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Evaluation of a DIRFloortime® Program for Autism Spectrum Disorder

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Abstract

Problem. Parents with children who have neurodevelopmental disorders, such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) experience high levels of parenting stress. The prevalence of ASD is on the rise in the United States. As a result, there has been an increase in the use of treatment modalities, in effort to better understand which modalities have the most positive impact on children and their parents. DIRFloortime® is a developmental treatment modality used to help strengthen the parent-child bond and used to decrease parental-child stress. The Autism Parenting Stress Index (APSI) measures the impact of an intervention on parental stress levels.

Methods. A Plan-Do-Study-Act (PDSA) model was utilized, and data was obtained over a three-month period. An observational cohort design was utilized using a questionnaire. A purposive sample of parents of children with neurodevelopmental disorders (ASD and ADHD) aged 4 to 14-years-old who are enrolled in the DIRFloortime® program at a small rural midwestern non-profit agency participated.

Results. The total monthly APSI questionnaire scores for each parent decreased an average of six and a half points after three months (N=6).

Implications for Practice. Additional PDSA cycles are needed to assess for efficacy and trends of the DIRFloortime®program. Limitations of this quality improvement project include small sample size and short length of time.

Evaluation of a DIRFloortime® Program for Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurodevelopmental disorder in which symptoms are usually present by a child's second birthday (American Psychiatric Association [APA], 2013). The diagnosis of ASD can only occur when the patient experiences social communication deficits, that are accompanied by markedly repetitive behaviors, limited interests, and insistence on likeness (APA, 2013). Parents with children who have neurodevelopmental disorders experience high levels of parenting stress with some studies finding four times as much parental stress compared to parents with neurotypical children (Silva & Schalock, 2011). In matched case-control studies from Phetrasuwan and Miles (2009) and Johnson et al. (2009) (as cited in Silva & Schalock, 2011), the increased parenting stress is related to the challenges experienced due to their child's physical, and co-morbid behavioral symptoms associated with ASD. Montes and Halterman (2007) (as cited in Silva & Schalock, 2011) state these symptoms can impact nearly every part of a child's functioning, which can negatively influence a parent's ability to cope.

The prevalence of ASD is on the rise in the United States. In 2014, the prevalence of ASD was one in 60 children (Knopf, 2020). In 2016, the prevalence of ASD was one in 54 among 8-year-olds (Knopf, 2020). According to Connell, Petersen, and MartinRogers (2019), since the prevalence of ASD is on the rise, there has also been an increase in the determination to better understand what treatment modalities have the most positive impact on children with ASD and their parents. Currently, it is known that early interventions for children who have ASD result in better outcomes, such as

improved parental coping skills, improved parent self-efficacy, and improved child functioning (Pellechia et al., 2020).

Due to this increase in national prevalence, in 2013, the Minnesota Legislature passed a law that helped create the Early Intensive Developmental and Behavioral Intervention (EIDBI) (Connell, Petersen, & MartinRogers, 2019). Through EIDBI children 0 through 21-years-old with neurodevelopmental disorders, are provided with periodic and early screening, diagnostics, and treatment (Connell, Petersen, & MartinRogers, 2019). One of the treatment modalities offered through EIDBI is DIRFloortime®.

The 'DIR' in DIRFloortime® stands for developmental, individual difference, and relationship based (Pajareya, Sutchritpongsa, & Kongkasuwan, 2019). DIRFloortime® is a developmental intervention that emphasizes the child's capability for communicating, processing information, understanding sensations, and planning their actions (Connell, Petersen, & MartinRogers, 2019; Pajareya, Sutchritpongsa, & Kongkasuwan, 2019). Within the true nature of the name, DIRFloortime® uses playtime on the floor to help to guide children through tasks by gradually increasing difficulty of task level (Connell, Petersen, & MartinRogers, 2019). Although the children are completing tasks, the focus lies on the child and caregiver interacting (Hess, 2013). A goal of DIRFloortime® is to help strengthen the parent-child interaction (Boshoff et al., 2020).

The Autism Parenting Stress Index (APSI) was created to identify areas where parents need additional support with skills, their coping abilities, and assesses the impact of an intervention on their stress (Silva & Schalock, 2011). The purpose of this project is to implement a standardized method of stress screening. The APSI instrument will help

assess the child's outcomes and the impact on them and their parents stress as it relates to the DIRFloortime® program (Connell, Petersen, & MartinRogers, 2019)**.** The utilization of the APSI will make this possible by evaluating the trends among parental stress levels related to their child's core and co-morbid symptoms (Silva & Schalock, 2011).

The APSI will help identify gaps and strengths of both the program and the parental skills (Appendix A). The APSI is a 13-item instrument measuring parental stress levels from zero to five and are correlated to the behaviors of the children. The domains of these items can be classified as overall parental stress, core behavioral symptoms, co-morbid physical symptoms, and co-morbid symptoms (Silva & Schalock, 2011). The purpose of identifying what areas cause parents the most stress is to help further individualize the plan of care for each child and their parents. For example, if the area of 'not feeling close to your child' is causing a parent significant stress, then additional DIRFloortime® hours of parental EIDBI training be added to their regimen. A Plan-Do-Study-Act (PDSA) method will be utilized. The aim of this pilot project is to implement the use of APSI screenings to at least 50% within 3 months. APSI will be implemented to show efficacy of the DIRFloortime® program. The primary outcome measures for this project include parental APSI scores and referral to resources. The secondary outcome measures are the subscale scores to assess for trending. The questions are: In parents with children aged 1-year to 14-years, who have been diagnosed with neurodevelopmental disorders such as ASD and attention deficit hyperactivity disorder (ADHD) and who's children are enrolled in the DIRFloortime® program:

1) what is the effect on the APSI scores at the beginning of the program when compared to three months into the program?

2) of those who were identified to have high APSI scores, what was the likelihood of referral to resources?

Literature Review

The second stage of the review process is the literature search detailing strategies used to obtain the relevant literature for the proposed research questions. In this phase, literature searches were conducted using CINAHL, Medline (EBSCO), and PubMed. The key terms of "clinical problems in autism", "autism education". "autism parent knowledge", "autism", "autism behavior issues", "autism assessment tool", "early intensive developmental behavioral intervention" and "DIRFloortime®" were included in all searches and connected with the Boolean operator "AND". Every search included multiple terms representing those keywords. For example, "autism parent knowledge" also included search terms such as "parent education on autism", "autism education", connected by the Boolean operator "OR". The inclusion criteria for this search were English publications and children (birth to 18-years-old). Exclusion criteria for this project were studies before 2010, published in languages other than English, and subjects older than 18-years-old.

A total of 17,990 initial publications were generated through the three previously mentioned databases. After setting the databases to only include publications from 2010 to 2020 7,263 articles remained. Duplicates were removed which lowered the total number to 3,457 publications. Titles of those articles were screened to verify they met the search terms. It was determined that 700 records were relevant. These 700 records were then assessed to make sure their abstracts met both inclusion and exclusion criteria. Through this assessment, 450 records were excluded because they were deemed

irrelevant. Of the 250 records remaining, all abstracts were then reviewed to determine their relevancy to the proposed research questions, leaving 10 publications relevant for this literature review.

The final 10 studies used in this review include randomized control trials (RCT), systematic reviews, and surveys. The studies discussed several aspects related to the research question, three studies focus on discussion of interventions and stress levels of parents; one study focuses on the need for parent input and interventions, six studies focus on interventions used for improvement of behavioral systems, with one study discussing the role of social determinants of health on parents beliefs about ASD and a few having some pertinent aspect overlap.

When looking at interventions for children that address parental stress level, Boyd, Odom, Humphreys, and Sam (2010) (as cited in Dababnah & Parish, 2015), found many ASD interventions do not include the child's parents despite knowing the increased parental stress experienced by the parents of children with ASD. Dababnah and Parish (2015) performed a systematic literature review of randomized control trials (RCT) with the intent to establish which interventions will improve the behavior of children with ASD and improve the parents' well-being. The final sample included only seven RCTs, from which the researchers created a coded list of primary attributes of each study. Results concluded that EIDBI is more likely to include parents, improve the behavior of children with ASD, and decrease the stress level of parents (Dababnah & Parish, 2015). The strengths of this study were the inclusion of the detailed search strategy, minimal selection bias, and assessors blinded to treatment. The limitations were that the

randomized control studies included a small sample size which decreased statistical power, unclear research methods, no long-term follow-ups, and poor external validity.

Silva and Shalock (2012) also focused on stress levels and intervention to decrease the stress levels of parents. In 2012, they sought to create an instrument measuring parents' stress which correlated with the child's interventions. This study resulted in the creation of the APSI a 13-item instrument measuring parental stress levels from zero to five and are correlated to behaviors of the children. Once a validated instrument such as the ASPI can be used, various interventions design to improve challenging behaviors of children to decrease parental stress should include specific outcome measures such as potty training, tantrums, child's social development, and self-injurious behavior (Silva & Schalock, 2012). Skill attainment of developmental and behavioral measures should include parental input on interventions.

By focusing on parental input on interventions, McConachie et al. (2017) conducted a systematic review of qualitative studies to determine which outcome measures should be used for their children with ASD. They concluded that parents find anxiety, sleep problems, relationships, hypersensitivity, happiness, parental stress, and irritability to be of some the highest graded outcome measures (McConachie et al., 2017). These outcome measures align with research by Silva and Schalock (2012) which stated the most common ASD symptoms are sleep dysregulations, self-injurious behavior, and irritability. With this knowledge, Silva and Schalock (2012) developed the APSI, a tool that measures the caregiver self-reports of the ASD symptoms experienced by the child and caregiver outcome measures. The APSI is designed to illustrate how interventions

play a role in parental stress relative to child symptoms. The Cronbach's alpha is 0.827 (Silva & Schalock, 2012).

The studies that focused on interventions used for the improvement of behavioral symptoms include the RCT conducted by Pajareya, Sutchritpongsa, and Kongkasuwan (2019) which found that adding a modest home-based DIRFloortime® parent training approach may produce significant improvements in socioemotional development. The strengths of this study include having high internal validity and good sample size. The limitations of this study include unknown long-term effects of the interventions and the intervention group used both DIRFloortime®and their regular child's routine. Hess (2013) strengthens the fact that as the prevalence of ASD diagnoses steadily increases, more understanding of ASD and how to treat it is needed. Hess (2013) agrees with Pajareya, Sutchritpongsa, and Kongkasuwan (2019), that using the developmental treatment modality of DIRFloortime® is important for both children to grow their skills and to help strengthen their ability to form relationships with their caregivers.

Tanner, Hand, O'Toole, and Lane (2015) appraised evidence for interventions within occupational therapy that addresses common difficulties that people with ASD may experience. One intervention that showed a positive impact on social participation was social skills groups and parent-mediated strategies. The strengths of this study included large sample size, diverse group of authors, and good internal validity. The limitations of this study included the inclusion of studies within the scope of occupational therapy practice, limited generalizability, and limited external validity. Hong, Neely, Gerow, and Gann (2018) conducted a systematic literature review and meta-analysis dealing with the impact of parent-mediated interventions on social skills in children with

ASD. Strengths for this including a large number of articles to review, graphs and charts used, strong external validity, and affordability. The limitations were poor internal validity, some bias, and some data used was older than 10 years.

In a systematic review by Howlin (2011), the question was posed to see if EIDBI was effective at improving the cognitive functioning and aggressive behavioral outcomes for children with ASD. Howlin (2011) found EIDBI may provide children with ASD some benefit. Boshoff et al. (2020) state research on DIRFloortime® is still up and coming. Boshoff et al. (2020) found that DIRFloortime® can positively impact the socioemotional development of children with ASD.

The next topic of review relates to the impact of SDOH on parents' beliefs regarding ASD. Zuckerman, Lindly, Sinche, and Nicolaidis (2015) found that there were some social determinants of health (SDH) related variances with beliefs about ASD, but they are not the main factor that determines a parent's belief about ASD. Additionally, they found that parents with a lower level of education or lower income were more likely to not have a good understanding of ASD (Zuckerman et al., 2015). The strengths of this study include affordability, multiple surveys being used, and the use of national datasets. The limitations were the parents' beliefs about ASD were not specifically measured, limited generalizability, limited external validity, and lack of a detailed search strategy.

The PDSA cycle was selected to guide this project. The PDSA cycle is an improvement model that consists of four cycles: plan, do, study, and act (Hickey & Brosnan, 2017). The PDSA cycle helps provide the necessary structure that is needed to make implementation easier (Melnyk & Fineout-Overholt, 2019). According to Hickey and Brosnan (2017), the PDSA cycle offers users a structured method to accomplish the

desired outcomes. Additionally, this framework was selected because of its ability to test a new idea on a small scale (Melnyk & Fineout-Overholt, 2019).

In summary, the developmental treatment modality DIRFloortime® is important for children to enhance their skillsets, to help strengthen their ability to form relationships with their parents, and to help decrease parental stress (Boshoff et al., 2020; Hess, 2013; Howlin, 2011; Pajareya, Sutchritpongsa, & Kongkasuwan, 2019). Key characteristics that parents felt were most important when it came to outcome measures for ASD interventions included: relationship development, anxiety, mood, sleep problems, hypersensitivity, parental stress, and irritability to be of some the highest graded outcome measures (McConachie et al., 2017). Gaps identified in literature included limited number of studies conducted on DIRFloortime® and limited number of studies with clearly described research methods. Studies with larger sample sizes and multi-site experiments are also needed. Lastly, studies using the APSI are also limited in number.

Method

Design

This was a quality improvement project using an observational cohort design. The data was obtained over a three-month period from parents of children who were enrolled in the DIRFloortime program. Use of the APSI tool was used over this time to monitor parental stress levels. The quality improvement project began February 2021 and ran through April 2021.

Setting

This first PDSA cycle took place in a small rural midwestern area surrounded by lakes with a population of approximately 3,000 people. The health care setting was a

small midwestern non-profit agency that serves children with neurodevelopmental disorders. This agency employs six full-time individuals. Two small hospitals serve this community.

Sample

The sample type was purposeful. The participants were the parents of children enrolled in the DIRFloortime® program. The inclusion criteria included parents of children (birth to 18-years-old), diagnosed neurodevelopmental disorder(s), and enrolled in the DIRFloortime® program. The exclusion criteria included parents of children older than 18-years-old, no neurodevelopmental disorder(s), and not enrolled in the DIRFloortime® program.

Approval Processes

Approval for this quality improvement project included the agency in which the program was conducted, committee chair, graduate program director, and graduate school dean. Additional approvals were obtained from the University of Missouri-St. Louis Institutional Review Board (IRB). There were no ethical issues or conflicts of interest for this project.

Data Collection and Analysis

Parents of children enrolled in the DIRFloortime® program filled out the APSI once a month for three consecutive months (Appendix A). The agency's Executive Director at the site gave parents the instrument, ensured they filled it out, and then emailed the results to the primary investigator (PI). Both email and computer of the PI were encrypted, and password protected. Data received by the PI was deidentified. Data was collected using an Excel spreadsheet that recorded each participant total score and

sub scores results each month. At the start of the project, demographics were sent to the PI and included age, gender, diagnosis, and hours of EIDBI.

Procedures

The team of stakeholders was emailed to inform them of a free research opportunity. The word 'free' was used in the subject of the email and emphasized multiple times throughout the email. By writing 'free' multiple times within the email created interest and curiosity because of the rarity of someone to offer a free service such as this. The team responded and expressed interest. A phone interview was scheduled. During the phone interview, all team stakeholders were present, and excitement was created about the proposed change (APSI implementation). Excitement was created by the PI through an oral presentation, which convinced the agency to implement the quality improvement program. After the phone interview, the agency agreed to have the parents fill out APSI every month for three consecutive months to evaluate parental stress levels and the impact of DIRFloortime®.

Results

Demographics

The total number of participants were six (*N*=6). Additionally, 66.67% (*n*=4) of the children identified as male, and 33.33% (*n*=2) as female. The age breakdown for the children are as follows, 33.33% (*n*=2) were aged 1 through 4 years old, 50% (*n*=3) were aged 5 through 8, and 16.67% (*n*=1) were 9-14 years old. One hundred percent of participants were Caucasian (*n*=6). The children's diagnoses included 33.33% (*n*=2) had ADHD, 33.33% (*n*=2) had ASD, 16.67% (*n*=1) had both ADHD and ASD. One participant had a diagnosis of complex trauma (16.67%). When analyzing the marital

status of parents 6.67% (*n*=1) were divorced, 33.33% (*n*=2) were married, and 50% (*n*=3) were single. Hours of EIDBI varied for each of the children from seven to thirty hours. Concomitantly, parents weekly EIDBI hours varied from zero to three hours.

APSI Tool scores

Descriptive statistics were calculated for each monthly total APSI score for each parent (Appendix C). The total monthly APSI scores for each parent decreased from the start of this quality improvement project to the end of it (Appendix D). Total monthly APSI score for each parent decreased an average of six and a half points.

The APSI is a 13-item instrument that measures parental stress levels from zero to five and are correlated to the behaviors of the children. The domains correlate to top stressors for parents of children with ASD. Monthly sub scales of the APSI scores of the parents illustrated that the top stressor domains for this sample included tantrums/meltdown, concern for the future of your child living independently, child's diet, and ability to communicate. The domains of tantrums/meltdown and concern for the future of your child living independently showed to most improvement, along with stress regarding their child's diet. The ability to communicate showed a small improvement within scores. Out of all 13 domains, all showed improvement, except for sleep problems and social development. Throughout the three months of this quality improvement project, parents identified to have high APSI scores (30 points or higher), one parent was referred to mental health services.

Discussion

The domains which showed the most stress for parents were making transitions and concern for the future of your child being accepted by others. Parents scored the

areas of self-injurious behavior, not feeling close to your child, bowel problems, and potty training, as the least stressful domains. By the end of this quality improvement project, the area in which the parents had the most improvement in stress levels were concern for the future of your child living independently. The domains that showed an increase in parental stress levels were social development and sleep problems.

Results of this quality improvement project found a decrease in parental stress scores over a three-month period. This project evaluated the DIRFloortime®program, suggesting that it might be useful in helping decrease stress for parents of children enrolled in the program. Most likely these results are dependent on the weekly EIDBI hours for each child and parent. This data was deidentified for the PI. Decreases in the identified parental stress domains may also result from the fact that children and parents accumulated more hours of DIRFloortime® training by the end of April data collection. These decreases possibly result in improvement in the behavior of the children due to the DIRFloortime® intervention, which lessened parental stress levels. These results suggest that early intervention for children who have ASD, help decrease parental stress.

The limitations of this project were the small sample size and short time frame in which it was conducted. Additionally, the APSI tool was designed to assess the parental stress levels of parents with children who have ASD, but the sample included other diagnoses in addition to ASD. Recommendations for the next PDSA cycle include further assessments for trending, and the use of the APSI tool to check the efficacy of DIRFloortime® program. The next PDSA cycle would be a larger sample size and a 6–8-month time for data collection using the APSI. Finally, future recommendations include

include agency referral for parents with high APSI scores be referred to mental health resources.

Conclusion

Stress screening for parents of children with ASD who are enrolled in the DIRFloortime® program using the APSI tool is a beneficial practice. Before implementation of this project, parents were not being stress screened using the APSI tool. Concomitantly, no parents could be identified as having high parental stress levels. After implementation of this quality improvement project, there is now a baseline assessment using the APSI and suggested the DIRFloortime® program might be useful to help decrease stress for parents of children diagnosed with ASD and enrolled in the program.

Due to the increase in the ASD diagnosis, it is important for providers to advocate for their patients and parents. Continued attention and increased APSI use will help identify more parents who are struggling with high levels of parental stress, which in turn will help parents be vulnerable about their struggles.

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Appendix A

Figure 1

Data Collection Instrument

Date: _____ Name of child: _____ Person completing checklist:_____

Autism Parenting Stress Index

	Stress Ratings				
Please rate the following aspects of your child's health according to how much stress it causes you and/or your family by placing an X in the box that best describes your situation.	**Not stressful**	**Sometimes creates stress**	**Often creates stress**	**Very stressful on a daily basis**	**So stressful sometimes we feel we can't cope**
Your child's social development	0	1	2	3	5
Your child's ability to communicate	0	1	2	3	5
Tantrums/meltdowns	0	1	2	3	5
Aggressive behavior (siblings, peers)	0	1	2	3	5
Self-injurious behavior	0	1	2	3	5
Difficulty making transitions from one activity to another	0	1	2	3	5
Sleep problems	0	1	2	3	5
Your child's diet	0	1	2	3	5
Bowel problems (diarrhea, constipation)	0	1	2	3	5
Potty training	0	1	2	3	5
Not feeling close to your child	0	1	2	3	5
Concern for the future of your child being accepted by others	0	1	2	3	5
Concern for the future of your child living independently	0	1	2	3	5
		Subtotal			
				Total	

Note. APSI instrument retrieved from Silva & Schalock, 2012.

Appendix B

Table 1

Demographic Data (N=6)

Demographics	Number (*n*)	Percentage
Age		
1-4	2	33.33%
5-8	3	50%
9-14	1	16.67%
Gender		
Female	2	33.33%
Male	4	66.67%
Transgender	0	0%
Race		
Black	0	0%
Caucasian	6	100%
Diagnosis		
ADHD	2	33.33%
ASD	2	33.33%
Both	1	16.67%
Complex Trauma	1	16.67%
Marital Status of Parents		
Divorced	1	16.67%
Married	2	33.33%
Single	3	50%
Weekly Hours of EIDBI		
0-10	2	33.33%
11-20	2	33.33%
21-30	2	33.33%
Weekly Hours of Parent EIDBI Training		
0	4	66.67%
1	0	0%
2	1	16.67%
3	1	16.67%

Note. Due to rounding errors, percentages may not equal 100%. Age is displayed in years.

Appendix C

Table 2

Summary Statistics Table for Interval and Ratio Variables by Parents

Variable	*Total*	*M*	*SD*	*n*	SE_M	Min	Max	Skewness	Kurtosis
February									
Parent A	8.00	8.00	-	1	-	8.00	8.00	-	-
Parent B	24.00	24.00	-	1	-	24.00	24.00	-	-
Parent C	22.00	22.00	-	1	-	22.00	22.00	-	-
Parent D	24.00	24.00	-	1	-	24.00	24.00	-	-
Parent E	31.00	31.00	-	1	-	31.00	31.00	-	-
Parent F	18.00	18.00	-	1	-	18.00	18.00	-	-
March									
Parent A	8.00	8.00	-	1	-	8.00	8.00	-	-
Parent B	22.00	22.00	-	1	-	22.00	22.00	-	-
Parent C	9.00	9.00	-	1	-	9.00	9.00	-	-
Parent D	16.00	16.00	-	1	-	16.00	16.00	-	-
Parent E	22.00	22.00	-	1	-	22.00	22.00	-	-
Parent F	19.00	19.00	-	1	-	19.00	19.00	-	-
April									
Parent A	6.00	6.00	-	1	-	6.00	6.00	-	-
Parent B	16.00	16.00	-	1	-	16.00	16.00	-	-
Parent C	11.00	11.00	-	1	-	11.00	11.00	-	-
Parent D	16.00	16.00	-	1	-	16.00	16.00	-	-
Parent E	22.00	22.00	-	1	-	22.00	22.00	-	-
Parent F	17.00	17.00	-	1	-	17.00	17.00	-	-

Note. '-' indicates the statistic is undefined due to constant data or an insufficient sample size.

Appendix D

Table 3

Average Monthly APSI scores (N=6)

Variable	Mode	*M*	*SD*	Min	Max
February Total	24.00	21.17	7.70	8.00	31.00
March Total	22.00	16.00	6.23	8.00	22.00
April Total	16.00	14.67	5.50	6.00	22.00