


A Toolkit to Measure Success: Assessing the Impact of Learning Activities for Social Skills and Parent's Group for Perceived Social Support

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We have no known conflicts of interest to disclose

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Abstract

Objective: This quality improvement (QI) program provided staff implementing a non-profit organization's intervention program to enhance social skills with resources needed to measure the impact the program has on participants who are neurodiverse. This QI project also provided staff implementing the parent's support group for caregivers of those who are neurodiverse, resources needed to measure changes in perceived social support of the caregivers after 12 weeks. These resources include the Social Emotional Assets and Resilience Scale and the Multidimensional Scale of Perceived Social Support and will be provided to the organization as a toolkit used to test reliability and validity of the intervention programs offered. **Design:** A repeated measures quality improvement project. **Setting:** A small non-profit organization in an urban area of North Carolina. **Measurements:** Surveys were electronically mailed to 27 new participants and their caregivers before starting the programs and after 12 weeks of participation. **Results:** The organization received the toolkit with resources needed to measure the effectiveness of their offered programs. Though the organization planned to utilize these resources, the surveys were not sent or returned in a timely manner and therefore no data was able to be analyzed. **Conclusions:** Although the current project was unsuccessful, the organization has been provided with the necessary tools and resources to be able to positively impact the neurodiverse populations. Future research should attempt to analyze the effects of the organization's intervention programs on social skills of individuals who are neurodiverse and perceived social support of caregivers of those who are neurodiverse.

Keywords: neurodiverse, caregivers of those who are neurodiverse, social skills, social support, perceived social support, toolkit

A Toolkit to Measure Success: Assessing the Impact of the I-Can Program on Social Skills and Perceived Social Support

Neurodiverse is a term used to describe the variations in brain function of certain individuals that may be considered different from those whom society considers normal (Baron-Cohen, 2017). Individuals who are neurodiverse are usually labeled with disabilities such as attention deficit hyperactivity disorder, autism, dyslexia, or social anxiety disorder and typically present with social deficits. (Baron-Cohen, 2017; Masataka, 2017). Overall prevalence of individuals who are neurodiverse are separated by diagnosis with ADHD at 10.5%, autism 19.2%, dyslexia 15%, and dyspraxia and like disorders at 10% (CDC, 2021; Gibbs, et al., 2007; International Dyslexia Association, 2016). These difficulties can lead to further issues such as increased levels of anxiety and depression for individuals who are neurodiverse with social deficits (Johnston & Iarocci, 2017).

Although there is research showing training can improve social skills for individuals who are neurodiverse, there is a need to properly implement such programs and skills (Wisner-Carlson et al., 2020). After implementing social skills training for children and adolescents with ASD, Choque-Olsson et al. (2017) concluded after modest and inconsistent findings in social skills improvement that more research is needed to find effective instruction to optimize outcomes for the participants who are neurodiverse. Social skills may be taught by incorporating evidence-based practices into a curriculum designed with activities and criteria specifically customized to the learning-based needs (Decker et al., 2016).

Adequate social skills are an important component for integrating individuals who are neurodiverse into a society designed to fit the needs of individuals who are neurotypical. An increase in social and behavioral skills can improve quality of life for individuals who are

neurodiverse (Ali et al., 2021). Social skills training in young adults with autism shows increases in social functioning and confidence, psychological wellness, and a decrease in anxiety and depression (Connor et al., 2019). Instruction using current evidence-based practices within principles of applied behavior analysis if properly implemented using demonstration, practice, and visual representation has been shown to result in desired social skills (Ng et al., 2016).

Literature Review

Neurodiversity

In a society designed specifically for the inclusion of individuals who are neurotypical, individuals who are neurodiverse struggle with social cues, implications, and adaptive behavior struggle to effectively communicate and form relationships (Chan & Leung, 2022).

Consequently, these struggles can promote increased anxiety and depression among this population (Robertson, 2009). Social deficits of individuals who are neurodiverse negatively impact developing relationships with peers, social communication, and classroom performance (O'Handley et al., 2016).

Focusing on teaching social skills to children who are neurodiverse and those who have intellectual disabilities generates newly acquired social skills, maintains targeted social skills, and generalizes said social skills (Ng et al., 2016). One small study ($n = 3$) trained adolescents with autism using three specific social skills: ability to express their needs, conversation and taking turns. The participants showed measurable improvement during the training period and reported positive results from the participant's teachers in general (O'Handley, et. al., 2016). Programs based on social cognitive interventions have resulted in parent reported positive changes in the behavior of individuals who are neurodiverse after just ten weeks, leading to an improvement in social participation at home, school, and in the community as well as more

advanced social interaction skills among parents and family members (Cheung et al., 2020). Hood et al. (2017) found teaching basic greeting and conversation skills to learners with autism resulted in generalization, maintenance, and treatment extension of the learned material. Participants' attempts to further their learned skills were discovered, indicating increased opportunities to extend their social skills to more complex social interactions. Long-term benefits of training programs may exceed those of other treatments (DuPaul et al., 2019). Training programs usually focus on specific skills, implementation, and frequent performance feedback. (Evans et al., 2016).

Social Support for Caregivers of Individuals who are Neurodiverse

Neurodiversity not only affects the lives of those living with it, but also impacts the lives of family and caregivers. For some caregivers, the responsibility of caring for an individual who is neurodiverse is a lifelong responsibility (Marsack-Topolewski, 2019). Caregivers of individuals who are neurodiverse have increased levels of stress, decreased mental health, decreased physiological health, and overall lower quality of life (Ault et al., 2021; Kuru & Piyal, 2018; Lovell et al., 2012; Pratesi et al., 2021). Lifestyles of caregivers of individuals who are neurodiverse often lack in self-care, leisure, and socialization outside of the family setting. The demands of caring for an individual who is neurodiverse can completely overwhelm every aspect of daily life (Pratesi et al., 2021).

Often, these caregivers have lower levels of social support than those who care for individuals who are neurotypical (Kuru & Piyal, 2018). Some of these caregivers of individuals who are neurodiverse never receive social support (Kuru & Piyal, 2018). Social support can positively impact the quality of life, mental health, and well-being of these caregivers. In fact,

there have been studies showing that social support is one of the most important predictors of quality of life within this population (Kuru & Piyal, 2018).

Social Emotional Assets and Resilience Scale (SEARS)

The Social Emotional Assets and Resilience Scale (SEARS) is a tool designed to measure social and emotional strength in self-regulation, empathy, responsibility, and social competence in individuals aged 5- 20 (Klages et al., 2021). Originally a tool developed within the school system, SEARS is diverse and can be used with many at risk populations, including those who are neurodiverse. Furthermore, the SEARS has been highly correlated with other evidence-based scales such as the Social Skills Rating Scale (SSRS) and the Behavioral Assessment System for Children Second Edition (BASC-2) (Klages et al.,). SEARS, including the short forms, display valid psychometric properties and can be used to monitor progress with high sensitivity to change due to its focus on specific behaviors (Nese et al., 2012). There are two self-reported SEARS, one parent reported SEARS, and one teacher reported SEARS which are all similar in content. SEARS comes in long and short versions of all four scales, all of which are reliable and valid (Klages et al., 2021).

Multidimensional Scale of Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) is a 12-item self-reporting scale that is used to measure perceived social support of family, friends, and significant others. This seven-point scale ranges from “very strongly disagree” to “very strongly agree” and is scored based on the sum of all items. It is considered psychometrically sound and has exhibited good internal reliability in a broad variety of populations (Zimet et al., 1990). The scale has been reliably used as valid measurement tool for perceived social support over 30 years.

Purpose

This quality improvement project was created to help implement a positive system change for an organization that designs programs and activities aimed at improving the lives of individuals who are neurodiverse and their caregivers. The organization lacked evidence of effectiveness for programs offered to clients, therefore a toolkit was created to provide clients and caregivers with the resources needed to initiate and continue measures of effectiveness of programs offered by the organization. Creating a toolkit for the organization has provide them with the resources needed to initiate and continue to measure the effectiveness of the interventions they offer. This toolkit included the SEARS-P short, SEARS-T short, and MSPSS scale.

Methods

Intervention

This quality improvement project was implemented in an urban setting in North Carolina over a three-month period using the toolkit provided to the organization. Delivery of the toolkit provided staff of the organization instruments for initial measures of the effectiveness of the intervention programs offered for individuals who are neurodiverse and their caregivers.

A Non-profit Organization© Intervention Programs

Located in an urban area of North Carolina, there is a small, non-profit organization that implements two important programs created specifically for individuals who are neurodiverse. The first program was designed using learning activities and games that mimic real-life interactions and situations. These activities aim to improve the social skills of participants who are neurodiverse through guided interactions with staff members and peers. The second program is a parent's support group which was created for the caregivers of those who are neurodiverse. During the support group meetings, caregivers discuss questions, concerns, and topics pertaining

to caring for individuals who are neurodiverse. Discussions can focus on many different topics including meltdowns, gender identities, or employment.

Participants

The primary Investigator (PI) was introduced to the organization's staff through the stakeholder. The PI, stakeholder, and several staff members had in person meetings when first developing the plan for the QI project. All meetings in the last year were virtual due to COVID-19 concerns for safety. This sample population consisted of the founder of the organization (a registered nurse), a social worker, and a program coordinator. All staff members were directly involved in working with the individuals who are neurodiverse, and their caregivers enrolled in the organization's interventional programs.

Procedures

Implementation of this quality improvement project began with a virtual educational meeting describing the purpose of the toolkit and how to use it. The target population for this project was the staff of the organization working directly with the individuals participating in the organization's interventional programs. Staff members were mailed several copies of each of the resources provided in the toolkit. The principal investigator (PI) then provided staff education on how to utilize each resource included in the toolkit. To do this, the PI verbally and visually exemplified how to score all three of the surveys being utilized. Data was to be collected for new participants before the initiation of participation in the organization's interventional programs and then again after twelve-weeks. These surveys were sent to 27 new program participants and were to be returned to the organization's staff via email. However, program participants did not respond to the surveys in a timely manner to be able to collect data.

A post-intervention survey was sent to the sample population of staff member involved in the QI project. The survey consisted of four open-ended questions (See Table 1) designed to qualitatively measure the perceived impact the success of this project may have had on the current organization and its programs, the future of the organization, and the participants in the programs of the organization.

Outcome and Measures

Instruments

The staff implementing the organization's interventional programs who were working directly with participants who are neurodiverse were provided with a toolkit that allowed them to assess the effectiveness of the program on enhancing social skills. The toolkit provided instruments that acted as resources for the organization to be able to measure the effectiveness of two of their interventional programs. These instruments, the SEARS and the MSPSS scale, were to be completed by participants of these programs before starting and again after twelve weeks of participation. The PI providing the toolkit also provided instruction on how to score completed surveys. Once data collection was complete, the PI was to instruct the staff to utilize the program Intellectus™ Statistics to calculate each set of surveys using a paired sample t-test. Project data was to be managed and organized by both the staff at the organization and the PI. Surveys were to be completed electronically and sent and returned via email.

Resources Provided in the Toolkit

The SEARS- P and MSPSS scale are meant to be scored by the staff of the organization after they were completed by program participants. The SEARS-P is also scored reflecting a total score with four subcategories of cooperation, assertion, empathy, and self-control. MSPSS is calculated as three sub scores of friends, family, and significant other.

The SEARS required a “B” qualification level to obtain through Psychological Assessment Resources. This required that the PI hold a degree from an accredited four - year university in psychology or a related field as well as completion of coursework that included statistics. The SEARS materials were then mailed to the PI, who included them in the toolkit provided to the organization. All members in the sample population met the requirements of a “B” qualification level.

The MSPSS survey is a free measurement tool available to all individuals online and was downloaded and printed to include as a resource in the toolkit provided to the staff of the organization.

Distribution of Resources in the Toolkit

The toolkit was sent to staff through mail services. The resources provided in the toolkit were then scanned and electronically sent through the organization’s secure email system to 27 new participants who have been involved in interventional programs as of February 2022. Staff at the organization were interviewed to discuss methods of compliance in securely handling materials delivered to and from program participants.

Data Analysis

Data analysis was to be performed both qualitatively and quantitatively. Qualitative measures were to be taken through completion of the surveys within the toolkit. A simple paired sample t-test was to be used to quantitatively analyze and determine the significance between the scores of the paired samples. Comparing participants’ before and after scores at the end of the twelve-week period was to be performed using a simple paired sample t-test through the program Intellectus™ Statistics. Both SEARS and MSPSS scale surveys were to be measured and analyzed using this test.

Ethical Considerations

This quality improvement project was reviewed and approved by the Lenoir-Rhyne University Institutional Review Board (IRB) and classified as exempt. Participation in the project was voluntary and participants had the right to freely withdrawal at any time. The contact information for the PI, Lenoir-Rhyne IRB, and faculty advisors were made available to the participants of the project in case of question or concerns. All data obtained during the quality improvement project was kept confidential. The project followed the guidelines of the Health Insurance Portability and Accountability Act (HIPPA). All collected data was stored using the secure program Intellectus™ Statistics. Data will be securely stored for five years and then destroyed. There was no funding for this project. The use of the toolkit was a system change for this facility. The comprehensive curriculum and training materials will be retained by the facility for use in the future.

Results

Results would have ideally determined the impact of the organization's social skills program for participants who are neurodiverse and of the perceived social support of caregivers of individuals who are neurodiverse involved in the programs. Due to unforeseen circumstances, statistical tests reflecting changes between the before and after surveys could not be performed. There was a 0% return rate on the 27 surveys sent to new program participants, resulting in an inability to calculate any potential impact of the interventional programs. The post-intervention survey resulted in zero responses from the sample population and therefore remains inconclusive.

Discussion

The goal of this quality improvement project was to provide a toolkit including resources to measure the effectiveness of programs offered by a non-profit organization to enhance social skills of those who are neurodiverse and perceived social support of their caregivers. While the organization was provided with the toolkit, there has been no initial data collection, measures, or analysis due to both time constraints and inconsistencies with survey completion. Unfortunately, there were several obstacles that prevented the timeliness of the distribution of surveys. First, due to COVID-19 the social skills program and parent's groups, which were designed to be implemented in-person, had to be adjusted to promote safety precautions for all participating individuals. This required staff to execute the program's learning and group activities virtually. The organization prioritized this adaption, and the QI project was put on hold for over a year. Second, data collection was unsuccessful, as there were no responses provided from the distributed surveys. Although the current QI project has been unsuccessful, the toolkit provided continues to be available for utilization of the staff in the organization, to increase the likelihood that data may be collected in the future.

Increased consistency in the timing of survey completion should be addressed upon initial addition of program participants. For example, when new participants register for either program, the initial survey can be included in the registration process.

Limitations

This quality improvement project has limitations to be addressed. First, the sample size was small at $n=3$. Second, the surveys were not completed within the allotted time for the project, and therefore no data was able to be analyzed. Positive qualitative feedback about the organization and its intervention programs were verbalized by current participants in the program but were not validated through any evidence-based foundations.

Like many other organizations, universal safety measures implemented for COVID-19 put a halt on normal company routines and production (Goswami et al., 2021). Unfortunately, the QI project was put on hold for over a year by the organization in consideration of the safety of its participants. Although staff was still dedicated to providing services during this time of need, the mechanism of providing these services was initially unknown. Creating an entire virtual platform while still capturing the core concepts of the in-person learning activities to provide the best services for participants took longer than expected. Furthermore, the organization suffered losses during the pandemic as well ultimately having to relocate to a smaller facility to cover the financial responsibilities of continuing the programs. Currently, the programs are returning to their pre-COVID structures, opening doors of possibility for continuation of future positive system changes.

Future Directions

Future research should attempt to analyze the effects of the organization's intervention programs on social skills of individuals who are neurodiverse and perceived social support of caregivers of those who are neurodiverse. Further research may indicate the need for two separate studies for social skills and perceive social support.

Conclusions

Project implementation may not always yield desired results in an ideal amount of time. Obstacles are consistent during practice and should be expected. Future findings from this quality improvement project have the potential to positively impact the lives of individuals who are neurodiverse and their caregivers. Although currently the project is unsuccessful, the organization has been provided with the necessary tools and resources to be able to positively impact the neurodiverse populations.

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Table 1*Post-intervention Survey*

1. How do you believe the results obtained from this project will impact the participants of the programs?
2. How do you expect the project to impact the organization's current programs?
3. How will this project impact the future of the organization?
4. How will this project impact the staff of the organization?