



Published in final edited form as:

Pediatr Phys Ther. 2022 April 01; 34(2): 246–251. doi:10.1097/PEP.0000000000000872.

Using Telehealth to Conduct Family-Centered, Movement Intervention Research in Children with Autism Spectrum Disorder during the COVID-19 pandemic

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Abstract

After the COVID-19 pandemic, several randomized controlled trials (RCTs) came to a halt, however, we chose to reinvent our study and shifted to a home-based, telehealth format for intervention delivery to support children with Autism Spectrum Disorder and their families. Children with ASD have social communication impairments and perceptuo-motor and cognitive comorbidities. Continued access to care is crucial for their long-term development. We created a general movement intervention to target strength, endurance, executive functioning, and social skills through goal-directed games and activities delivered using a telehealth intervention model. Our family-centered approach allowed for collaboration between trainers and caregivers and made it easy for families to replicate training activities at home. While more studies comparing telehealth and face-to-face interventions are needed, we encourage researchers and clinicians to consider family-centered telehealth to increase the likelihood of carryover of skills into the daily lives of children and ultimately enhance their long-term development.

Introduction

The COVID-19 pandemic impacted healthcare delivery around the world as a result of mandatory lockdowns and virus transmission safety protocols (i.e., social distancing and limited in-person services). At the onset of the pandemic, 74% of children with disabilities in the US lost access to at least 1 therapy or educational service.¹ Children with developmental disabilities, such as those with Autism Spectrum Disorder (ASD) and their families experienced high levels of stress due to the loss of services. The sudden disruption

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Conflict of Interest statement: The authors declare no financial or other conflicts of interest.

to routines, transitions in and out of online learning, and lack of one-on-one support have presented significant challenges for children with ASD who lack the cognitive flexibility to easily adapt to changes, thereby exacerbating their negative behaviors². Parents provided new structure to the daily schedules of their children, managed their problem behaviors, and ensured their continued developmental progress.^{2,3} Many also experienced the extra burden of managing their child's needs with their own workload from home.

Clinical researchers and clinicians made similar adaptations to continue offering therapeutic services to children and families. Within a few months, healthcare providers moved to telehealth using privacy-compliant videoconferencing technologies (Zoom, Webex, etc.). They developed instructional materials for parent education in the form of handouts, visuals, and instructional videos. They also offered shorter and more flexible scheduling options to accommodate parent schedules. During telehealth delivery, parents played a more active role in guiding and assisting their children. Through our experiences conducting intervention research during the pandemic, we learned that there is more than one way of providing care in addition to face-to-face interactions. In this brief report, we describe our experiences of modifying a face-to-face movement intervention for children with ASD into a telehealth format.

Children with ASD have social communication impairments such as poor social reciprocity and impaired verbal and non-verbal communication skills.^{4,5} They have perceptuo-motor comorbidities including poor motor coordination, balance, strength and endurance, and motor planning and praxis.⁴⁻⁹ They also have impaired executive functioning associated with motor impairments such as response inhibition, cognitive flexibility, and working memory.^{5,8-10} Our past face-to-face interventions using music, robot interactions, and yoga have shown positive effects in children with ASD including improved verbalization, imitation, and gross motor skills compared to a comparison group receiving standard-of-care seated play.¹¹⁻¹⁵

In our ongoing randomized controlled trial (RCT) we compared the effects of a general movement intervention devoid of creative/musical activities to a standard-of-care, seated play intervention (Figure 1, Tables 1 and 2). The standard of care for children with ASD involves facilitating academic and communication skills during contexts such as book reading or naturalistic seated play during special education and speech therapy as well as fine-motor skills (e.g., hand dexterity games, building, arts and crafts, writing practice, etc.) during occupational therapy (Table 2). The general movement intervention developed in this study targets gross-motor abilities (i.e., strength, endurance, agility and coordination), cognitive skills (i.e., executive functioning), and social communication skills (i.e., turn taking, spontaneous and responsive communication, and relationship building) through a variety of goal-oriented games and exercises (Table 1). For instance, strength is targeted through whole-body exercises such as pushups, lunges, etc., endurance is built through timed locomotor games involving jumping, hopping, running, etc., while agility and coordination are practiced during object control games and obstacle courses. The games are played between children and trainers using a turn taking model to encourage continuous social monitoring and back and forth communication and imitation. Executive functioning skills are challenged by incorporating task shifting, object sorting, directional changes,

multistep movement sequences, and movement inhibition within a variety of goal-oriented games. One example game is the “triathlon” that uses 3 different props, each associated with a unique gross motor skill that changes after each round of play. During the different practice rounds, the trainer, parent, and child take turns hopping across a line of yoga spots, lateral jumping over plastic cups, and leaping over beanbags on the floor. The use of different props associated with different motor skills promotes executive functioning skills such as response inhibition, task shifting, and working memory. The children are motivated by friendly competition with social partners which in turn improves the child’s confidence in their own ability to participate in socially-embedded motor games. Testing measures include subtests of the Bruininks-Oseretsky Test of Motor Proficiency (BOT) and the Test of Gross Motor Development (TGMD) for motor skills, computerized Flanker and Reverse Flanker tests of executive functioning for cognitive skills, and video coding of verbalization and affective states during training sessions for social communication skills. Although originally planned as a face-to-face intervention study, with the onset of the pandemic, we were forced to rethink our study’s method to enable continued research through the lockdown and limited social contact periods.

Reinventing our research approach during COVID-19

While many RCTs came to a halt, we chose to reinvent our study by shifting to a home-based, telehealth format using Zoom videoconferencing (Figure 1).^{16–18} Given that families were concerned about lack of optimal learning experiences for their children¹, it was crucial for our research team to create materials and strategies that would best support children in our study. Similarly, some families had financial difficulties during the pandemic.¹⁹ By providing intervention materials to families, we reduced the participation-related burden associated with travel and obtaining intervention supplies.^{2,16–18} Additional steps to make the intervention feasible, meaningful, and easy-to-implement for families included designing of exercise picture cards, development of activities utilizing household objects (i.e., baking sheets and water bottles), creation of instructional videos and visuals for the games, caregiver input to tailor activities appropriately, and additional meetings with caregivers to promote a researcher-caregiver team-based approach (Figure 2). A change in our reinvented intervention is the addition of family involvement that provides an opportunity for multiple family members (caregivers and siblings) to remain physically active and socially connected during the pandemic. Family members take on various roles as the child’s peer, facilitator, and teacher or co-therapist while also developing rapport with the remote expert trainer. The trainers demonstrate the activity on the screen. The parent and/or child view the demonstrated activity (note that some children required additional trainer and caregiver prompting to initiate and sustain attention towards the screen). In some cases, the parent participates by taking a turn and modeling the activities to provide an additional demonstration to the child. Parents are encouraged to provide additional visual, verbal, or gestural prompts/feedback as needed by the child as well as affirmations/reinforcement. The parent and trainers work together to facilitate both spontaneous and responsive, verbal and nonverbal communication. For example, the hello and goodbye conditions typically involve interactive games where the child is encouraged to talk about their daily routines, favorite things or every day challenges. Throughout the other session activities, the child is asked to choose exercises based on visuals shown (Figure 2), asked to come up with

own exercises/games and show them to the trainer, setup and cleanup the supplies (spots, beanbag, etc.) for games based on visuals or trainer demonstration. Each session includes helping bids, regular check-ins with virtual participants to ensure breaks as needed, and time for reflections about /session activities. All of these strategies help elicit a natural back and forth communication between the child and the parents and help build relationships between the child and adults involved across training sessions. We find that this family-centered, collaborative effort has been invaluable in creating positive experiences for the children in our study.

The value of the telehealth approach to intervention research

As clinical research and practice models change, it is important to identify critical challenges, collaborate with families and healthcare professionals, be open to new ideas, and continue to innovate and learn from past experiences. Previously, telehealth interventions were considered an option for families in rural areas who had difficulty traveling to the clinical site; however, telehealth interventions may also provide opportunities to better engage families across rural and urban settings by following a family-centered approach when caring for children with ASD. The telehealth approach allows researchers to expand participation over a larger geographic area, reduce commuting costs, and offer more flexible schedules to families. Children with ASD learn in their natural environment, while expanding their social network. Similarly, parents and children interact as they learn together and explore creative ways to spend time together engaged in therapeutic games/ activities. Our family-centered, collaborative approach using household supplies is much more pragmatic and replicable for families to continue independently beyond the research study, thereby increasing the likelihood of long-term carryover of skills into daily life.

Limitations and Future Recommendations

The transition to a telehealth format has not come without its limitations including establishing comfort navigating videoconferencing platforms, issues with unstable internet connections, audio and visual synchronicity delays, and audio override that only allows one person to speak clearly at a time. We provide parents with easy-to-follow instructional videos and documents to assist in troubleshooting, if necessary. Outside the realm of technology, caregivers are struggling with the increased workload brought on by the pandemic,^{3,16-18} and an additional responsibility of participating in training sessions may not be feasible in all households. Researchers should work with caregivers directly to set reasonable expectations given family constraints. Similarly, maintaining child engagement during online interactions is challenging and children with significant communication and behavioral challenges may not frequently attend to the computer screen. We recommend teaching the caregiver first such that the child can follow an in-person model when doing the activities.

We continue to learn and constantly make changes to best support our participants with varied abilities. Although findings from previous research are promising,²⁰⁻²¹ the effects of telehealth interventions in comparison to face-to-face interventions remain to be studied. We plan to recruit equal number of children across face-to-face and telehealth intervention delivery methods in both our experimental and comparison groups to systematically examine

the effects of telehealth versus face-to-face models of intervention delivery. Finally, we encourage researchers to consider the value of family involvement and individualized interventions to support skill carryover into daily life and promote children's long-term, multisystem development through the use of telehealth-based interventions.

Acknowledgments:

We are grateful to the SPARK children and families who participated in this study. We also thank the SPARK clinical sites and SPARK research participant match service staff for their help with participant recruitment. Researchers may contact SPARK study research participant match service here: <https://wp-qa.sparkforautism.org/spark-research-match/>. We would like to thank all the children and families who have participated in this intervention study, and the undergraduate students, Marissa Heino, Sarah Williams, Emily Longenecker, Emma Fallon, Jill Dolan, and Hannah Laue from the University of Delaware and Catherine Myers from the University of Connecticut for their help with data collections and data analysis.

Grant support:

AB's research was supported by a Clinical Neuroscience Award from the Dana Foundation and multiple National Institutes of Health grants (Grant #: 1S10OD021534-01, P20 GM103446, 1R01-MH125823-01). SS's research was supported by a seed grant from the Institute of Collaboration on Health, Intervention, and Policy (inCHIP) and a Research Excellence Program grant from the University of Connecticut. The funders had no role in study design, data collection/analysis, decision to publish, or preparation of this manuscript.

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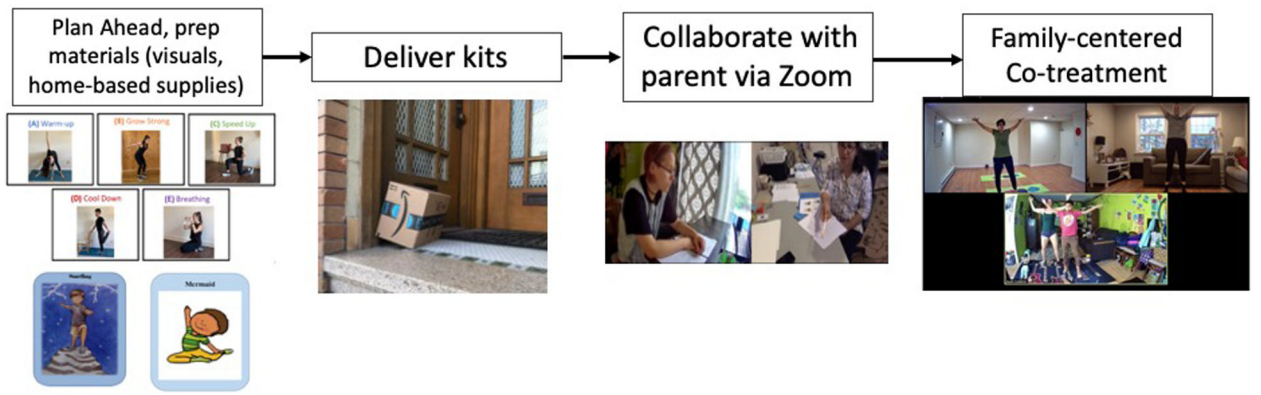


Figure 1:
A telehealth-based, general movement (1A) or standard of care, seated play (1B) intervention.

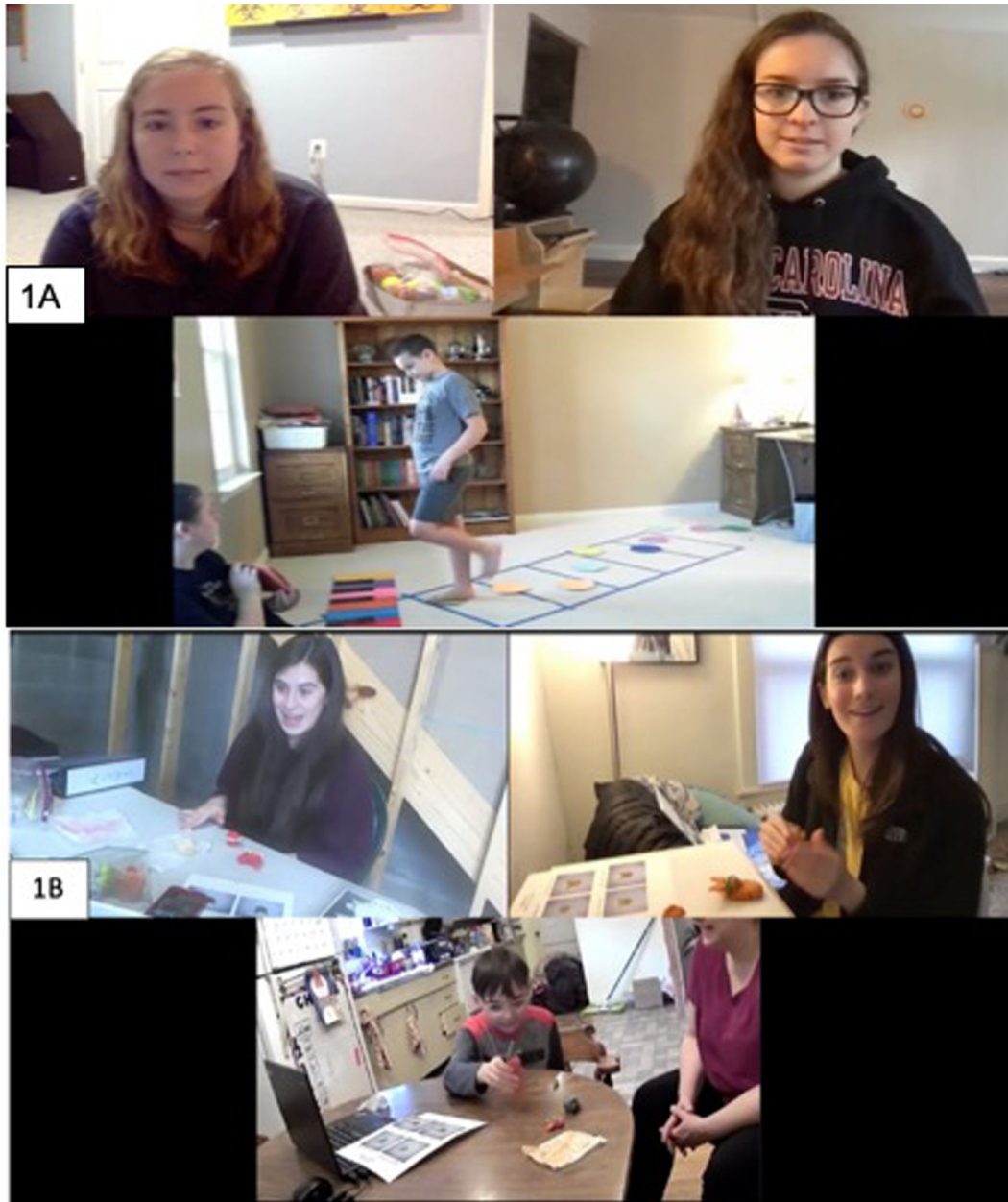


Figure 2: Telehealth-based, family centered-interventions by developing and delivering kits to families in their homes and meeting remotely to deliver the training activities.

Table 1:

Conditions and Skills Promoted In Each Session

General Movement Group - Exemplar Session				
	Condition	Training Activities	Props & Materials	Targeted Skills
1	Hello Game	Introductions and social bids: <ul style="list-style-type: none"> <i>Dice Game (say hello, roll the dice, perform movement shown, ask next player a question)</i> 	Movement dice with each face suggesting different actions and related questions to elicit conversations	<ul style="list-style-type: none"> Greetings Socially-directed attention and communication/turn taking
2	Warmup	Dynamic Stretches: <ul style="list-style-type: none"> <i>Twist and reach</i> <i>Standing side kicks</i> <i>Lateral lunges</i> 	None	<ul style="list-style-type: none"> Flexibility Gross motor coordination and imitation Socially-directed attention and communication/turn taking
3	Grow Strong	Strength Exercises: <ul style="list-style-type: none"> <i>Weighted arm circles</i> <i>Superman reach (prone spinal extension)</i> <i>Superman kicks (prone hip extension)</i> 	Water bottles as weights, yoga mat, pool noodle	<ul style="list-style-type: none"> Upper and lower body strength Complex movement sequences Bilateral and unilateral coordination Socially-directed attention and communication/turn taking
4	Speed Up	Endurance & Ball Games: <ul style="list-style-type: none"> <i>Wheelbarrow Cleanup (sorting balls and beanbags into buckets while sustaining various body positions such as cat position, kneeling, plank, etc.)</i> <i>Kick and Toss Combo (relay race combining various locomotor skills ending with a kick or throw of a ball at a target)</i> 	Balls, beanbags, boxes, yoga spots	<ul style="list-style-type: none"> Executive Functioning Skills (task shifting, working memory, response inhibition) Locomotor Skills Object control skills Visuomotor Skills (catching, throwing, targeting) Strength Socially-directed attention and communication/turn taking.
5	Cool down	Static Stretches: <ul style="list-style-type: none"> <i>Lateral Neck Stretches</i> <i>Standing Toe Touch</i> <i>Supine Spinal Twist</i> 	none	<ul style="list-style-type: none"> Flexibility Gross motor coordination Socially-directed attention and communication/turn taking.
6	Breathing	Deep Breathing Practice: <ul style="list-style-type: none"> <i>Arm breath (arms lift while inhaling and lowering while exhaling)</i> 	none	<ul style="list-style-type: none"> Mindfulness Sensory modulation Socially-directed attention and communication/turn taking.
7	Goodbye	Cleanup & Farewell: <ul style="list-style-type: none"> <i>Reflection questions about favorite exercises/games</i> <i>Cleanup of supplies</i> 	none	<ul style="list-style-type: none"> Prosocial Behaviors/Helping Socially-directed attention and communication/turn taking.

Table 2:

Conditions and Skills Promoted in Each Standard of Care, Seated Play Session

Standard of Care, Seated Play Group - Exemplar Session (<i>Space theme</i>)				
	Condition	Training Activities	Props & Materials	Targeted Skills
1	Hello Game	Introductions and social bids: <ul style="list-style-type: none"> <i>Name Game (say hello, choose a letter, perform a movement, ask next player a question)</i> 	Alphabet movement chart	<ul style="list-style-type: none"> Greetings Socially-directed attention Reciprocal communication
2	Reading	Child-appropriate books: <ul style="list-style-type: none"> <i>E.g.: Pete the Cat Out of This World, Stella Luna.</i> <i>Interactive questions requiring verbal/gestural responses.</i> 	Book chosen based on child's reading level (based on parent input)	<ul style="list-style-type: none"> Reading skills Listening skills Responding to questions Spontaneous sharing of information
3	Hand & Finger Warmup	Quick/Coordinated Hands Movements: <ul style="list-style-type: none"> <i>Stringing Beads (string "planets" onto lace)</i> <i>Placing pegs in a board to form shapes</i> 	String, beads; Peg, pegboard	<ul style="list-style-type: none"> Fine motor skills Manual dexterity Bilateral and unilateral hand movements Listening / responding to instructions. Spontaneous sharing of information
4	Building	Playdoh, Lego, or Zoob: <ul style="list-style-type: none"> <i>Playdoh Earth (follow instructions to create the planet out of playdoh)</i> 	Playdoh	<ul style="list-style-type: none"> Fine motor skills Symmetrical/Asymmetrical actions Rolling, pinching, pressing, etc. Sharing supplies and help make choices Describing the creation Listening / responding to instructions. Spontaneous sharing of information
5	Free Build	Playdoh, Lego, or Zoob: <ul style="list-style-type: none"> <i>Make any shape or creation of their own choice</i> <i>Can follow the adult's suggestions or lead, if needs more help.</i> 	Playdoh moon and stars	<ul style="list-style-type: none"> Fine motor skills Symmetrical/Asymmetrical actions Rolling, pinching, pressing, etc. Creativity Spontaneous play Listening / responding to instructions. Spontaneous sharing of information
6	Arts & Crafts	Coloring, Cutting, Pasting: <ul style="list-style-type: none"> <i>Create an outer space scene (trace, color, cut, and decorate,</i> 	Planet coloring sheet, crayons, glue-stick, glitter	<ul style="list-style-type: none"> Fine motor skills Bilateral and unilateral hand movements

Standard of Care, Seated Play Group - Exemplar Session (<i>Space theme</i>)				
	Condition	Training Activities	Props & Materials	Targeted Skills
		<i>may follow visual schedule or make your own)</i>	glue, construction paper, scissors	<ul style="list-style-type: none"> • Drawing, coloring, cutting, pasting. • Creativity • Sharing supplies and helping make choices • Describe creation • Spontaneous play • Listening / responding to instructions. • Spontaneous sharing of information
7	Goodbye	Story Book & Farewell: <ul style="list-style-type: none"> • <i>Add creations to storybook developed across sessions</i> • <i>Session reflection questions</i> • <i>Cleanup</i> 	Storybook binder, construction paper, pen/marker, glue	<ul style="list-style-type: none"> • Prosocial Behaviors/Helping • Socially-directed attention • Reciprocal communication (spontaneous and responsive)

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