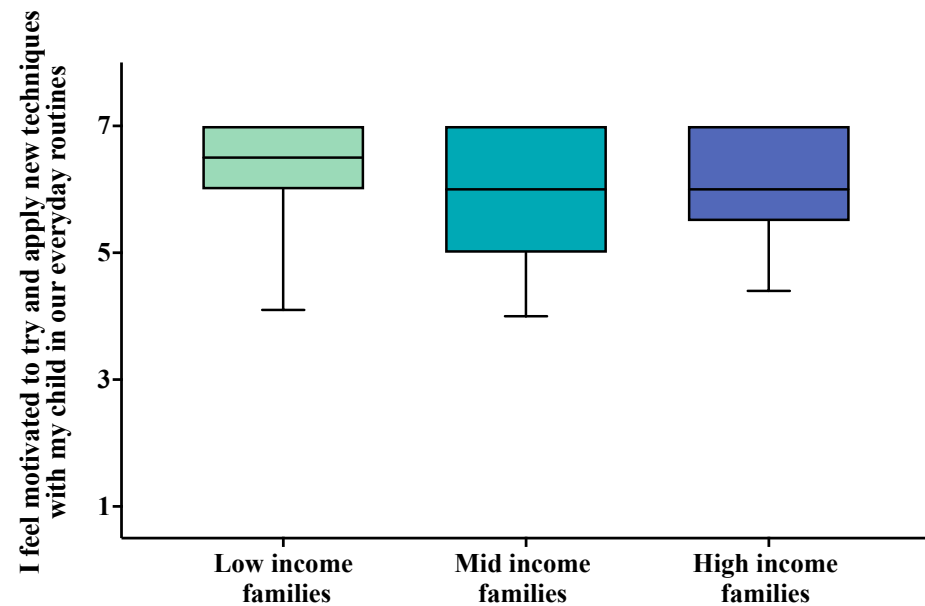
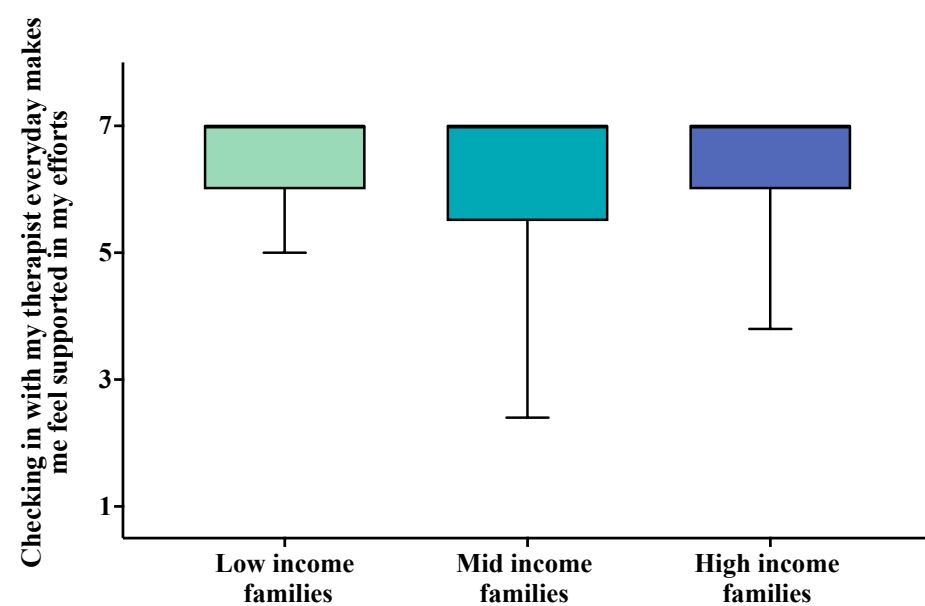
D

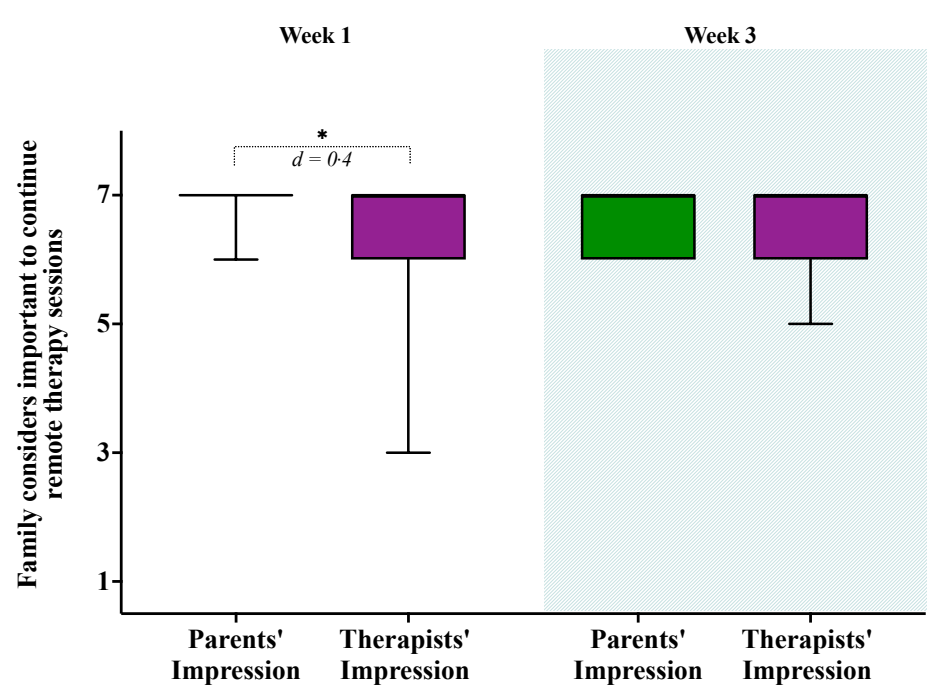
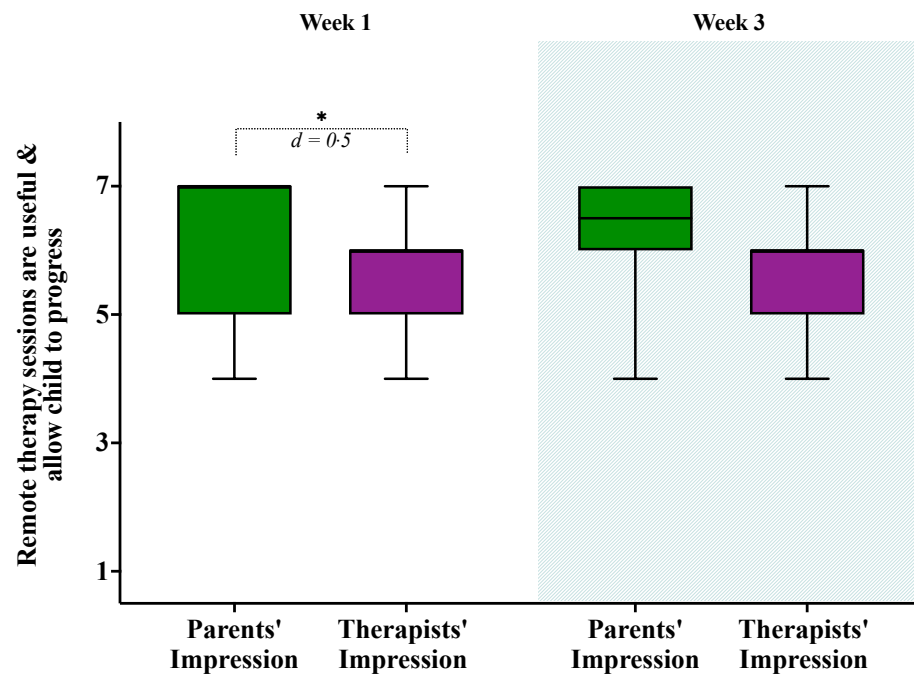
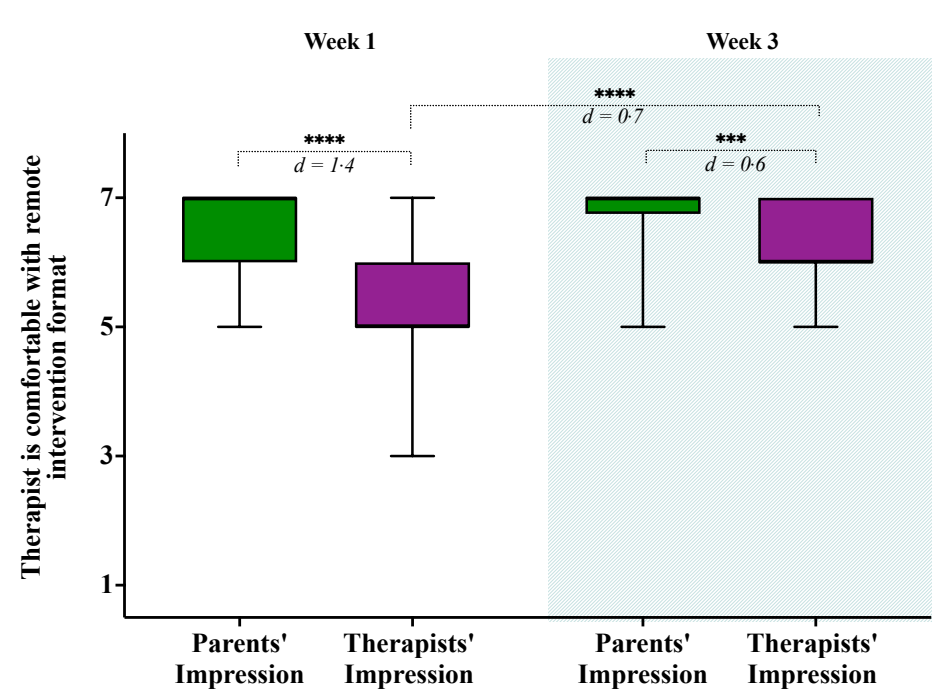
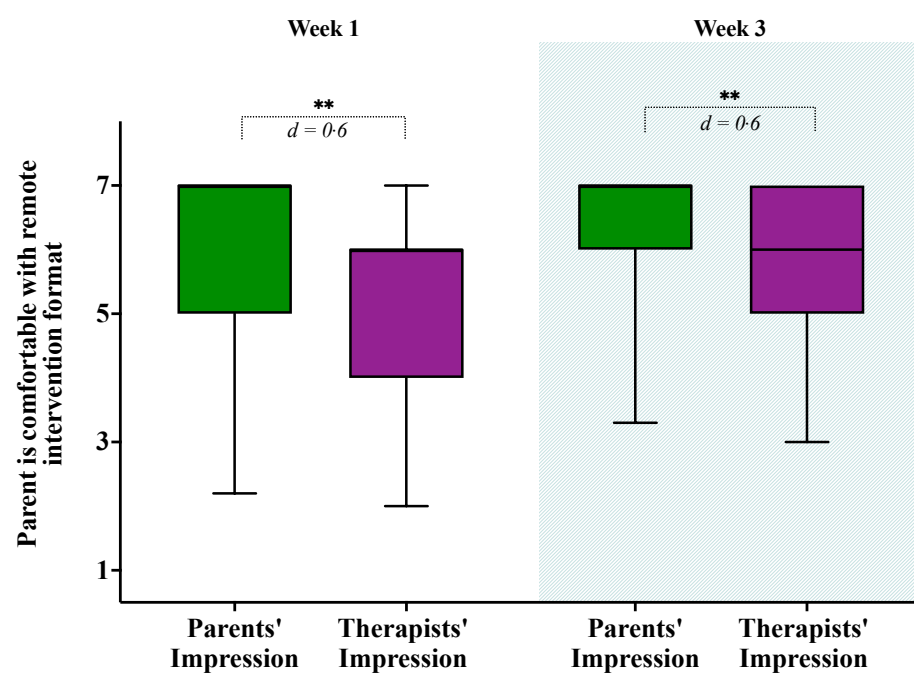
Therapists

Strongly Disagree Disagree Somewhat Disagree Neither Agree Nor Disagree Somewhat Agree Agree Strongly Agree

1. I feel that the child made progress in their objectives over the weeks of telehealth services
2. I feel that I made progress in my ability to support the parents over the course of the weeks of telehealth coaching sessions
3. Following these weeks of online sessions, I now have a better understanding of what the child's functioning at home and the needs of the family



A**B****C****D**



ESDM-CC level

