Research

Parent Perspectives on Social Skills Instruction of Transitioning Adults with Autism Spectrum Disorder

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ABSTRACT

The purpose of this study was to determine parent perspectives of social skills instruction for their transitioning or adult child with an autism spectrum disorder diagnosis age 18-28 years. The leading research question asked was, "What is the perception of classroom engagement for students with ASD who participate in social skills intervention?" One hundred and thirty-one parents volunteered to participate in the first part of this mixed-methods explanatory design study. The information in this study may allow educators to understand the lifelong benefits of social skills instruction for individuals with autism spectrum disorder and the importance of parent-mediated instruction and education. The findings in this study require further research to assist in understanding how the lack of social skills instruction during school hours and parent partnerships by stakeholders can become a barrier to employment, community participation, and quality of life for individuals with a diagnosis of autism spectrum disorder.

Keywords: Autism spectrum disorder; Social skills instruction; Evidence-based practices; Co-morbidity

PURPOSE OF THE STUDY

The purpose of this study was to explore the parental perspective of social skills instruction (SSI) of adult children with autism spectrum disorder (ASD) transitioning into adulthood. Several studies spanning over a decade have discussed the viewpoints of parents whose children are affected by autism spectrum disorder concerning the transition to adulthood [1,2].

Current studies Leonard confirm what Chambers noted sixteen years ago that there is an increasing number of young adults affected by ASD; thus, parents face challenges concerning social communication skills and social cognition that create a barrier to obtaining and maintaining gainful employment and independent living [3-5].

This study would be of interest to stakeholders from early intervention to university settings, speech therapists, behaviorists who work with students and adults with ASD and parents of individuals with ASD and other intellectual disabilities.

STATEMENT OF THE PROBLEM

The goal of this mixed-methods sequential explanatory study was to investigate the parent perspective of social skills instruction for their transitioning adult child with autism spectrum disorder (ASD). An early research study devoted to perceptions of parents of an adolescent with cognitive and communication impairment or severe ASD and IDD found that they expected for their child to obtain employment in a segregated environment that did not require extensive social interaction and to live at home [6]. This study was followed up by other scientific studies that continue to describe young transition-age adults with ASD (up to 90%) with little to no participation in employment and poor outcomes due to a lack of continued services [7-10].

According to recent studies, one of the leading barriers to obtaining and maintaining meaningful employment that contributes to the quality of life for adults with ASD are deficits in social communication skills [5,7,9]. While the literature continues to support a need for SSI, parents suggest that the lack of training provided to parents, and the information withheld by schools and other providers, such as the ability to use insurance

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for certain services outside of the school day, heavily contributes to the poor outcomes for individuals with ASD post-secondary school [3,4,8,11,12]. Moreover, while SSI training is well documented in peer review journals for individuals with high-functioning autism (HFA), Asperger's syndrome (AS), and younger preschool and elementary students, it is concerning that SSI is not well studied in adolescents with IDD or moderate to severe ASD.

The ability to communicate effectively and engage with others, whether it is with parents, teachers, therapists, or peers, is essential to an adolescent and adult with ASD self-esteem and self-worth. Poor social skills can frustrate and inhibit individuals with ASD from establishing meaningful relationships. Poor social skills can also create adverse behaviors that impact academic performance by being denied access to the general classroom or least restrictive environment. These concerns should be carefully studied and addressed. Moreover, the ability to maintain meaningful employment within the dynamic of high rates of unemployment and underemployment are challenges faced by adults with ASD. Parent perspectives about adolescents transitioning to adulthood are based on parent expectations. Anxiety, frustration, and social challenges for both the parent and child, and the aspirations of parents of highfunctioning adolescents with ASD to succeed create stress for parents, family members and caregivers.

Social skills deficits in communication-based skills, social cognitive executive functioning and adverse behaviors associated with the essential abilities necessary to participate in society have been associated as major challenges for adults with ASD in obtaining and maintaining employment. The lack of SSI during the school day may lead to the inability to eventually obtain employment, live independently, and increase mental health issues such as suicidal thoughts, depression, and prolonged anxiety as well as a decrease in life expectancy. The need for direct intervention for adults with ASD to develop social skills continues to be well documented in the literature.

RESEARCH QUESTION

This research addressed the following question to obtain a gauge of parents understanding of the importance of SSI:What is the parent perception of classroom engagement for students with ASD who participate in SSI?

Two sub-questions were asked,

- (a) To what extent do parents perceive the usefulness of SSI?
- (b) What are parent perceptions of SSI strategies that have enhanced engagement of their transitioning child?

RESEARCH METHOD AND DESIGN

The researcher conducted a mixed-methods sequential explanatory design in a two-phase process. A mixed-methods sequential explanatory design involves a two-phase method with phase one being the quantitative data and phase two being the qualitative data [13].

Quantitative and qualitative was collected from parents in the following order:

- Likert-scale demographics questionnaire.
- Do2Learn.com JobTIPS Part II Survey Tool.
- Adaptive Behavior Evaluation Scale Revised Second Edition: 13-18 Years (ABES-R3) Survey.
- Open-ended interview questions.

The quantitative data came from the JobTIPS Part II and ABES-R3 surveys with 131 participants in the JobTIPS Part II and the sample group of 27 participating in the ABES-R3 survey. The qualitative data came from the answer to this question from the interviews of 27 random participants from the first survey.

POPULATION AND SAMPLE

The participants in the study were predominantly white females. The largest group ranged greatest in the age group between 50 to 59 years old and 40 to 49 years. Most of the participants, 33.59% (n=44), stated they had earned at least a bachelor's degree, followed by 25.19% (n=33) with at least a graduate degree. Incomes of the 131 participants ranged from \$75,000 to over \$150,000 per year. Most of the transitioning children or adults were male, 106 (80.92%); females represented 25 (19.08%). The largest age group was transitioning young adults, 18 to 22, 64.88%, (n=85), followed by 23 to 27 years, 29.01%, (n=38), and a small minority, eight (6.11%) within the age group 28 to 32.

FINDINGS

Research question

What is the parent perception of classroom engagement for students with ASD who participate in SSI?

To understand if parents were aware of and understood social skills EBPs within the classroom, participants were given the option to select from a selected list of current social skills EBPs that are being used in public and private school systems today and rank them in order of preference as (1) Most Preferred (2) Less Highest (3) Average (4) Below Average (5) Less Preferred (6) Not Applicable.

The responses revealed that parents perceive Modeling as the most preferred social skills intervention that has enhanced the classroom engagement for their child followed by Visual Prompts, and thirdly Role-Playing Scenario ranked as average. The Video Tutorial was the less preferred method along with Social Stories. However, in contrast when asked which of the five forms of EBPs social skills instruction did not apply to classroom instruction, the 131 participants replied that Video Tutorial ranked less applicable in JobTIPS, followed by Role-Playing Scenario which ranked average. The research revealed thatthe responses were similar in both surveys and that the participants did understand SSI within the classroom of the selected social skills EBPs in the study.

SUB-QUESTIONS

What are the parent's perceptions of social skill strategies that have enhanced engagement of your transitioning or adult child?

The researcher asked this sub-question to the sample group after the participants completed the ABES-R3 question 103 of the survey which gave a detailed construct of what SSI is and the deficits and strengths that should be achieved from SSI instruction. The study found that most, 11 of 21, of the participants to this question did not respond with a proper answer and showed a lack of understanding of what social skill intervention strategies were available to their transitioning or adult child. However, parents who showed an understanding of the question after taking the ABES-R3 felt Peer Mentoring, which was not one of the EBPs listed, Role-Playing, and work programs were strategies that have enhanced the engagement of their transitioning child or adult.

The data concluded from the parent's responses that while 29.63% stated that SSI is helpful, there needed to be more qualifying questions asked of the participants such as the level of their child's disability (e.g., moderate, severe, high functioning), if there are other comorbidities, whether or not their child participated in SSI through an IEP or independently outside of the school day, and if parent-mediated instruction was offered by the school district or through a private SSI program and utilized.

What are parent perceptions of SSI strategies that have enhanced engagement of their transitioning child?

This sub-question, was asked to the 131 participants in the JobTIPS Part II survey and again as a follow-up open-ended interview question with the 27 participants in the ABES-R3 survey to determine if the sample group who participated in the first survey perceptions remained the same or changed from their response in question 47 of JobTips survey tool.In the first survey, JobTIPS Part II, 129 of the 131 participants responded with the possible responses of, (1) A great deal, (2) A lot, (3) A moderate amount,(4) A little, or (5) Not useful at all. Almost half, 48.84% (n=63), perceived social skills intervention useful (1) a great deal for their transitioning child or adult. Very few 3.88% (n=5) perceived social skills intervention to be not useful at all. Overall, the means suggest that social skills intervention is perceived as useful a great deal in nearly half of the participants who answered the question.

The qualitative data from this sub-question in JobTIPS Part II and later interview question with the sample group was used to refine the results of the quantitative data [14]. The results from the ABES-R3 sample group strongly supports the findings from the JobTIPS Part II survey; SSI is very useful/very important, and parents perceive its usefulness as a great deal/a lot and as a necessary component of their child's educational and functional development.

LIMITATIONS OF THE STUDY

One of the significant limitations of this mixed-methods explanatory sequential study was the small population size rendered from the total number of participants who initially participated. The first survey, JobTIPS Part II, was opened for a

short time, October 1, 2019, to October 15, 2019. Although the original request was for 75 to 100 participants, the survey rendered 279 participants. However, of the 279 parents who participated in the JobTIPS Part II survey, only 131 met the survey criteria of a parent of a transitioning or adult child with ASD between the ages of 18-28 and completed the entire survey. The other 148 participants were parents of adolescents, age 13-17 and many of them stated that they knew they did not qualify for the study but wanted to take the survey to either understand SSI or see if their adolescent child was on target socially in areas of future employment, and social communication.

The researcher concluded from the eagerness of parents of the 148 parents of adolescents who desired to participate in the study that there is a need for parents to understand their perceptions of classroom engagement of SSI or to learn more about the benefits of SSI instruction for their child with ASD.

Another potential limitation of the research was the participation in the second survey, which was randomly sent to approximately 33 (25%) of the 131 participants for a sample subset; 27 parents agreed to participate. Additionally, the study rendered a broad pool of participants from all over the United States. The researcher did not include a breakdown of geographical availability or ask if SSI was available to participate in within their region. The researcher did not ask if parent-mediated instruction was offered in the school the participant's child attended or what type of school (public, private, or institutional school setting) the child attended.

Other limitations to consider was whether the parents' understood the many areas of daily life skills and quality of life factors that SSI encompasses, and if the parents' hesitancy to state whether or not they understood the questions asked could be due to embarrassment or lack of exposure to the subject. Parents did not have full knowledge of the different forms of evidence- based SSI, and the researcher did not give definitions of the five social skills EBPs.

RECOMMENDATIONS FOR FUTURE STUDIES

Future possible studies might explore parents' perception of what SSI or combination of SSI has had the most effect on improving behavior, social communication, engagement, and work-related social cognition for transitioning and adult individuals with ASD. Another study might research the level of SSI provided in the school system, whether or not it is provided during the day by teachers, support staff, or therapists (e.g. speech, ABA) or taught to parents to support after school and community goals. The study attracted parents from the uppermiddle-class to higher socio-economic status. A future study is recommended comparing the SSI skills of individuals with ASD and their parent's perspectives from the lower end to the higher end of the socio-economic status to determine if economic factors attribute to better outcomes and possible contributing factors of those outcomes.

CONCLUSION

The findings from this study indicate a considerable need for the inclusion of EBPs social skills instruction from early intervention and throughout the lifespan of an individual with ASD. The findings reflect what previous studies have discovered that a vast majority of adolescents and young adults are not able to make the transition from high school and post-secondary programs successfully into the workforce.

One of the factors identified in this research but was not a part of this study is that socioeconomics had little effect on the deficits in social skills, cognition, and communication of the age group. Even among parents with financial means, the research revealed that either SSI was not available, the child continued to require on-going SSI or parents may not have had a clear understanding of SSI. Conversely, the theme of medical support consistently was identified as a barrier to SSI competence, which indicates that comorbidity could have contributed to some of the SSI deficits.

Moreover, by doing a mixed-methods sequential explanatory design, the researcher was able to identify through the quantitative data, JobTIPS Part II what social skills employers require for a successful transition into the workforce for individuals with ASD. The qualitative data, ABES-R3 mirrored the social skills required in JobTIPS for quality of life for individuals with ASD. Moreover, the ABES-R3 provided a detailed breakdown of each area of social development that can transcend into an intensive SSI curriculum for transitioning adolescents 13 to 18 years.

While this study focused on the transitioning adolescent and young adults age 18 to 28, both the quantitative and qualitative research revealed that the targeted age group was still not able to perform the social skills necessary for employment and independence because they did not possess the social skills described in the ABES-R3 that identifies the skills necessary for 13 to 18 years. It is recommended that SSI become standard practice from early intervention through the transition program in school districts nationally. It is further recommended that parent-mediated instruction be supported to provide a cost-effective means for establishing successful outcomes that will lead to an enhanced quality of life for individuals with ASD.

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