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BRIEF REPORT

Short Report on Effectiveness of an Autistic-Delivered Peer Support Program: Preliminary Results

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Abstract
There is little research on the effectiveness of autistic peer-delivered services. This study examines early outcomes associated with the Community Autism Peer Specialist program (CAPS), which was created in partnership with autistic individuals and is delivered by autistic adults who have received training in the delivery of peer support services to enhance the community functioning of autistic youth and adults. A single group pre-test/post-test design was used to examine early outcomes in the areas of independent living needs, social functioning, service engagement, and quality of life. A total of 23 individuals with autism aged 14–41 years were included in the study. Reductions were found in social functioning impairments and unmet needs after three months in the program. Participants also reported greater engagement in mental health services and activities that promote wellness compared with before the program. This study suggests that peer support services delivered by autistic peers may be an effective intervention approach for autistic youth and adults. Future studies with a more rigorous study design (e.g., randomized controlled trials), a larger sample size, and longer-term outcome measurements are needed to further investigate the effectiveness of CAPS and similar autistic-delivered services.

Keywords Autism · Peer-delivered services · Community-based program · Effectiveness · Adults

Introduction

There is a need for more services that promote community functioning among autistic youth and adults (Cameron et al., 2021; Song et al., 2022; Sosnowy et al., 2018). Peer support services are one promising approach that is already Medicaid-reimbursable in more than 80% of U.S. states for people with mental illnesses such as schizophrenia, bipolar disorder, and depression (Open Minds, 2018). Similar funding is not yet available for peer support among autistic adults, and the peer support services that have been developed for autistic people nearly always involve services delivered by non-autistic rather than autistic peers in secondary educational settings (e.g., Ashbaugh et al., 2017; Gillespie-Lynch et al., 2017; Thompson-Hodgetts et al., 2020). Peer support delivered by autistic peers may be especially impactful as autistic peers have fewer stigmatizing beliefs and attitudes about autism than non-autistic people (Bertilsdotter-Rosqvist, 2019; Gillespie-Lynch et al., 2017), and non-autistic supporters (e.g., non-autistic peers, family, service staff) may be more inclined to overly assist autistic individuals, limiting their ability to develop new skills and learn from their own mistakes (i.e., the dignity of risk) (Deegan, 1996; Marsh & Kelly, 2018). Autistic adults express preferences for interacting with other autistic adults rather than typically developing peers (Crompton, Hallett et al., 2020; Morrison et al., 2020) and are more interested in participating in autistic-led programs (Crane et al., 2021). Previous studies have found that autistic people can develop close bonds, demonstrate empathy, and have less stressful communication with other autistic people compared to non-autistic people (Crompton, Hallett et al., 2020; Morrison et al., 2020). Moreover, autistic people can effectively communicate information to their autistic peers (Crompton, Ropar et al., 2020).

Only one study has been found that describes the outcomes of an autistic-delivered peer support program that helped autistic adults learn about their condition (Crane et

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al., 2021). Participants in Crane et al. (2021) ‘s study appreciated that the program was delivered by autistic peers and reported having a more positive outlook on their lives and more awareness about what impacts them because of their involvement in the program. This study expands knowledge about autistic-delivered peer support by examining the effectiveness of an autistic-delivered peer support intervention called the Community Autism Peer Specialists (CAPS) program. This program seeks to enhance independent living and community functioning among autistic youth and adults. CAPS initiative is particularly important because it was developed in partnership with autistic individuals and was recently approved for Medicaid reimbursement. A study has demonstrated the feasibility and acceptability of the CAPS program for transition-age youth and adults (Shea et al., 2022). The present study builds upon this foundation by aiming to assess the preliminary effectiveness of the CAPS program. This evaluation will provide valuable insights into the practical application of such peer support initiatives for autistic individuals.

Methods

Intervention

The CAPS program is an autistic-led one-to-one peer support intervention designed to promote community living for autistic youth and adults. Those working as peers in the program were at least 18 years old, had a high school education or more, were participating in their community (e.g., going to school, working, maintaining social and family relationships), and participated in a novel 75-hour training that addressed listening skills and provision of peer support, building self-knowledge, advocacy skills, goal setting for an array of life domains such as school life, relationships, home life, community services, working and volunteering.

The CAPS program has been described in more detail elsewhere (Shea et al., 2022) but generally involves supporting participants in identifying their goals (e.g., jobs, relationships, services, or transportation) and then assisting them in developing objectives to meet their goals and a realistic time frame for doing so. Peer specialists provide encouragement and information, promote problem-solving and skills development, including interpersonal skills, and introduce participants to additional resources and services that might assist them in achieving their goals. The autistic peer specialist and participant typically meet at least once per week for up to a few hours in the participant’s home, community, or agency.

Procedure

Program participants were recruited through advocacy, services, and policy networks in the city of Philadelphia, Pennsylvania. Service providers that serve autistic individuals were made aware of the availability of the CAPS services through direct outreach. Enrollment in the CAPS program required a referral from a licensed healthcare professional, participants needed to be 14 years old or older, have a formal autism diagnosis, be eligible for Medicaid, and be a resident of Philadelphia. For those that met the criteria, the CAPS program leadership reviewed an intake evaluation form and paired the interested individual with a peer specialist based on their availability, shared interests, and preferences (e.g., gender, meeting locations, and transportation options).

This study was approved by the City of Philadelphia Department of Public Health Institutional Review Board (Assurance Identification No. FWA00003616). This study was conducted as part of a program evaluation, which fell under the category of quality improvement initiatives intended to monitor and improve the CAPS services, and thus did not require individual participant consent. Members of the Steering Committee established a set of measures. Measures were compiled into an online survey tool – REDCap. Participants received a survey link and completed a baseline assessment prior to initiation of services and then a 3-month follow-up assessment.

Participants

Twenty-nine individuals participated in the CAPS program and completed an initial assessment between September 2019 and January 2021. Given that this is a pre-post-intervention study, completing both baseline and 3-month assessments was crucial for valid comparison. Thus, 23 participants who completed assessments were included in the analysis. Table 1 displays sample characteristics. The age of the sample ranged between 14 and 41 years old, with a mean of 20.57 years (SD = 6.47). There were 83% males and 17% females. About 44% of participants identified themselves as non-Hispanic Black (n = 10), 39% as non-Hispanic White (n = 9), and 17% as Hispanic/Latino (n = 4). In terms of mental health conditions, 22% of the sample (n = 5) had anxiety, and 13% (n = 3) had depression. Two (9.1%) participants visited an emergency room, hospital, or crisis center for mental health, psychiatric, or emotional health in the last 12 months. One participant reported a diagnosis of intellectual disability.

Table 1 Baseline demographic characteristics of participants receiving the community autism specialist (CAPS) service (N = 23)

Variables	*n (%)*
Gender	
Male	19 (82.6)
Female	4 (17.4)
Other	0 (0.0)
Race and Ethnicity	
Black	10 (43.5)
white	9 (39.1)
Hispanic	4 (17.4)
Age	
Average Age (SD)	20.57
Age Range	(6.47)
	14 to 41
Mental Health Diagnoses	
Attention Deficit Hyperactivity Disorder	4 (17.4)
Depression	3 (13.0)
Anxiety	5 (21.7)
Posttraumatic Stress Disorder	2 (8.7)
Bipolar	0 (0.0)
Any mental health diagnosis	8 (34.7)
Intellectual Disability	1 (4.3)
Average number of visits to an emergency room, hospital, or crisis center for mental health, psychiatric, or emotional help in the past 12 months.	0.23 (0.87)
Number of peers who visited an emergency room, hospital, or crisis center for mental health, psychiatric, or emotional help in the last 12 months.	2 (9.1)

Measures

The following measures were used to assess the preliminary effectiveness of the CAPS program. First, to assess the changes in social functioning and skills, we used Social Responsiveness Scale 2nd edition. Second, we used the Camberwell Assessment of Needs to examine if the CAPS program helped participants meet desired needs in their daily lives. Third, we asked about the utilization of other services during the 3-month intervention to examine if the program promoted participants' engagement in other services.

Social Functioning

The widely used Social Responsiveness Scale 2nd edition (SRS-2) Adult Self Report (65 items) was used in this study to assess changes in social awareness, social cognition, social communication, social motivation, and restricted interests and repetitive behavior. T-scores are used to categorize individuals as follows: ≥76 suggests severe impairments, 66–75 is considered moderate, 60–65 is mild, and ≤59 or below is in the normal range (Bruni, 2014).

Needs Assessment

A modified version of the Camberwell Assessment of Need (CAN; Phelan et al., 1995) was used to identify unmet needs in 23 areas, such as housing, daytime activities, mental health care needs, social life, education, and employment. Some items on the original CAN were modified to better capture the specific needs of autistic individuals, such as autism information and treatment. A "Desired Need" was determined as an area where the individual reported a need and desired assistance with addressing that need in the next year. The total number of desired needs was calculated for every one (0–23).

Engagement in Other Services

Seven items were used to measure engagement in other services (e.g., mental health services), including (1) "I miss fewer appointments with other mental health service providers (for example, psychiatrist, case manager, etc.);" (2) "If applicable, I take medications more regularly;" (3) "I feel more engaged in mental health wellness;" (4) "I feel more motivated to engage in activities that promote wellness;" (5) "I develop a better relationship with my treatment team;" (6) "I feel more in control of my wellness;" (7) "I feel more supported in wellness." Responded answered "yes" or "no" to each item.

Quality of Life

One item from Lehman's (1988) Quality of Life Interview to measure the overall quality of life: "How do you feel about your life in general?". The responses were based on a 7-point Likert-like scale (1 = Terrible to 7 = Delighted).

Analytic Methods

Descriptive statistics were examined for demographic and outcome variables. Due to the small sample size, nonparametric tests were used to test changes in outcomes of interest between the baseline and 3-month follow-up assessments. The Wilcoxon test was used to examine the differences in SRS total scores and domains, the total number of desired needs, and the general quality of life indicator. The McNamar test was used to examine the changes in indicating needs in individual areas. All statistical analyses were conducted using SPSS 26.

Table 2 Results of SRS-2 (N = 19)

	BASELINE		3 MONTHS		
SRS range based on T-score	n	%	n	%	
Within normal limits	2	10.5	7	36.8	
Mild range	4	21.1	3	15.8	
Moderate range	9	47.4	8	42.1	
Severe range	4	21.1	1	5.3	
	M	SD	M	SD	Wilcoxon test (p value)
Total SRS score	95.16	24.73	78.00	30.81	-3.33 (< 0.001)
SRS subscales					
Social awareness	10.42	3.13	11.21	2.10	-0.92 (0.360)
Social cognition	16.89	5.46	12.95	5.71	-2.93 (0.003)
Social communication	31.95	9.59	26.16	10.48	-2.77 (0.006)
Social motivation	17.42	5.35	13.63	6.86	-2.42 (0.016)
Restricted interests and repetitive behavior	18.47	7.37	14.05	9.60	-3.07 (0.002)

Results

Social Functioning

A total of 19 participants completed both baseline and 3-month follow-up SRS-2. Results in Table 2 showed decreased total SRS scores, indicating reduced impairments in social functioning on the SRS between baseline and the 3-month follow-up (95.16 vs. 78.00, z=-3.33, p < 0.001). Regarding severity, 10 out of 19 participants moved to a lower severity range. Specifically, four participants fell into the severe range at the baseline, and three moved to the moderate range at the 3-month follow-up assessment. Among nine participants in the moderate range at the baseline, three moved to the normal range, and two moved to the mild range. Two participants in the mild range at the baseline also moved to the normal range at the 3-month. Significant decreases were observed in four out of five domains: social cognition (z=-2.93, p = 0.003), social communication (z=-2.77, p = 0.006), social motivation (z=-2.42, p = 0.016), and restricted interests and repetitive behavior (z=-30.07, p = 0.002).

Needs Assessment

A total of 23 participants completed both baseline and 3-month follow-up Camberwell Needs Assessment (Table 3). The results showed that the total number of desired needs (ranging between 0 and 23) decreased from baseline to the 3-month timepoint (9.35 vs. 5.57; z=-2.89, p = 0.004). When examining individual need area, participants were less likely to report desired needs in autism spectrum disorder treatment (60.9% vs. 21.7%; p = 0.004), psychological distress (65.2% vs. 39.1%; p = 0.031), social life (87.0% vs. 47.8%; p = 0.012), and benefits and entitlements (56.5% vs. 17.4%; p = 0.035). There were no significant differences in other needs areas.

Table 3 The changes desired needs (N = 23)

	Baseline		3 Month Follow Up		McNemar test p value
	N	%	N	%	
Housing	3	13.00%	2	8.70%	1.000
Food	3	13.00%	3	13.00%	1.000
Taking care of your home	4	17.40%	6	26.10%	0.727
Keeping clean and well groomed	10	43.50%	4	17.40%	0.109
Daytime activities	13	56.50%	10	43.50%	0.453
Physical health care need	0	0.00%	2	8.70%	0.500
Mental health care needs	4	17.40%	2	8.70%	0.687
Autism spectrum disorder & treatment	14	60.90%	5	21.70%	0.004
Psychological distress	15	65.20%	9	39.10%	0.031
Social life	20	87.00%	11	47.80%	0.012
Intimate relationships	11	47.80%	7	30.40%	0.289
Sexual expression	7	30.40%	2	8.70%	0.063
Education	11	47.80%	6	26.10%	0.180
Telephone communication	10	43.50%	5	21.70%	0.180
Transportation needs	14	60.90%	10	43.50%	0.289
Financial needs	12	52.20%	8	34.80%	0.344
Benefits and entitlements	13	56.50%	4	17.40%	0.035
Relationship with parents and/or siblings	8	34.80%	2	8.70%	0.070
Physical activity and exercise	15	65.20%	10	43.50%	0.125
Religious or spiritual life	1	4.30%	2	8.70%	1.000
Voting, volunteering, or other civic engagement	9	39.10%	4	17.40%	0.227
Employment	10	43.50%	10	43.50%	1.000
Legal rights and advocacy	8	34.80%	4	17.40%	0.289
	M	SD	M	SD	Wilcoxon test
Total number of needs	9.35	4.15	5.57	4.74	0.004

Engagement in Other Services

Most of the respondents who completed this measure (N = 19) reported being better supported in their overall wellness (n = 16, 84%), more engaged in mental health wellness (n = 15, 79%), more in control of one's wellness (n = 15, 79%), higher motivation to engage in activities that promote wellness over time (n = 14, 74%), and a better relationship with treatment teams (n = 13, 68%). Among those who used medication (n = 11), more than half (n = 6, 55%) reported taking their medications more regularly. About 42% (n = 8) of participants reported missing fewer appointments with other mental health service providers.

Quality of Life

No differences over time were found in the quality of life (M = 4.27 ± 1.55 vs. M = 4.14 ± 1.61, z=-0.44, p = 0.662).

Discussion

This study found that autistic youth and adults who participated in an autistic-delivered peer support program aimed at enhancing independence and community functioning experienced positive impacts in a relatively short period of time (i.e., 3 months). Participants were generally in the moderate and severe range of social impairments at baseline, with 10 (43%) participants moving to a lower severity category. Participants also reported fewer needs over time and more engagement in services.

The CAPS program focuses on all of these areas. One of the priorities is the opportunities for social interactions with other autistic individuals and peers. This emphasis fosters a supportive environment for the development of interpersonal skills, which could assist participants in understanding and interacting effectively with their friends and family members. By facilitating better communication and mutual understanding, the program empowers participants to enhance their social functioning. Moreover, peer specialists assist participants in identifying emotional triggers and learning alternative strategies for responding to them. Peer supporters also work with participants to identify and address their own needs, which likely explains the reduction in needs seen over a very short period of time. Addressing needs often included helping participants effectively utilize services that promote wellness. This likely explains the self-reported increases in engagement in mental health and other services, improved relationships with providers, and resulting in enhanced overall wellness. No significant changes were found in quality of life; however, we might expect little change given the short timeframe (i.e., 3 months). Previous intervention studies with autistic adults (e.g., leisure program intervention; Cognitive Behavioral Therapy) showed significant improvement in quality of life only after 8–12 months of the intervention (e.g., Ayres et al., 2018).

The development of CAPS as a Medicaid-funded autistic-delivered peer support program (Shea et al., 2022), including a novel training curriculum, combined with these promising results, raises awareness of a relatively new type of service that could enhance the independent living and community functioning of autistic adults. Autistic-delivered peer support may be more sensitive to the needs of autistic adults and more likely to promote self-determination in achieving their goals.

This study lays the foundation for future efforts to generate an evidence base that would further expand peer programs as a Medicaid-reimbursed service. Further expansion of the CAPS program in Pennsylvania and other states requires further development of the program and evidence base (e.g., randomized controlled trials).

Study Limitations

While the results are promising, this is a small-scale study with clear limitations. There was no control group to help address potential threats to internal validity. The sample size was small, although we were still able to detect some statistically significant effects. We also only examined outcomes at 3 months post-baseline. For some parameters, such as quality of life, significant alterations may not be evident within this relatively short timeframe. Moreover, there is a need to see whether outcomes are sustainable. Future research with larger sample sizes and over a longer duration is recommended to corroborate the findings. Finally, this study partially occurred during the early days of the COVID-19 pandemic, and several individuals received virtual support instead of the intended in-person support. Also, the peer specialists needed to learn how to provide service virtually. This may have impacted the outcomes in unmeasurable ways. Future research on the in-person delivery of the program would provide information about its impact during more typical times.

Conclusion

Due to the lack of service options for autistic youth and adults, innovative interventions are needed to support this population. This study is one of the first to investigate the effectiveness of a peer-support program delivered by autistic individuals using a quantitative approach. Preliminary results showed that the CAPS program could benefit autistic individuals with a wide range of needs. Future research is needed on such interventions, but overall, autistic-delivered peer support services are feasible, potentially beneficial, and worthy of exploration in terms of future funding and implementation to enhance the continuum of care, especially to expand services aimed at promoting independence and community functioning.

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Declarations

Conflicts of Interest The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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