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- Promoting the continued development of adequate resources and programs that address the many areas of need associated with serving children and adults with physical and/or multiple disabilities, and special health care needs.

- Sharing relevant and timely information on current issues, instructional strategies, adaptations, and research through the annual CEC convention, professional meetings, training programs, and publications.

- Providing technical assistance and preservice and in-service education.

- Advocating for funds and policies that promote supportive legislation and funding for persons with physical disabilities, multiple disabilities, and special health care needs.

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Article

FEASIBILITY OF A HOME MOTOR SKILL INTERVENTION FOR CHILDREN WITH CHARGE SYNDROME

Lauren J. Lieberman[1]
Pamela Beach[1]
Melanie Perreault[1]
Ali Brian[2]
Luise Bebrisa-Fedotova[2]

[1]State University of New York at Brockport
[2] University of South Carolina

Abstract: This study examined the effect of a home-based six-week motor skill intervention for children with CHARGE syndrome. Six families with children with CHARGE syndrome participated in this study. The children were assessed on their motor skills with the Test of Gross Motor Development-3 prior to the intervention and then again on the four most practiced motor skills after the intervention. Parents were also given a Child Movement Skills Research: Parent Questionnaire before and post intervention. The families were provided a Gross Motor Development Curriculum, videos, tip sheets, and equipment to support the intervention. Families maintained weekly logs of their specific training practices. Each family was interviewed, and the transcripts were analyzed for themes. The four themes that emerged were Personal goals, Improvement, Barriers, and Overcoming challenges. Results revealed that it is feasible to utilize this protocol to improve motor skills for children with CHARGE syndrome.

Keywords: *assessment, disability, visual impairment, deaf-blind, deafness, parent perceptions, motor development*

Feasibility of a Home Motor Skill Intervention for Children with CHARGE Syndrome

CHARGE syndrome refers to coloboma, heart defects, atresia choanae, growth restriction, genital abnormalities, and ear abnormalities (Blake et al., 2006). CHARGE syndrome encompasses multiple disabilities that typically affects more than one part of the body and most often multiple body systems (Blake et al., 2006). CHARGE syndrome generally affects one in every 10,000 births and occurs when a gene mutation presents itself during prenatal development (Thelin et al., 2006). Since CHARGE syndrome affects both hearing and vision, many children are identified as deaf-blind, which is one of the 13 disability categories under the Individuals with Disabilities Education improvement Act (IDEA, 2004). Due to the various medical complications inherent within CHARGE, approximately 40% of children will not develop functional communication skills and many more may exhibit difficulties with speech and oral communication (Thelin et al., 2006). The name CHARGE was from the characteristics of Coloboma of the eye, Heart defects, Atresia of the choanae, Retardation of growth and development, and Ear abnormalities and deafness. Currently, a diagnosis of CHARGE is made without the child necessarily demonstrating all of the traits.

In addition to the unique various medical characteristics, children with CHARGE syndrome often encounter motor skill delays impacting their flexibility, balance, and hand-eye coordination (Haibach-Beach et al., 2019; Haibach & Lieberman, 2013; Imel et al., 2020; Lalani et al., 2006; Möller et al., 2011; Perreault et al., 2020). For example, age of walking for children with CHARGE syndrome often occurs 14 months later than children with Usher syndrome, the second leading genetic cause of deaf-blindness, and approximately 25 months later than children without disabilities (Dammeyer, 2012). Age of walking is a critical underlying mechanism supporting locomotor skill development (Haibach-Beach et al., 2020). In addition, age of onset of walking is closely connected with other significant developmental outcomes such as sleep difficulties (Hartshorne, et al., 2009), adaptive behaviors (Salem-Hartshorne & Jacob, 2005), language delays (Dammeyer, 2012), and medications (Wachtel et al., 2007). Thus, it is critical to ensure stakeholders provide children with CHARGE syndrome a solid gross motor skill foundation during early development.

During early childhood, a solid gross motor foundation must include fundamental motor skills. According to Clark and Metcalfe (2002), fundamental motor skills are the foundational components of specific sport skills and are essential in promoting lifelong physical activity. Children with low competence in gross motor skills tend to choose a less physically active lifestyle partially due to avoidance of movement challenges (Wrotniak et al., 2006). There is also a relationship between limited motor development and language development which can influence social skills (Houwen et al., 2016). Unfortunately, limited involvement in physical activity during childhood will often lead to physical inactivity in adolescence and throughout adulthood (Telama, 2009). For these reasons, early opportunities and involvement in motor skill development, and therefore a physically active lifestyle, is critical. Moreover, fundamental motor skills are the foundation of recreational programming for all children including those who are deaf-blind (Lieberman et al., 2018). Without acquiring competence in fundamental motor skills, children with CHARGE syndrome may have difficulty participating in free time recreational

activities when they transition into adolescence and adulthood (Imel et al., 2020; Štěrbová et al., 2014). This also impacts social skills.

Difficulties with motor skill development are not surprising due to medical complications and extended hospitalizations experienced by children with CHARGE syndrome (Hartsthorne et al., 2011; Salem-Hartshorne & Jacob, 2005). Medical complications necessitate multiple surgeries that include frequent hospitalizations interfering with natural development in motor milestones and educational programming. Even when children with CHARGE syndrome return from their medical leave, they are typically excused from physical education for long periods of time (Hilgenbrinck et al., 2020). Extended absences from physical education and skill development opportunities may greatly affect the gross motor development of children with CHARGE syndrome if they are not afforded individualized and adapted services and programs. Thus, interventions that focus on fundamental motor skills are warranted and necessary to steer children with CHARGE syndrome towards a positive developmental trajectory for health.

Currently, early intervention programs tend to include parents as a key part of the process; however, these programs typically focus on the improvement of communication skills with much less attention on motor skill development (Bremer et al., 2015). Interventions addressing the motor skill development of children with disabilities, particularly those including parents as facilitators, are limited at best (Colombo-Dougovito & Block, 2019; Hurley & Burt, 2015). In one study, Altunsöz et al. (2016) compared a Head Start intervention program with children with developmental delays and a parental supported home intervention program with a control group that received no intervention. Both intervention groups improved their locomotor skills in comparison to a control group. Interestingly, there were no differences with the parental support condition. In another study, Hamilton et al. (1999) demonstrated that children with developmental delays who received additional parental support (in combination with teacher instruction) did better than the students who only received instruction from their teachers. This is important because research has shown that although children with autism may participate in physical education at school, in some instances, the fundamental motor skills they acquire at school are not generalizing to the home environment and community recreation facilities (An & Goodwin, 2007; Chaapel et al., 2013). Lastly, in a large parent intervention by Scully et al. (2019), physical activity packs were delivered to 53 children, aged 5–15 years, with a visual impairment with 63% with additional disabilities. The activity packs included equipment and instructions and the intervention was three weeks long. Participants' experiences of physical activity prior to receiving this pack and after the intervention were documented. The study revealed inequitable experiences of physical activity related to limited opportunities, inaccessible programs, and discrimination due to the child's visual impairment. The First Steps pack helped to decrease these barriers which led to increased physical activity levels, perceived improvements in gross motor skills, and developments in children's social skills. In addition, the children's motor skills, social interactions, and confidence improved.

Parents should be part of the intervention process as their perceptions related to motor skills can play a critical role in the motor competence of their children with visual impairments or deaf-blindness (Authors, Under Review; Imel et al., 2020). As early as birth, parents are key players in a child's development (Harter, 1987; Reed, 1991). Parents create environments for

their children to engage with and practice motor tasks (Silva et al., 2017). Additionally, parents also provide toys and equipment in their immediate environment that improves competence in motor skills (Barnett et al., 2013; Cools et al., 2011). Parents may be a more critical component of their children's motor development if their child has a disability. For example, parents of children with visual impairments promote elevated levels of encouragement to their children by supporting them to be active and providing transportation and financial assistance (Linsenbigler et al., 2018). Alternatively, overprotecting their children from getting hurt may be a barrier to motor skill development (Lieberman et al., 2006). A study by McKittrick (2019) revealed valuable insights into the various and vital roles that parents of children who are deaf-blind play on their child's IEP teams. These include case management, advocacy, and knowledge sharing with team members.

Unfortunately, there is no intervention research (with or without the inclusion of parents) on motor development in children with CHARGE syndrome from which to create an evidence-based intervention (Hurley & Burt, 2015). As a result, we must first test the feasibility of a home-based intervention (Osmund & Cohn, 2015). A feasibility study is an assessment of the practicality of a proposed project with the intentional purpose to thoroughly understand all aspects of a project, so that we may become aware of any potential problems that could occur while implementing the project (Kenton, 2019). Moreover, feasibility trials must occur to determine if, after considering all significant factors, the project is viable and worth scaling up in future trials (Kenton, 2019). Thus, the purpose of this study was to examine the feasibility of a home-based gross motor program for children with CHARGE syndrome. The intervention feasibility indicators included 1) adherence to the intervention, 2) participant acceptability, and 3) intervention efficacy. We hypothesized that the majority of parents of children with CHARGE syndrome would adhere to the intervention protocols, families would be committed to the intervention, and that children would improve their motor skills as parents change their perceptions of their children's motor skill competence.

Methods

Participants and Setting

Participants included a convenience sample of children ($N = 6$; $M_{age} = 5.8$, $SD = 1.9$) and their parents who attended an International CHARGE Syndrome Foundation Conference. Pseudonyms were used throughout to retain confidentiality. All children could independently walk without assistance and possessed documentation of CHARGE syndrome. Participants revealed various degrees of severity regarding each of the six characteristics of CHARGE syndrome. See Table 1 for the overview of each child. Four of the participants communicated verbally and two of the participants communicated through American Sign Language.

Table 1

Demographic Information of Participants

Sex	Age	Vision	Hearing	Semicircular canals	Atresia of Choanae	Heart defects	Growth Delay	# of surgeries	Age of independent walking
F	3	Low vision, B4	Right ear moderate, left ear severe	Left partially formed	Yes	No	Yes	7	24 months
F	6	B3 in both eyes	Both ears profound	Both partially formed	Yes	Yes	Yes	8	48 months
F	5	B3 in both eyes; bilateral optic nerve colobomas	Right ear normal; left ear profound	Both partially formed	No	Yes	Yes	10	24 months
F	6	Bilateral colobomas; Missing upper field; Right eye B3 and Left eye B4	Right ear profound; left ear moderate	Missing both	Yes	Yes	Yes	11	40 months
F	6	Nystagmus, colobomas and B3 in both eyes	Right ear severe; left ear is profound	Missing both	Yes	Yes	Yes	22	27 months
M	9	B3 in both eyes	Both ears moderately severe	Fully developed	Yes	No	Yes	5	24 months

Instrumentation

Test of Gross Motor Development, Third Edition (TGMD-3)

The TGMD-3 is a process-based measure of 13 gross motor skills that are divided into two subtests: locomotor skills and ball skills. Locomotor skills require moving the body from one location to another (run, hop, skip, gallop, slide, jump) and ball skills include the handling of an object via force (overhand throw, kick, two-hand strike, underhand roll), interception (catch), or both (dribble, one-hand strike). Participants performed two trials of each skill and were scored on each trial based on the presence of specific criteria (i.e., 1 = criteria present; 0 = criteria absent). Each skill is assessed on three or four criteria, with a maximum score between six and eight for each motor skill. A trained researcher in the TGMD-3 assessed all of the performances from digital recordings. An expert in motor development assessment trained the researcher. The researcher and the trainer practiced analyzing the videos until reliability reached over 85%. The TGMD-3 shows robust psychometric properties in children ages 3 to 10 years, 11 months who are typically developing (Webster & Ulrich, 2017) and children up to age 18 years who are visually impaired (Brian et al., 2018).

Parent Perceptions Questionnaire

The Child Movement Skills Research: Parent Questionnaire was used to examine parent perceptions (Clancy et al., 2017; Jackson et al., 2012). This questionnaire includes 32 items and

is subdivided into three sections. The first section examines parental views on their child's motor abilities in 12 of the motor skills the children were assessed in the TGMD-3 in comparison to their perception of their child's skills related to same aged peers. These questions were rated using a 5-point Likert scale ranging from 1= no confidence to 5 = complete confidence. The second section examined the importance of motor skills from the parents' view and how likely their child or other individuals are able to change their abilities with scores ranging on a 7-point Likert scale from 1 = strongly disagree to 7 = strongly agree. The third section examined parental support of their child in regard to developing and promoting their motor skills with scores ranging on a 5-point Likert scale from 1 = never or rarely to 5 = daily or always. A reliability analysis revealed excellent internal consistency for each set of items (α = .83 - .96) except those measuring if parents feel that people in general can do much to improve their motor competence (α = .039); thus, these items were removed from the analysis.

Intervention Programming

Families were provided a variety of tools to help with the home intervention that included curricula, videos, tip sheets, and equipment. Families were also provided with an e-book, *The Gross Motor Development Curriculum for Children with Visual Impairments* (Lieberman & Haibach, 2016). This manual provides descriptions of object control skills, such as batting, kicking, throwing, underhand roll and catching, and locomotor skills, such as running, skipping, sliding, leaping, jumping, and hopping. The curriculum manual describes the steps for performing these skills as well as a variety of strategies and specific modifications to teach children with visual impairments or deaf-blindness. Participants were also provided an accompanying video that parallels the content in the manual. The Gross Motor Development video is offered through the American Printing House for the Blind and on the Camp Abilities website (Camp Abilities N.D.). Additionally, participants were provided with tip sheets that provided a snapshot of the components of each of the locomotor and object control skills as well as the most commonly used modifications, cue words, and strategies. Each family was also provided three colorful plush balls and a bell kick ball. All materials and equipment were used as part of the intervention.

Procedures

Prior to the selection of the participants, the lead investigator's Institutional Review Board approved all procedures. Parents/guardians provided written consent prior to the start of the research. Out of the 14 families that were initially interested in participating in the study, six agreed to allow their child to be assessed and then to utilize the intervention materials and implement a six-week gross motor skill home intervention. First, parents completed a survey about their child's demographics and CHARGE syndrome characteristics and the Parent Perceptions Questionnaire. Then, members of the research staff assessed the motor skills of the children using the TGMD-3 and video-recorded all trials for scoring purposes. When needed, modifications made during the TGMD-3 included multiple demonstrations, sound source or clapping for locomotor skills, and a bell ball for catching. Children were communicated with using their preferred mode, which included American Sign Language for some children. The research staff consisted of four professors with expertise in working with children with

CHARGE syndrome, two were motor development specialists and two were adapted physical education specialists. The team also included four research assistants who had expertise in kinesiology and adapted physical education. Two of the researchers were fluent in sign language. After each child completed the TGMD-3, the parents were provided with materials and equipment to implement the home-based intervention.

Afterwards, parents conducted a six-week gross motor skill intervention program in their homes with their child with CHARGE syndrome utilizing the materials described above. Parents also completed a log which included the dates, durations, activities, equipment used per practice session, and a comment section for how it went each day. The researchers sent regular weekly email reminders to continue practicing and logging activities. Participants were also offered opportunities to ask questions to the researchers in regard to any of the activities or modifications. Most families worked on four main gross motor skills. These motor skills were ones that the parents felt the child would use most often, and also ones that they felt they knew how to teach comfortably. Following the intervention, parents were instructed to video record their child performing two trials of the four motor skills they worked on the most during the intervention and send it to the researchers to be scored based on the TGMD-3. Motor skills were chosen by the researchers based upon the four most frequently reported activities practiced according to their logs. Parents also completed the Parent Perceptions Questionnaire electronically post intervention. Please see Figure 1 for the overview of the feasibility process.

Feasibility Measures

Intervention Adherence

To assess intervention adherence, families were instructed to record every practice session (including activity type and duration) into activity logs. Families were instructed to practice two times per week for a minimum of 30 minutes each practice session for six weeks. All activities were considered safe activities, but families were recommended to report any accidents or injuries to the researchers.

Intervention Acceptability

Following the entire intervention, researchers set up phone interviews with a parent to examine the acceptability of the home intervention. During the interviews, parents were asked about facilitators of the home intervention, use of the materials and equipment provided, their intentions to continue working with their child on gross motor skills, and whether they would recommend the home intervention to other families of children with CHARGE syndrome. Parents were also asked about the activity log and their participation in the study. Two researchers were present during each interview to ask the questions and record information.

Researchers developed the interview guide with the advice of a panel of six experts. The experts included four professionals in the fields of adapted physical education and motor behavior with experience with deaf-blindness and CHARGE syndrome, one physical education teacher, and one parent of a child with CHARGE syndrome. The interview guide helped ensure that the line of questioning for the qualitative portion of this study was similar. Interviews lasted 15 to 45

minutes depending upon the duration of the responses. Interviewers took reflective notes during the interviews and then met to debrief after each interview. Research staff audio recorded all interviews and transcribed them verbatim. The interview data was coupled with the logs to ensure triangulation of the data. Data were analyzed for clarity of the training protocol.

Sample interview questions:

- Can you please explain to us how you used the motor development assessment for planning your intervention with your child?
- Did you look at or use any of the gross motor assessment curriculum that we sent you of the tip sheets or videos? Were they helpful?
- How often did you have the opportunity to work with your child on a typical week during this intervention?
- Who worked with your child on their motor skill intervention?
- What roles did each person play?
- What did you use the most? (Tip sheets, videos, book, balls, etc.)

Intervention Efficacy

Intervention efficacy was determined by assessing changes in the four most practiced motor skills of the child with CHARGE syndrome. In addition, changes in the parent's perceptions of their child's motor skill abilities from pre- to post-intervention were analyzed.

Analysis

Descriptive statistics were used to report the profiles of the participants. Measures of attendance and adherence were reported as frequency distributions. To analyze intervention adherence, members of the research staff analyzed and descriptively reported data from the parent's logs.

To assess intervention acceptability, the audio recordings of the parent interviews were transcribed verbatim by the researchers. Two of the researchers independently conducted a thematic line-by-line analysis of interview data with themes and subthemes of various aspects of the intervention. Once these themes and subthemes were created, the researchers compared their findings with each other to ensure each theme was included (Vaismoradi et al., 2016). The data was then reviewed and revised with the focus on the main themes with supporting quotes until consensus was reached between the researchers. A "critical friend" was included once the initial themes and supporting quotes were developed to ensure the data matched what was said in the interviews. The recommendations from the "critical friend" were reviewed and added upon consensus of all parties (Coughlan et al., 2014).

To assess changes in TGMD-3 skills before and after the six-week intervention, members of the research staff hand calculated Cohen's *d* effect sizes and reported all data descriptively. Cohen's *d* effect size interpretation includes .03 = small, .05 = moderate, and .08 = large (Cohen, 1986). Due to the lack of statistical power from the small sample, we were unable to conduct any inferential statistics.

Results

Six families of children with CHARGE syndrome recruited from the International CHARGE Syndrome conference participated in this study. From this sample, five parents participated in interviews, four submitted activity logs, and four completed post-testing assessments. Descriptive data on the children with CHARGE syndrome is included in Table 1. In this section we will review: (a) adherence to the intervention, (b) intervention acceptability, and (b) intervention efficacy.

Intervention Adherence

According to the logs, each parent adhered to the recommended dosage of six weeks, twice a week for 30 minutes each, and practiced locomotor and object control skills from the TGMD-3. See Table 2 for further description of total log activity. The most practiced activities were those that could easily be transformed into a game, sport, or activity. Table 3 provides a summary of activities, games played, equipment, resources, and who facilitated the intervention.

Table 2

Logs of the Activities and Time Spent in Each one

Skill	Frequency (n)	Time (mins)
Overhand throw	16	430
Kicking	15	445
Hopping	15	380
Underhand throw	12	335
Jumping	10	225
Sliding	9	270
Catching	7	225
Two hand strike	7	185
Galloping	4	120
Skipping	4	135
One hand strike	2	20
Run	2	32

Table 3

Log Reports Summary

Parent	Equipment	Skills	Activities	Resources	Support
Mother of Kiera	squishy balls kickball bell ball goals tee ball Beanbag	Overhand throw Kicking Two hand strike Hopping Sliding Jumping	Threw small ball against hose, kick in a "Goal", two hand strike of the tee, hopping and sliding like dance moves with music, kicking ball with sister, jumping into beanbag	Tip sheets, Music	With older sister and herself
Mother of Latisha	Tee ball set Balls	underhand throw overhand throw Catching Kicking Two hand strike	Hot potato, catch Toss, cornhole Soccer into net, Tee ball	Tip sheets Music YouTube videos, Games, Stickers	Mostly herself, husband was there for 3-4 sessions
Mother of Sienna	Bean bags, Plastic clubs, Large rings, large balls, laundry basket, soft balls Elastic strips Tee ball set Bowling pins	Jumping Hopping Underhand throw Sliding one hand strike Overhand throw Galloping Kicking Skipping Catching Run Two hand strike	Obstacle course, Golfing Bean bag toss Kicking and throwing a ball changing distance, Bowling	Tip sheets Videos Colors sheet	Just herself
Mother of Clara	Exercise balls	overhand throw Hopping Skipping Kicking Jumping Running			Chad, private PT, school PT assistant, Two PE instructors, her intervener & herself

Intervention Acceptability

According to the interviews, parents reported intervention acceptance when discussing the activities, modifications, and interests of their child participating. The four themes that emerged from the parent interviews were: (a) I just want her to do anything she can do: Personal goals, (b)

Gains confidence every time: Improvement, (c) I don't know enough: Barriers, and (d) It is just play time: Overcoming challenges.

I just want her to do anything she can do: Personal goals

Many of the parents shared how they approached the intervention focusing on the personal, physical, and social goals for their children. Related to gait, the mother of Latisha, stated "I was really hoping to see her gait kind of adjust and change to be more typical, and it actually did**.** I'm totally contributing it to the study." This same mother said

> She [Latisha] had her reevaluation with her therapist last week, and now we moved down to every other week instead of weekly because her gait has really come in. It's more stable. She is now stepping up by herself onto like a curb-sized step, jumping with both feet independently (Latisha's mother).
>
> Kiera's mother envisioned her daughter doing typical activities that her peers do. She stated: I just want her to do anything that she can do. If any kid can do it, then I want her to be able to do it too. So, if she wants to run a marathon. So, she has a bike right now and she might bike, and I want her to be able to bike by herself someday, you know.

Gains confidence every time: Improvement

The second theme encompassed notions of improvement. All of the families wanted their child to improve on their motor skills, stamina, and balance.
Bradley's mother stated

> Whatever you are doing, it is helping because he (Bradley) has picked up a lot of the gross motor skills that they had been working on for his goals and he kind of achieves everything they were working on in that.

The idea that the parents wanted the children to thrive in life and not allow the medical complications to hold them back was evident. Kiera's mother shared

> I like the idea of an intervention to focus on something that we can do and that is something beyond medical because a lot of stuff the CHARGE kids deal with is very doctor orientated. I like that this was something that was more play. It was physical and it was important to do. It was fun and just a whole different ball game in my mind as far as something that we can work on together. Like we can sit down and work on your letters or eating, but this was like, hey, let's go outside and kick a ball. This will be huge. I don't know, it was kind of like a lightbulb, I guess.

The fact that gross motor development is not a major focus area for stakeholders within the esoteric world surrounding CHARGE syndrome was stated by several parents. They felt that this was an area that professionals and the community should focus on more often. Sienna's mother shared

> It is something that they do not focus on a lot in CHARGE. It's hearing, vision, hearing, vision, oh yeah, they have low tone. It's just not focused on a lot, so it was kind of nice

> and kind of refreshing to see a little study on that. I would say honestly, I have never seen an intervention other than walking. I thought it was kind of refreshing to enjoy and interesting something that you don't often see, and in terms of CHARGE Syndrome.

Clara's mother said "She gains confidence every time she is able to successfully do something. You build enough successes, then it's not such a battle or struggle."

The increase in motor skill performance was pronounced when two of the participants were released from physical therapy and one decreased his hours per week in physical therapy. Latisha's mother, shared "….it was interesting to see all of the gross motor work together to help every other skill that she needs." She and two other parents shared their relief that their children can now run on different surfaces more easily. Latisha's mother said "….she's comfortable on dynamic surfaces … she'll go in grass and granted it's more of a slower run, but she does feel more confident moving on different surfaces and that was worth it in and of itself, just to see her be able to keep up with her peers"

Several parents said they were reluctant to work on catching due to difficulties with vision. However, parents were willing to try catching after they received the modified balls. Latisha's mother stated, "I would say that she went from catching every one out of five throws to fifty percent of the throws." Other areas that parents worked on were: running on different surfaces, catching (improvement from 20%-50% improvement on self-report), jumping, kicking (3), striking (2), rolling (2), sliding, throwing, hopping, and skipping. The least practiced skills were one hand striking, two hand striking, kicking, and hopping.

I don't know enough: Barriers

The major barriers to the motor skill intervention were the child's vision, attention span, time of year, being inside, time, balance issues, strength, and level of comfort of the child with some of the activities. Some of the parents said they did not know how to teach motor skills. Sienna's mother said, "Galloping, I have a hard time teaching how to do that. I just can't break that down well enough. I don't know enough of it." Not knowing how to teach some of the skills was a reason why some parents taught more of one skill or not another.

Some of the parents were very creative, such as Clara's mother who said, "…she is much more willing to try if she had something that made her feel safe, like a wall for hopping." Latisha's mother claimed that her daughter did not want any modifications and that was a barrier. "…the biggest thing for her is, she doesn't like modification, she likes to do what the big kids are doing." Not knowing how to teach the skills to their child and the child not wanting any modifications can be definite impediments to learning.

It is just play time: Overcoming challenges

This particular group of parents of children with CHARGE syndrome were resilient and very creative in overcoming challenges to instructing motor skills for their children. For example, the parents figured out positioning related to the child's muscle imbalances and vision. Parents also

created a variety of modifications that facilitated success with motor skills. For example, modifications ranged from larger equipment, to cueing attention, and changing distances of kicking and catching.

Some facilitators that worked for most of the children were making the skill development activities into games and making it fun. Latisha's mother stated, "If we could find a way to make it fun, she was down for it". Kiera's mother said "…we just did the hopping and sliding as like a dance move and we would have the music on, and she loves music." Kiera's mother also mentioned that they "…would set up goals in the backyard and be like okay let's see if you can kick it through here", that's what made activities more enjoyable.

Bradley's mother on recommending this program "I think it helps them (the child- Bradley) understand more why gross motor skills are so important. Also, learning the different activities that you could do and then realizing that it is just play time, it is not really a chore."

The parents were able to create positive reinforcers, such as music, stickers, siblings (for motivation), encouragement, and verbal cuing. Related to sibling motivation, Kiera's mother stated "The things she did the best would be the days that her sister was there with her and just to make it more fun…. She was like, this is cool and all, but it was way more fun when she had big sister helping her." Related to positive reinforcement, Kiera's mother stated "we made it a big deal if she could kick it through the goal".

All of the families said that repetition and practice were necessary to see improvement. Many of the parents had to give their children breaks due to issues with stamina and attention. Many also had to decrease the distance for kicking, throwing, and catching to help with vision issues and attention. As far as instructional strategies many parents used adapted balls, physical guidance, and verbal cues. The training materials that helped most were the training videos, the tip sheets, and the modified balls. Kiera's mother said "We weren't just modifying it for her to be able to do it, but modifying it to make it more interesting"

For the five families who implemented this gross motor development program, it appears that the resources were helpful in improving motor skills and they really enjoyed the process. Although parents gave recommendations for improving the program, the overall feeling was that the parents would recommend the intervention to other parents of children with CHARGE syndrome.

Intervention efficacy

Motor skill performance

Of the six participants, four participants completed both the pre- and post- motor skill assessments. Participants completed four pre-selected motor skill assessments chosen by the researchers based upon the frequency of the motor skills practiced according to the activity logs. Across these four participants, there were 15 pre- and post-intervention scores for eight motor skills from the TGMD-3: hop (n = 1), jump (n = 1), slide (n = 1), two-hand strike (n = 1), catch (n = 1), kick (n = 4), overhand throw (n = 4), and underhand toss (n = 2). More than half of the

scores increased from pre- to post-intervention (n = 10) while the others either remained stable (n = 3) or decreased (n = 2). See Table 4 and Figure 1. Improvement in skill scores ranged between 12.5% and 50% (d = .89 - 2.29). Across participants, the skill that each family practiced the most resulted in the greatest improvement (see table 3). For example, Latisha improved her kicking performance by 50% after practicing it during 58.3% of the practice sessions, but she only improved her overhand throwing score by 12.5% after practicing it during 16.7% of the practice sessions.

Table 4

Change in pre- and post-intervention scores for each participant

	Latisha			Kiera			Clara			Sienna		
Motor Skill	Skill Change	Rate Change	Practice Freq	Skill Change	Rate Change	Practice Freq	Skill Change	Rate Change	Practice Freq	Skill Change	Rate Change	Practice Freq
Hop							+25%	+40%	8/10 (80%)			
Jump							+12.5%	0%	5/10 (50%)			
Slide										+12.5%*	+20%	5/12 (41.7%)
Strike				+10%	0%	2/14 (14.3%)						
Catch	0%	0%	2/12 (16.7%)									
Kick	+50%	+40%	7/12 (58.3%)	-25%	0%	2/14 (14.3%)	+12.5%	+20%	2/10 (20%)	0%	+20%	4/12 (33.3%)
Overhand Throw	+12.5%*	+40%	2/12 (16.7%)	+25%	+20%	4/14 (28.6%)	+25%	+20%	3/10 (30%)	0%	0%	6/12 (50%)
Underhand Toss				+25%		0/14 (0%)				-25%		7/12 (58.3%)

Parent perceptions

Overall, parents' ratings of their children's motor skill ability remained stable or increased from pre- to post-intervention with the largest increases for two of the children, Latisha and Clara (see Table 4). The majority of parent ratings of their child's motor skill ability from pre- to post-intervention aligned with actual changes in skill performance across participants. Out of the 13 ratings (the underhand toss did not have an equivalent parent rating), nine parent ratings were consistent with the child's motor performance. For example, the parent rating for Clara's hopping ability increased by 40% and her actual hopping performance increased by 25%. However, parents' views on their child's ability to change his or her motor skills did not vary from pre- to post-intervention with the exception of Sienna whose parent rating dropped by over a point. There were no other noteworthy changes in parent ratings for the remaining questionnaire items.

Discussion

The purpose of this study was to determine the feasibility of a home-based gross motor skill intervention for children with CHARGE syndrome including intervention adherence, intervention acceptability, and intervention efficacy. All hypotheses were met including that most families would adhere to the intervention protocols, children would engage in the intervention, and children would show motor skill improvements and parents would change their perceptions of motor skill competence.

Intervention Adherence

Overall, the parents in this study followed the protocols for the motor skill intervention as directed by the research team. This current study has similar findings to the recent research by Scally et al., (2019). This study determined that a "First Steps" activity pack parent intervention led to increased physical activity and motor skills. Our intervention was similar to the intervention in this larger study in that we provided the parents with the equipment and curriculum resources to build skill acquisition. In the current study the parent intervention was for six weeks as opposed to the three weeks in the Scully et al., 2019 study. Both of these interventions led to improvements in motor skills with the equipment and guided lessons provided.

Intervention Acceptability

The parent interviews revealed intervention acceptance when discussing the motor skill activities, modifications, and movement interests of their child during the intervention. In the first theme "I just want her to do anything she can do: Personal goals", parents shared that they wanted their children to be able to do what their peers do. This is similar to the findings by Lane et al. (2020) where the parents wanted their children to do what their peers were doing in physical education. The parents believed that the improvement of these fundamental movement skills would help them with their involvement in typical skills. The second theme "Gains confidence every time: Improvement" illuminated the idea that their child could improve their motor skills with practice. This is similar to the Hamilton et al. (1999) study where the children with developmental delay improved their skills with parental support.

Opportunities and parental support for improving competence in fundamental motor skills are vital for children with CHARGE syndrome; otherwise, they may struggle to participate in free time recreational activities in adolescence and into adulthood (Imel et al., 2020; Štěrbová et al., 2014). Gross motor skills have also been used as the foundation of placement decisions in physical education (Hilgenbrinck et al., 2020). The child's gross motor skills helped drive the programming in physical education to ensure that they had the strong foundation of gross motor skills for their lifetime of involvement which may therefore increase opportunities for socialization and friendships. Appropriate motor development contributes to children's physical, cognitive, and social development in addition to their health and well-being (Piek, Baynam, et al., 2006; Haga, 2008.

However, the third theme "I don't know enough: Barriers" shared the very real issue of parents not knowing the process with some of the motor skills. This illuminates the need for parent training to help them understand how to teach their children with CHARGE Syndrome. To date there is no research to outline the training protocol of parents with children with CHARGE syndrome. The last theme "It is just play time: Overcoming challenges" described the parents as resilient and creative. They found ways to motivate and engage their child in some activities that they may not have wanted to do. This is similar to the findings of Lane et al. (2020) and Lieberman et al. (2012) where parents had to be creative and help the physical education teachers

because they did not know how to teach children with CHARGE syndrome in physical education.

Intervention Efficacy

Of four participants completing both the pre- and post- motor skill assessments, more than half of the scores increased from pre- to post-intervention (n = 10) while the others either remained stable (n = 3) or decreased (n = 2). Not surprisingly, it was consistently seen that the skill that each family practiced the most resulted in the greatest improvement. This is important to know as it has been found that running, kicking, leaping, and catching are skills where delays are seen for children with visual impairments (Wagner et al., 2013). Knowing the skills that are deficits for this population can help families target needed areas for improvement.

Related to the parents' ratings of their children's motor skill ability, it was found that the rating either remained stable or increased from pre- to post-intervention. As shared in the results, there was alignment with the parent ratings of their child's motor skill ability from pre- to post-intervention with actual changes in skill performance across participants. This is similar to the tripartite model where the belief of the parents in motor skills aligned with their actual performance with children with visual impairments (Lent et al., 2002). Knowing this, it is important for the parents to have high expectations for their children related to motor skill potential in order for the children to truly reach their potential.

In this study, 66% of the participants improved on the gross motor skills that they practiced during the intervention. The families that participated in this study were grateful that the simple auditory and bright balls they were given. They also appreciated the free resources of the curriculum, the videos, and tip sheets. In addition, the parents improved their perceptions of what their child could do related to the motor skills assessed. These results are similar to the findings of parent lead motor skill interventions of children with developmental delays (Altunsöz et al., 2016; Bremer et al., 2015; Hamilton et al., 1999). In the current study, the skills that were worked on the most were skills that the parents felt would be used in sports opportunities and skills that they knew how to do in order to teach them.

Early opportunities and promoting motor skill development is critical to leading a physically activity lifestyle also associated with language and social skill development (Stodden et al., 2008). Additionally, fundamental motor skills are the basis of recreational programming for all children including those who are deaf-blind (Lieberman et al., 2018). With the absence of fundamental motor skills, children with CHARGE syndrome will likely have difficulty participating in recreational programming when they transition into adolescence and adulthood (Imel et al., 2020; Štěrbová et al., 2014). This very issue was highlighted in the research on the transferability of fundamental motor skills to home and the community (An & Goodwin, 2007; Chaapel et al., 2013).

One major issue with children with CHARGE syndrome as discussed in the introduction is the medical complications and extended hospitalization stays. These hospitalizations can have long lasting effects on growth and development including fundamental motor skills (Hartsthorne et

al., 2011; Salem-Hartshorne & Jacob, 2005). These prolonged absences from physical education and skill development opportunities may greatly affect the gross motor development of children with CHARGE syndrome (Hilgenbrinck et al., 2020). Thus, interventions such as this home intervention study are paramount in order to lay the foundation of fundamental motor skills to prepare the child for a lifetime of physical activity and recreation.

The findings from the current study support the notion that motor skill interventions for children with CHARGE syndrome should include parents in the process (Imel, et al., 2020, Scully et al., 2019). According to previous research, parents may be a more critical component of their children's motor development if their child has a disability (Altunsöz et al., 2016; Bremer et al., 2015; Hamilton, et al., 1999). For example, it is known that parents of children with visual impairments often promote and encourage their children by supporting them to be active and providing transportation and financial assistance (Linsenbigler et al., 2018). Alternatively, overprotecting their children from getting hurt may be a barrier to motor skill development (Lieberman et al., 2006). Parents can help with motor skills as well as their child's academic and transition goals of their IEP. The more motor skills the child can engage in the more sports and activities will be available to them- thus increasing the number of people they can engage with. In addition, the more sports and activities they can do the more they have to talk about with family, peers, and community members therefore increasing socialization and self-determination (Lieberman, et al., 2021).

Similar to previous studies, this study supports the importance of parents of children who are deaf-blind in facilitating goals and objectives of the IEP with the many roles that they play (McKittrick, 2019). These important and impactful roles include case management, advocacy, and knowledge sharing with team members. These roles on the IEP team can transfer to the home to promote motor skills and then back to school and the IEP team to share benchmarks and goals learned. Clearly parents, and their perceptions related to motor skills, do play a critical role in the motor competence of their children with visual impairments as seen in the current study.

Limitations

This study provided an important first step toward developing a robust intervention to be implemented with children with CHARGE syndrome. The resources and equipment can be used by families who have children with visual impairments, deaf-blindness, or other sensory impairments and severe disabilities. However, this study was not without limitations. These results indicate that this study is feasible and should be conducted on a larger sample size. The very small sample size limits the generalizability of the results. In addition, it should be noted that CHARGE syndrome is a highly variable and unique disorder, which is why interventions should be individualized for each child. In addition, it should be noted that the pre-test was conducted at the International CHARGE Syndrome Conference with the post testing being conducted in the individual homes of the participants. Parents received training videos for recording their child's motor skill performances, however, parents did not have previous experience with conducting motor skills assessments. Reduced space or poor camera angles may have affected the assessments of the post testing. It is likely that these conditions would have only limited their scores, meaning it is more likely that participants would have performed even

better with trained researchers due to demonstrations, instructions, more space, and optimal camera angles.

Another limitation could have been the weather as the intervention occurred during the winter months of January and February. Even parents of children in warm climates indicated that the weather was a deterrent in some instances preventing them from working on a wider range of skills. This is similar to the findings of Scully et al., (2019) where weather had an impact on the intervention protocol. In addition, the intervention was conducted just before COVID hit, which caused delays and challenges with the post testing. It should also be cautioned that the implication of school and many event closings due to COVID may have negatively impacted the children's motor gains. Finally, future motor skill intervention research on children with CHARGE syndrome should include other practices such as physical therapy, occupational therapy, and/or orientation and mobility services that the child is receiving that could affect their motor skill development as well as include a control group which does not receive the treatments.

Conclusions

Children who have CHARGE syndrome have significant health issues early in their lives that often delay their motor development significantly. This delay in motor skills can have negative consequences for their future. This feasibility study showed that parents can implement a gross motor intervention at home with resources that can be accessed on-line and with equipment found in common stores or websites. The more practice and feedback children experience the more they can improve on these fundamental skills and the higher potential for a better quality of life in their future.

Corresponding Author:
Lauren J. Lieberman
State University of New York at Brockport
llieberman@brockport.edu

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Article

HIGH SCHOOL GENERAL EDUCATION TEACHERS' PERCEPTIONS OF STUDENTS WITH SIGNIFICANT DISABILITIES

Allison M. Kroesch
Katherine N. Peeples

Illinois State University

Abstract: Thanks to legislation that supports inclusion of students with significant disabilities in general education, content area teachers need to have appropriate knowledge, training, and self-efficacy to work successfully with these students in their classrooms. In this study, a survey of high school general education teachers investigated their perceived knowledge and capabilities related explicitly to teaching students with significant disabilities. We surveyed a range of subject areas, years of experience, and educational/training attained. The findings support existing, recent research highlighting the challenges of securing a high-quality inclusive learning experience for students with significant disabilities. Implications include the need for training and experience in special education topics for general education teachers to support their ability to teach students with significant disabilities in inclusive settings.

Keywords: *inclusion, high school, significant disabilities*

High School General Education Teachers' Perceptions of Students with Significant Disabilities in Inclusive Settings

As they go through their college preparation programs, general education teachers focus on their content area material, classroom management skills, and assessing students. Often, these preparation programs prepare pre-service teachers to work with homogeneous groups (Kent & Giles, 2016). In reality, general education teachers work with a wide variety of students, including students with individualized education plans (IEPs) in their classrooms. More than 6.6 million students in the United States receive special education services to meet their academic and behavioral needs (Blackwell & Rossetti, 2014). Although special education teachers are usually trained as learning & behavior specialists (LBS), general education teachers are also part of the IEP team, attend and contribute to IEP meetings, and are responsible for implementing the IEP (Blackwell & Rossetti, 2014).

The inclusion movement has advocated over the last several decades to include more students with a variety of disabilities in general education classrooms, emphasizing access to the general curriculum. For these placements to be successful, general and special education teachers must collaborate to serve all students, yet this continues to be a barrier for inclusion (Carter & Hughes, 2006). Research has explored the effectiveness of traditional preparation programs for these two fields (Gehrke & Cocchiarella, 2013). Still, many preparation programs train these pre-service teachers separately, each requiring different coursework, different faculty instructors, and different clinical or field experiences. More often than not, this results in general and special education teachers having little understanding of each other's roles. Very few programs to date offer a dual certification, and those institutions typically only offer a dual certification for elementary educators.

Because of this divide in teacher preparation programs, general education teachers often lack the necessary skills to implement evidence-based practices (EBPs) for students with significant disabilities (e.g., autism, multiple disabilities, deafblind, severe disabilities, intellectual disabilities; (Carter & Hughes, 2006) and/or behavioral disabilities (Gable et al., 2012) in an inclusive environment. Most students with more significant disabilities continue to receive instruction in self-contained classrooms (de Boer et al., 2014; Kleinert et al., 2015). However, research supports the benefits of inclusion in general education classrooms using EBPs at the elementary level (Coleman et al., 2015; Smith et al., 2013; Spooner et al., 2014), middle/junior high school years (Browder et al., 2007; Hudson et al., 2016; Knight et al., 2015), at the high school level (Creech-Galloway et al., 2013; Jameson et al., 2012; Kroesch et al., 2020; Yakubova & Bouck, 2014).

Agran et al. (2002) surveyed special education teachers of students with severe disabilities about access to the general curriculum, including inclusion in a general education classroom, whether that access was appropriate, and whether co-planning (i.e., the general education and special education teachers planning curriculum together) occurred. Results indicated that although most special education teachers participated in some degree of inclusion (i.e., co-teaching in a general education classroom), most teachers believed that access to the general curriculum was not

appropriate for students with severe disabilities and had minimal participation in co-planning their students' access to the general curriculum.

Research Purpose and Questions

With so much at stake for students with significant disabilities, we surveyed general education high school teachers on their perception of including students with more significant disabilities in their classes. Specifically, we focused our questions on their perception/self-rating related to IEP and IDEA terminology and the use of EBPs and supports. The research questions we addressed were: (1) How do general education teachers rate their understanding of implementing IEP components for students with significant disabilities who are placed in general education settings? (2) How do general education teachers rate their knowledge about specific disability areas? (3) How do general education teachers rate their knowledge about EBPs and research-based supports for students with significant disabilities?

Method

Participants

We collected names and email addresses of high school mathematics, science, social studies, language arts, and foreign language teachers to identify potential participants. After obtaining IRB approval, the first author and a graduate assistant created a database of participant email addresses and school names using the Illinois State Board of Education (2017) and individual high school websites. We sent an email to potential participants explaining the purpose of the study with a link to the survey using a database of contact information publicly available from the State Board of Education targeting 1,000 general education high school teachers. Participants responded to this invitation by first completing screening questions to ensure they were eligible to participate in the study. We required survey participants to be current high school teachers with at least one year of teaching experience in mathematics, science, social studies, language arts, and/or foreign language. If responses did not indicate that the person met these criteria, they were redirected to a page thanking them for their time. A total of 103 participants (10.3%) submitted surveys.

Instrument

We developed a 35-item survey for this study. The first five items requested demographic information such as subject taught, highest degree earned, and years of experience (see Table 1). Then, participants read a statement (e.g., "I understand the legal requirements of the least restrictive environment in regards to students with severe disabilities") and rate whether they agreed or disagreed with the statement, using a 5-item Likert scale (1 = "Strongly Disagree" to 5 = "Strongly Agree"). Researchers wrote each item to target one of three specific areas regarding students with severe/multiple disabilities: (a) knowledge about IEPs (7 items), (b) knowledge about specific disability areas (using IDEA terminology; 6 items), and (c) knowledge about EBPs and supports to be used in an inclusive classroom (17 items). The survey questions can be found in Appendix A. These topics were not identified in the participant version of the survey. Additionally, we did not provide supplemental definitions, as we wanted to investigate what participants currently knew about these topics.

The original draft of the survey was reviewed for clarity and face validity by faculty colleagues who also had teaching and research expertise working with students with severe/multiple disabilities. Additionally, five high school general education teachers who were not part of the participant pool piloted the original draft. Using feedback from faculty reviewers and pilot teachers, we developed the final 30-item survey. As a reliability measure, we calculated the internal consistency of the final draft for each subgroup of items and the complete survey using Cronbach's alpha. This analysis returned good internal consistency for the full final version (a = .93). Participants (N=1,000) received the link to the survey in their email with an introductory cover letter informing them of the study's purpose and IRB approval status and specific instructions for accessing and completing the survey online (Select Survey), including the confidentiality statement.

Survey Responses

The informed consent for our survey, per IRB guidance, allowed participants to skip any item or item(s) they chose. Ultimately, this option limited the scope of the data we were able to analyze. Of the 103 completed surveys, 90 participants completed all of the demographic items and the Likert scale self-rating items. As a team, we decided to remove responses from participants who did not complete the entire survey, resulting in a final sample of 90 participants (87.3% of all responses received, but only 9% of the original recruitment pool).

Data Analysis

We collected the response frequencies for each item and each response option on the Likert scale items. We then disaggregated those frequencies along with the three topic areas (IEPs, disability areas, and EBPs) and examined the distribution (i.e., how many responded "Strongly Disagree") and mean response for each item. For reporting purposes, some item response frequencies were converted to percentages.

Results

We analyzed the results of participants' self-ratings about their knowledge about teaching students with significant disabilities within their general education classrooms using Statistical Package for the Social Sciences (SPSS) software, Version 26.

Participant Demographics

We asked participants to tell us the gender they identify with, the content area subject they were currently teaching, years of teaching experience, and the highest degree completed. Out of 90 participants, 62 were female (69%), and 28 were male (31%). Twenty-seven participants were English/language arts teachers (30%), 23 were mathematics teachers (25.6%), 21 were science teachers (23.3%), 13 were social studies/social science teachers (14%), and 6 were foreign language teachers (6.7%). For reporting their years of teaching experience, participants answered one of five options: 0-5 years, 6-10 years, 11-15 years, 16-20 years, or more than 20 years. For

reporting their highest degree earned, participants selected from one of five options: completed bachelor's degree, completed bachelor's degree plus some graduate-level course credits, completed graduate (master's) degree, completed graduate degree plus some doctoral-level course credits, or completed their doctorate (Ed.D. or Ph.D.). For a full breakdown of the participants' demographics, see Table 1.

Table 1
Participant Demographic Information

	Response	**Frequency**	**Percentage**
Gender	Female	62	69%
	Male	28	31%
Subject taught	English	27	30%
	Foreign Language	6	6.7%
	Mathematics	23	25.6%
	Science	21	23.3%
	Social Studies	13	14.4%
Educational attainment	Bachelor’s degree	11	12.2%
	Bachelor’s +	19	21.1%
	Master’s degree	20	22.2%
	Master’s +	36	40.0%
	Doctorate degree	4	4.4%
Teaching experience	0-5 years	16	17.8%
	6-10 years	19	21.1%
	11-15 years	20	22.2%
	16-20 years	15	16.7%
	20+ years	20	22.2%

N =90

Teacher Knowledge about IEP Implementation

For all of the Likert scale items, teachers had the option of selecting from a range of scores, from 1 = "Strongly Disagree" to 5 = "Strongly Agree." The average response for the seven items in this section of the survey ranged from 1.67 to 2.66, indicating that participants did not feel comfortable with, or understood fully, the various aspects of implementing the IEP of students with significant disabilities. See Table 2 for a complete summary of these responses by survey item and Appendix A for the entire survey questions with mean ratings. Items 11 and 12 referred to two specific supports often found in IEPs of students with significant disabilities: collaborating with related service providers (i.e., occupational/physical or speech therapists) and collaborating with paraprofessionals. Overwhelmingly, participants reported that they did not feel comfortable or knowledgeable about collaborating with these colleagues: 87.7% disagreed or strongly disagreed with the statement about collaborating with related service providers, and

83.3% disagreed or strongly disagreed with the statement about collaborating with paraprofessionals.

Table 2
Teacher Knowledge about IEP Implementation

Item #	Topic	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Did Not Respond
6	Least restrictive environment (legal requirement)	24 (26.7%)	49 (54.4%)	7 (7.8%)	5 (5.6%)	5 (5.6%)	0
7	Access to general curriculum (legal requirement)	23 (25.6%)	53 (58.9%)	10 (11.1%)	1 (1.1%)	3 (3.3%)	0
8	Access to general curriculum (in practice)	11 (12.2%)	39 (43.3%)	16 (17.8%)	18 (20%)	6 (6.7%)	0
9	Teacher's role in IEP implementation	25 (27.8%)	47 (52.2%)	12 (13.3%)	3 (3.3%)	3 (3.3%)	0
10	Collaboration with special ed.	43 (47.8%)	38 (42.2%)	4 (4.4%)	3 (3.3%)	1 (1.1%)	0
11	Collaboration with RSPs*	39 (43.3%)	40 (44.4%)	4 (4.4%)	4 (4.4%)	1 (1.1%)	2 (2.2%)
12	Collaboration with paraprofessionals	36 (40%)	39 (43.3%)	6 (6.7%)	7 (7.8%)	2 (2.2%)	0
Section means		31.9%	48.4%	9.4%	6.5%	3.3%	1.4%

Note. Likert scale responses were 1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree, 5=Strongly Agree
N=90
* Related service providers

Teacher Knowledge about Specific Disability Areas

This subset of survey items asked participants to rate how "capable" they felt of successfully including students with various disabilities. Each item asked about a specific disability area considered a significant disability under IDEA, such as intellectual disability or traumatic brain injury (see Table 3 for a complete summary of these responses by survey item). The average rating for the six items in this section ranged from 2.21 to 2.88, indicating that, on average, participants did not feel capable of working successfully with students with significant disabilities in their general education classrooms. Specifically, many participants indicated that they disagreed that they felt capable of working with students with moderate/severe intellectual disability (71.1% disagreed or strongly disagreed).

Table 3
Teacher Knowledge about Specific Disability Areas

Item #	Topic	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Did Not Respond
13	Student with a severe disability	17 (18.9%)	42 (46.7%)	16 (17.8%)	10 (11.1%)	3 (3.3%)	2 (2.2%)
14	Student with severe autism	9 (10%)	35 (38.9%)	22 (24.4%)	18 (20%)	3 (3.3%)	3 (3.3%)
15	Student with moderate to severe intellectual disability	17 (18.9%)	47 (52.2%)	12 (13.3%)	10 (11.1%)	1 (1.1%)	3 (3.3%)
16	Student with deafblindness	10 (11.1%)	33 (36.7%)	16 (17.8%)	19 (21.1%)	10 (11.1%)	2 (2.2%)
17	Student with severe traumatic brain injury	7 (7.8%)	26 (28.9%)	33 (36.7%)	15 (16.7%)	7 (7.8%)	2 (2.2%)
18	Student with multiple disabilities	11 (12.2%)	49 (54.4%)	15 (16.7%)	10 (11.1%)	3 (3.3%)	2 (2.2%)
Section means		13.2%	43%	21.1%	15.2%	5.0%	2.6%

Note. Likert scale responses were 1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree, 5=Strongly Agree
N=90

Teacher Knowledge about EBPs & Research-Based Supports

Many participants reported that they "understood and could implement" several EBPs common to teaching students with severe disabilities. 63.3% strongly agreed or agreed about implementing systematic instruction, and 70% strongly agreed or agreed about implementing constant time delay (see Table 4 for a complete summary of these responses by survey item). Interestingly, over two-thirds of participants disagreed or strongly disagreed that they could

implement the research-based supports or curriculum modifications and accommodations (67.8% and 68.9%, respectively). 77.8% of the participants disagreed or strongly disagreed that they could implement differentiation for students with significant disabilities in their general education classrooms.

Table 4

Teacher Knowledge about EBPs & Research-Based Supports

Item #	Topic	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Did Not Respond
19	Systematic instruction	2 (2.2%)	20 (22.2%)	8 (8.9%)	38 (42.2%)	19 (21.1%)	3 (3.3%)
20	Constant time delay	4 (4.4%)	10 (11.1%)	10 (11.1%)	45 (50%)	18 (20%)	3 (3.3%)
21	Progressive time delay	3 (3.3%)	11 (12.2%)	8 (8.9%)	47 (52.2%)	18 (20%)	3 (3.3%)
22	Most to least prompting	6 (6.7%)	12 (13.3%)	13 (14.4%)	41 (45.6%)	14 (15.6%)	4 (4.4%)
23	Least to most prompting	6 (6.7%)	12 (13.3%)	12 (13.3%)	42 (46.7%)	15 (16.7%)	3 (3.3%)
24	Simultaneous prompting	2 (2.2%)	16 (17.8%)	10 (11.1%)	42 (46.7%)	17 (18.9%)	3 (3.3%)
25	Differentiated instruction	17 (18.9%)	53 (58.9%)	10 (11.1%)	3 (3.3%)	4 (4.4%)	3 (3.3%)
26	Curriculum modification	15 (16.7%)	46 (51.1%)	15 (16.7%)	6 (6.7%)	3 (3.3%)	5 (5.5%)
27	Curriculum accommodations	16 (17.8%)	46 (51.1%)	11 (12.2%)	8 (8.9%)	3 (3.3%)	6 (6.7%)
28	Social Stories	7 (7.8%)	10 (11.1%)	13 (14.4%)	40 (44.4%)	15 (16.7%)	5 (5.5%)
29	Partial participation	4 (4.4%)	24 (26.7%)	13 (14.4%)	32 (35.6%)	11 (12.2%)	6 (6.7%)
30	Stimulus prompts	3 (3.3%)	11 (12.2%)	15 (16.7%)	41 (45.6%)	15 (16.7%)	5 (5.5%)
31	Students with AAC† devices	7 (7.8%)	18 (20%)	19 (21.1%)	22 (24.4%)	15 (16.7%)	9 (10%)
32	Assistive technology devices	9 (10%)	30 (33.3%)	19 (21.1%)	15 (16.7%)	6 (6.6%)	11 (12.2%)
33	Skill maintenance	2 (2.2%)	13 (14.4%)	15 (16.7%)	36 (40%)	14 (15.6%)	10 (11.1%)

34	Skill generalization	3 (3.3%)	9 (10%)	15 (16.7%)	40 (44.4%)	13 (14.4%)	10 (11.1%)
35	Willing to seek PD‡ to meet needs of students with severe disabilities	32 (35.6%)	37 (41.1%)	7 (7.8%)	3 (3.3%)	1 (1.1%)	10 (11.1%)
Section means		9.2%	24.7%	13.9%	32.7%	13.1%	6.4%

Note. Likert scale responses were 1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree, 5=Strongly Agree
N=90
† Augmentative and alternative communication
‡ Professional development

Discussion

General education teachers must implement and understand all components and collaborate as team members in the IEP process (Rotter, 2014). Yet, our respondents perceived themselves as not knowing how to implement an IEP for students with a significant disability. To support general education teachers' understanding of IEPs and the IEP development process, teacher preparation programs must better prepare teachers about their role on the IEP team. This presents a potential opportunity for collaboration with special education teachers at the pre-service level. In many special education preparation programs, teacher candidates participate in mock or simulated IEP meetings; including general education teacher candidates in these experiences could benefit both candidates in their development as pre-service teachers. Additionally, having pre-service general education teachers work with special education teachers in a co-taught environment as part of their clinical experiences could allow the general education teacher to implement modified and accommodated curricula for all students with and without disabilities.

Related service providers (e.g., speech pathologists, occupational therapists, physical therapists) and/or paraprofessionals are a common component of IEPs for many students with significant disabilities. Collaborating with related service providers and/or paraprofessionals is a considerable demand for general education teachers, including training staff members with fidelity. Paraprofessionals, for example, assume many types of duties within a classroom setting (e.g., instructional assistance, Mason et al., 2021). General education teachers need to understand these providers' roles in the student's education and IEP development. Yet, our respondents indicated not feeling comfortable or knowledgeable about collaborating with these individuals. Paraprofessionals could be utilized to implement EBPs (e.g., systematic instruction) and could be a true asset in the classroom (Mason et al., 2021; Walker et al., 2020) when working with students with significant disabilities. General education teachers should receive training on how to best collaborate with these essential professionals in their classrooms.

Based on the principles of applied behavior analysis, systematic instruction is a set of procedures that are often used for students with moderate and severe disabilities or, as we describe

throughout this manuscript, students with significant disabilities (Collins, 2012). Throughout the last several decades, special education professionals have used systematic instruction, a body of EBPs, to teach a variety of academic and functional skills to students with significant disabilities (Britton et al., 2017; Kroesch et al., 2020; Root & Browder, 2019). A surprising finding in our survey results was that the general education high school teachers we surveyed perceived themselves as having a good understanding of systematic instruction and how to implement it for students with significant disabilities. Yet, many (if not most) general education teacher preparation programs require only minimal and broad coursework in special education, often not including systematic instruction or other EBPs for working with students who have low-incidence disabilities. This broad coursework tends to focus instead on working with students with high-incidence disabilities.

The survey participants also indicated a lack of perceived ability to modify instruction to meet students with more significant disabilities in the general education classroom. Research has indicated that while modifying or differentiating instruction may be included in general education courses for pre-service teachers, making modifications that meet the more extensive support needs of students with significant disabilities is typically not covered in those courses. Since there was such a difference in the self-ratings (i.e., between implementing systematic instruction and modifying curriculum), teacher preparation programs and school professional developments should focus on implementing specific EBPs in the general education environment to meet the needs of all learners (Brown, 2020).

Implications for Research and Practice

Since rates of inclusion of students with significant disabilities in general education settings remain low (Kleinert et al., 2015), our results were unsurprising in that participants, for the most part, did not feel that they were adequately knowledgeable or capable of successfully including these students in their classrooms. However, because our survey results indicated that that knowledge did not change much for general education teachers who had taught students with significant disabilities, simply increasing rates of general education inclusion for these students would not likely change these findings. Future research in teacher preparation should examine whether general education teachers are taught about students with significant disabilities. More specifically, research should explore the effect of coursework and field experiences on the preparation of pre-service and novice general education teachers working with students with significant disabilities in their classrooms.

Our survey asked participants to indicate whether they would be willing to seek out professional development opportunities that would help them address the needs of students with significant disabilities in their classrooms. The vast majority (76.7%) of responses to this question were either "disagree" or "strongly disagree." We feel that this requires deeper examination in both general and special education research. Future research could explore the beliefs and attitudes of general education teachers towards the inclusion of these students in general education settings and what influences those beliefs.

General education teachers should have students with significant support needs placed in their classrooms only after adequate training and support in the school system. With more than three-quarters of our study's participants indicating that they were unwilling to seek professional development, we believe schools should be responsible for training and supporting their general education teachers.

Limitations

The results of our survey study should be viewed in light of some limitations and complications. First, to satisfy IRB expectations, we did not require participants to answer all survey items. As a result, many responses were considered incomplete and dropped from the analysis. In addition, the survey itself had some weaknesses. The wording of some questions may not have been clear enough to respondents. Additionally, we suspect many participants did not respond to questions where they did not understand or were unfamiliar with the topic (e.g., the various EBPs in systematic instruction). Our survey aimed to gather teachers' self-perceptions about their knowledge, simply their familiarity with the practices rather than measuring implementation of their knowledge. Future studies should explore teacher knowledge about these issues more deeply. The survey instrument should also undergo a more thorough expert review, piloting, and factor analysis to ensure more substantial validity and reliability in future studies. Finally, the response rate was low, and we should have adjusted our communication with the participant pool to encourage more responses. For example, a scheduled reminder email or communicating directly with school district leadership.

Conclusion

Our study explored the perceived knowledge and self-ratings of knowledge in general education teachers with regard to the inclusion of students with significant disabilities in their classrooms. Most participants reported not having a firm understanding or strong sense of capability in successfully teaching students with significant disabilities within general education settings. We feel that a lack of experience, training, and familiarity with many of the topics and issues involved in teaching students with significant disabilities may have contributed to these results. More research is needed to determine what specific coursework, training, experiences, or combination would best support general education teachers who work with students with significant disabilities.

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Appendix A

Survey of General Education Teachers

Survey Item	Mean Response (SD)
6. I understand the legal requirements of the least restrictive environment in regards to students with significant disabilities.	2.09 (1.03)
7. I understand the legal requirements of access to the general curriculum in regards to students with significant disabilities.	1.98 (.848)
8. I have the knowledge and skills needed to provide access to the general curriculum for students with significant disabilities.	2.66 (1.13)
9. I understand my roles and responsibilities for the IEP of a student with a significant disability.	2.03 (.917)
10. I am comfortable collaborating with special education teachers to include students with significant disabilities in my classroom.	1.67 (.807)
11. I am comfortable collaborating with related service providers (e.g., speech, OT, PT) to include students with significant disabilities in my classroom.	1.73 (.840)
12. I am comfortable collaborating with paraprofessionals to include students with significant disabilities in my classroom.	1.89 (.988)
13. I am capable of successfully including a student with a severe disability in my classroom.	2.32 (1.02)
14. I am capable of successfully including a student with severe autism in my classroom.	2.67 (1.03)
15. I am capable of successfully including a student with a moderate to severe intellectual disability in my classroom.	2.21 (.929)
16. I am capable of successfully including a student with deafblindness in my classroom.	2.84 (1.22)
17. I am capable of successfully including a student with a severe traumatic brain injury in my classroom.	2.88 (1.05)
18. I am capable of successfully including a student with multiple disabilities in my classroom.	2.38 (.963)
19. I understand what systematic instruction is and can implement it in my classroom.	3.6 (1.14)
20. I understand what constant time delay is and can implement it in my classroom.	3.72 (1.06)
21. I understand what progressive time delay is and can implement it in my classroom.	3.76 (1.03)
22. I understand what most-to-least prompting is and can implement it in my classroom.	3.52 (1.14)
23. I understand what least-to-most prompting is and can implement it in my classroom.	3.55 (1.14)

24. I understand what simultaneous prompting is and can implement it in my classroom.	3.64 (1.07)

(Table Continues)

25. I understand the principles of differentiated instruction and can implement it in my classroom to include students with significant disabilities.	2.13 (.925)
26. I understand how to modify curriculum to meet the needs of students with significant disabilities in my classroom.	2.25 (.950)
27. I understand how to make accommodations to the curriculum to meet the needs of students with significant disabilities in my classroom.	2.24 (.989)
28. I understand what social stories are and can implement them in my classroom.	3.54 (1.16)
29. I understand what partial participation is and could incorporate it in my classroom.	3.26 (1.15)
30. I understand what stimulus prompts are and can implement them in my classroom.	3.64 (1.03)
31. I am comfortable working with a student who uses an augmentative and alternative communication (AAC) device in my classroom.	3.25 (1.24)
32. I can implement assistive technology devices in my classroom to meet the needs of students with significant disabilities.	2.73 (1.13)
33. I understand what skill maintenance is and can help students with significant disabilities achieve this.	3.59 (1.04)
34. I understand what skill generalization is and can help students with significant disabilities achieve this.	3.64 (1.01)
35. I am willing to seek professional development to meet the needs of students with significant disabilities.	1.80 (.848)

Note. The first five questions related to demographic information.

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Article

EXAMINING THE IMPACT OF THE COVID-19 PANDEMIC ON CAREGIVERS OF CHILDREN WITH COMPLEX AND CHRONIC CONDITIONS

Molly Greer
Chelsea Pierce

University of Central Florida

Abstract: In March of 2020 the president of the United States declared a national emergency as COVID-19 transmitted across the globe. Over 18 months later , the pandemic continues to pose challenges as residents of the world adapt to the ever-changing shuffle of precautions, regulations, and restrictions. During this unprecedented time we have globally learned to expect the unexpected; which has become the norm. Caregivers of Children with Complex and Chronic Conditions wear multiple hats when taking care of their children. They may serve as a nurse, therapist, educational advocate, chauffeur, or personal assistant. Due to the ever-changing routines and mandates as a result of the pandemic, parents have become worn down, leading to mental health concerns and caregiver burnout. During the pandemic caused by COVID-19, caregivers of children with unique needs are faced with a new set of challenges

Keywords: *complex needs, pandemic, caregiver, COVID-19*

Vignette

Rebecca Jones is a full-time working mother with two children, Braxton and Leila. Braxton is a third-grade student who attends public school in a fully inclusive classroom. He has Cerebral Palsy and Dyslexia, and Leila is a seventh-grader with Sickle Cell anemia. Because both children have Complex and Chronic Conditions (CCCs), Rebecca often has to pick them up from school early or keep them at home if they have medical appointments. Braxton has an Individualized Education Plan (IEP) and receives support facilitation services in language arts & math.

Additionally, he attends physical therapy, occupational therapy, and speech/language therapy at school on a weekly basis. When not in school, he enjoys participating in adaptive art classes and boy scouts. Leila has an IEP as well and sometimes receives Hospital-Homebound support, as she misses at least six days of school monthly due to pain and hospitalizations. Rebecca is grateful for the support of Braxton and Leila's teachers, therapists, and community. Mr. Jones is the owner of a technology company and works from home most of the time. Since the pandemic's start, Rebecca's company transitioned her position to a fully-remote role. Because Braxton and Leila are medically fragile, Rebecca enrolled both students in fully virtual classes to limit their possible exposure to COVID-19. Unfortunately, this has limited their access to services received in school. Braxton's school tries its best to do virtual Speech and Language therapy, but occupational and physical therapy hasn't been able to conduct sessions virtually. Braxton often complains of missing his peers and doesn't understand why he needs to stay home. While Rebecca is glad she can work remotely while caring for her family, she is struggling. With two children with complex needs, two adults working from home, and a global pandemic, Rebecca and her husband are burnt out.

The Global Pandemic and the Impact on Families and Caregivers

"It takes a village to raise a child…" For students with complex needs, this multiple disciplinary village often includes educators, therapists, a medical team, and behavioral/mental health supports, who work alongside parents and other community resources. Pre COVID-19, children went to school, received outside therapies, or attended other public activities. Parents had more opportunities to work and manage other responsibilities. However, once the necessary precautions were put in place during quarantine, families became more isolated. Parents assumed new roles as quarantine became the new norm and the demands on parents increased.

As a direct result of the global pandemic, parents and caregivers have been tasked with new roles and responsibilities. While some parents educated their child/ren in the home for a portion of the pandemic, others facilitated their child's learning while attending virtual school. At the beginning of the pandemic, schools closed, teachers spent endless amounts of time preparing lessons for students to complete virtually, and parents took on the responsibility of their student's learning. Houses gained new purpose, kitchens across the world transformed into learning labs, bedrooms into classrooms, and living rooms served as a space for physical education class. In March of 2020, 42% of workers who were once working in a storefront or office space were now working

from home (Wong, 2020), while nearly 93% of students were transitioning to learning from home (McElrath, 2020).
According to the World Health Organization (WHO), people with disabilities may be at a higher risk for COVID-19 due to comorbid health conditions and challenges accessing healthcare services independently. Other factors such as the feasibility of social distancing and the implementation of hygienic practices must also be considered (WHO, 2020). In addition to changes in the mode of academic instruction, families of children with complex and chronic conditions have experienced fluctuations in the continuity of care for medical appointments, limited interactions with peers due to social distancing, and increased caregiver burnout and depression (Dhiman et al., 2020).

Complex and Chronic Conditions

Complex and Chronic Conditions (CCC) consist of "any medical condition(s) that can be reasonably expected to last at least 12 months… and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center" (Feudtner et al., 2000 & 2014). Depending on individual strengths and challenges, some children with CCCs attend inclusive schools and classes while others enroll in specialized centers or schools with educators equipped with in-depth training to accommodate students' needs. Some children with CCC are homeschooled or receive hospital-homebound services.

Parents of children with CCC advocate for their unique needs across a variety of settings, ensuring their children receive access to high-quality healthcare, education, and opportunities to engage with others. Although there are programs designed to meet the individual needs of children with common diagnoses, children with CCC often have comorbid medical conditions, compounding the trajectory of suggested interventions. Common services include speech-language therapy, occupational therapy, physical therapy, specialized medical care, respite care, and social and behavioral supports.

While each familial situation is different, common challenges faced by parents of children with complex medical needs include lack of sleep, challenges maintaining a job due to the amount of time dedicated to caregiving, and advocacy responsibilities, and loss of financial income (Pordes et al., 2018).

The Weight of the Pandemic

The sudden halt in "life as we knew it" and the shift to the "new normal" families experienced challenges unlike any they had ever endured before. According to the CDC (2020) and Hamel and colleagues (2020), families with children under the age of 18 reported three major stressors, 1) digital inequity or access to technology, 2) job stability/security, and 3) food security. Each stressor impacts families and caregivers differently; it is essential to understand the scope and magnitude of the impact.

Digital Equity: Digital Equity, also known as digital inclusion, is the ability to access and effectively use technology (Sharp, 2020). Caregivers and parents had the responsibility to not only gain access to the technology needed for their children to learn, and become proficient in the use of their student's digital platform to be considered effective. The Pulse Survey, sent by The United States Census Bureau (2020), uncovered that 66% of families with an income of less than $50,000 were able to access online educational platforms resulting in 21% of families accessing school through paper-based packets sent to families, and sadly 13% of families not able to access school curriculum at all. The percentage of families able to access online resources increased to 77% for families making up to $99,000 annually and 86% of families making above $100,000 annually.

Gaining access to the online educational platforms became a challenge for families, yet those families who had access faced another challenge, the number of screens in the household. Parent's working from home required access to their screen to complete their job and students needed access to screens to complete school work, whether that be synchronous or asynchronous. Families reported not having enough screens/devices for their children to attend class at the appropriate time as well as not having the internet capabilities to withstand the bandwidth of both the working parent/caregiver and the students learning online (Sharp, 2020)

Job Stability/Security: Parents with students with complex needs take on average 12 more days off than those without children with disabilities. As the pandemic closed the doors of schools, parents and caregivers faced a new stressor: how to manage their jobs and their child's education. A 2020 Catalyst Survey reported that 71% of women and 65% of men had to modify their work routines at the start of the pandemic. This modification of work routine resulted in 43% of parents sharing that they felt unable to perform to the extent their company required of them (Catalyst, 2020). As the demand for education and job performance, parents and caregivers reported that 33% of those parents/caregivers fear being laid off due to their newly acquired responsibilities (Catalyst, 2020).

The same Catalyst Survey (2020) shares that 41% of mothers and 36% of fathers felt the need to hide their caregiver stress from their employers and co-workers, resulting in adverse psychological effects for caregivers. These psychological effects not only impact the parent/caregiver but also their spouse and child in the household. A recent study found that parents with increased job stress due to the pandemic felt as if they were not able to control their frustration effectively and frequently overreacted to small issues with their families (Morelii, 2020).

Food Security: In the year 2020, 50.4 million people faced food insecurity, of which 17 million are school-aged children (Hake et al., 2020). As parents/caregivers increasing concerns with job security rose, the fear of not being able to provide food for their family rose. Though food insecurity rose 4.1% across the nation, there was no substantial increase in families applying for food assistance (Hake et al., 2020). Some states began food stamp programs for families with students in school to ease the burden of food costs on families, but personal reports state that those efforts were not enough to cover the increase in food prices at the beginning of the pandemic.

Parent and Caregiver Burnout

With stressors as substantial as those listed above, parents and caregivers were given a burden greater than they should bear alone. Parents and caregivers that experienced an increase in pandemic-related stress found it more difficult to understand their child's needs and hardships, and parents/caregivers struggled to respond to their students in a sensitive manner (Spinelli et al., 2020). As the parents' ability to emotionally regulate their emotions changed, children saw a similar shift in their ability to self-regulate (Morelli et al., 2020). Once a family is in a cycle of poor emotional self-regulation, they are at risk of remaining in this unhealthy mental state. Stress cycles and drains the individual, leading to caregiver burnout.

Caregiver burnout is when a parent or caregiver feels overwhelmed by the responsibilities of taking care of others, and this results in their inability to continue to provide effective care. As a caregiver, burnout is common, with approximately 12.7% more than average caregivers expressing they felt burnout with no support available to them. In 2020, 27% of parents reported worsening mental health and feeling unable to support their children the way they felt they should be (Patrick et al., 2020)

Three Tips for Families and Caregivers to Navigate the Pandemic

As the impacts of the pandemic continue to influence the daily lives of families across the globe. Below are three tips to help families and caregivers in ways to support their child and themselves in the midst of challenging times.

Tip One: Advocate

Continue to advocate for the specific needs of your child. If your child has an Individualized Education Plan (IEP), they are legally entitled to receive all services listed on the IEP whether there is a pandemic occurring or not. If a school does not provide access to specialized services as detailed on their IEP, your child may be entitled to receive compensatory services (Hurwitz et al., 2021). Determine the best method of communication for you and your child's teacher, and request updates and frequent contact to ensure your child is on track.

Advocating is an overwhelming task at some times, especially during a pandemic. It is during these times that it is important to stay current on local, state, and national legislation in the area of pandemic support. Local school districts should provide service plan updates to parents/caregivers of students with disabilities. If you have yet to receive a plan, contact your school and ask for such a plan, especially if your school remains or transitions to online learning. Also, during this time it is hard to remember that this is all still so new for teachers and school districts. Your child's school or teacher might only be able to give updates that reach only a few weeks into the future, and that will be okay. There is still a multitude of unknowns that schools are trying to navigate.

Tip Two: Practice

Keep the germs at bay by explicitly teaching physical distancing and hygiene practices in the home (WHO). Children with complex needs may need additional support applying social distancing practices outside of the home. Play social distancing games within the home to solidify their understanding of distancing regulations. Place a timer next to the sink or water source, and practice frequent hand-washing. If your child is medically cleared to wear a mask, add mask-wearing practice into your daily routine at home. The more opportunities for practice at home, the higher the likelihood of successful implementation in public.

Another important piece to practice is a "typical" routine. It is possible that students could be transitioning from school to learning from home to learn as a variety of variants arise. It is crucial for a child's success to continue to practice the school routines. According to the United States Department of Health and Human Services (2020), routines not only provide a consistent structure in which student learning thrives, but routines also provide a sense of security for children to know what is going to happen next. Security in a time of a plethora of unknowns will not only benefit your child but will also benefit you as a caregiver. Having a plan is a good way to start self-care routines as a caregiver

Tip 3: Support

You are not alone. It is crucial to talk to other parents about the challenges they've faced during the pandemic. Social support helps reduce parental anxiety and stress (Ren et al., 2002). Support groups provide a place to collaboratively brainstorm strategies to simplify complex tasks and routines, create a variety of resources to share among other caregivers, and a place to share your concerns and struggles safely. You may choose to chat with a friend through social media, join a virtual parent support group, or meet up with others in public. Support looks different for every person. Determine what kind of support you need, and reach out.

Caregiver burnout typically isn't felt gradually; instead, it impacts the caregiver in an instant. For most, it feels like you have been hit by a train emotionally, spiritually, and physically. Burnout is among one of the hardest barriers to overcome due to the impact on the whole being of the caregiver. Simple steps of self-care, reaching out for support, and building in accountability systems prevent the suddenness that caregiver burnout can have. Support from others is vital to the well-being of a caregiver. What is most frequently overlooked is the support of one's self. As humans, we are generally our own worst critics. Life happens, your child will have a bad day, you will burn dinner, knock your favorite coffee cup on the floor, or life will seem like it is falling apart at the seams. You are not defined by any of those things. Supporting one's self is the most challenging thing we as humans take on. It is important to remember to give yourself grace in the midst of this chaos. There are still aspects of life that many are unsure of when it comes to the pandemic, and it's okay that caregivers don't know it all or how to do it all. Take time to slow down and reflect on all the good things you are doing. Did you feed your child this morning? Perfect! What a rockstar! Did you get out of bed? Of course! Celebrate that! Celebrate the small things. That is where self-care begins.

Conclusion

For families like the Jones family, the global pandemic will continue to reveal new challenges. Advocating for your support needs as well as your children's specialized support is crucial to thriving during such unprecedented times. The global pandemic has shaken humanity to its core, and we are all trying to navigate through the ever-changing day-to-day routines. Our goal is that caregivers be aware of the stress they are in, the impacts of the pandemic, and ways that they can manage caregiver burnout.

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