

Bal & Kleiman

Research Summary, June 2022

Background

Autistic adults are at high risk for depression, anxiety, and other mood dysregulation. Autistic students in postsecondary education (PSE) also report increased depression, anxiety, marginalization, and social isolation. PSE may be a particularly stressful period, as autistic adults must navigate an ever-changing situational demands (e.g., varied class expectations, unpredictable social situations, overstimulating environments). Emotion regulation difficulties may make it hard for many autistic adults to cope with such stressors, leaving them vulnerable to prolonged periods of distress, which can negatively impact their academic performance and quality of life.

Considering the importance of psychological wellbeing in supporting successful completion of PSE, research suggests a clear need to build multifaceted approaches to support autistic students during PSE. Many universities have programs to support autistic students' transition to PSE and ongoing academic success. Such programs may also have mental health benefits for some students. These programs; however, are often time-intensive (several hours weekly across the course of a semester) and require active participation by the student (counseling sessions, online content and community-based outings) that may be difficult to fit into busy student schedules. Intensive programs also require more experienced clinicians or supervision by a clinician with autism expertise. Length and expertise therefore limit scalability of such programs, making them difficult for autistic adults to access.

The Emotional Support Plan (ESP) is a brief, telehealth-delivered intervention designed to help students anticipate stressful situations and proactively equip them with strategies to regulate negative emotions and promote awareness of different types of supports to mitigate distress. The ESP also includes contact information for social and professional supports, with the expectation that making resources known and contact information accessible, the ESP may also promote more timely access to psychological services if they are needed.

Led by Rutgers University researchers, Vanessa H. Bal, Karmazin & Lillard Chair in Adult Autism and Associate Professor and Evan Kleiman, Assistant Professor, the objectives of this study were to:

- 1: Identify mental health needs of autistic students to inform supports.
- 2: Develop resources to inform and guide mental health care of autistic students.
- 3: Pilot methods to create ESPs for autistic students.

Methodology

Objective 1.

We conducted focus groups with 6 autistic students in PSE and 4 parents/caregivers to understand the mental health needs of autistic college students and inform adaptation of resources in Objectives 2 and 3. Participants provided information about their knowledge of on-campus and general mental health resources for PSE students and asked questions about stressors in PSE and experiences with mental health supports.

Objective 3.

Recruitment. Information was disseminated directly to students in academic support programs for autistic students and publicly via social media and word of mouth.

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- Twenty-six students in a local college support program for autistic students were approached and given information about the clinician-guided ESP (ESP-C). Of these, 19 declined participation, several citing that they were too busy or overwhelmed to participate. Four additional students from the community filled out an interest form; one did not respond to follow up and one was deemed ineligible. A total of nine students completed the ESP-C.
- Twenty-eight individuals filled out an interest form to complete the self-guided ESP (ESP-S). Eighteen did not respond to repeated contact attempts. Of the remaining 10 who consented, two discontinued prior to creating the ESP-S, one was deemed ineligible and one was lost to followup. A total of six students completed the ESP-S.

ESP and follow-up procedures. All students completed telehealth visits and questionnaires to gather information about their current emotional functioning. Nine students participated in a 60-90 minute telehealth visit to complete their ESP with the support of a clinician (ESP-C); The other six students were sent links to videos and other electronic materials to complete a self-guided version of the ESP on their own (ESP-S) and provide experience. Participants were monitored for 15 weeks after completing their ESP; weekly for the first six weeks and biweekly for the remaining nine weeks. For ESP-C students, monitoring included online questionnaires and brief telehealth check-in meetings with a study team member. For ESP-S students, monitoring included online questionnaire and receiving prompts to complete brief questions about their emotional states four times per day for the first six weeks and bi-weekly questionnaires for the remaining nine weeks. Participants in both groups were asked to complete questionnaires about their emotional functioning and a telehealth outcome visit, where they were asked questions about their experiences with the ESP.

Findings

Focus Groups. The focus groups highlighted that while 3/5 students seemed to be aware of the university counseling center, none were aware of how to access its services (this is, unfortunately, likely true of many other colleges as well). Students had generally not heard of most other local mental health services. Three of six students reported awareness of national suicide prevention lifeline and crisis text line, though only 1 reported knowing how to access them. Only one parent was aware of university counseling and how to access services; parents indicated hearing of state and national supports but not knowing about the specific services provided or how to access them. While this was a small sample, these findings highlighted a potential need to ensure that autistic students and their families were aware of the range of different mental health supports or services available. This information, combined with experiences with ESP participants were used to inform development of the resource, “*Mental Health Guide for Autistic College Students*”.

ESP-C: For the nine ESP-C students, completion rates were high (91% for monitoring visits and 93% for monitoring questionnaires). All participant completed outcome visits and questionnaires. Overall, the ESP intervention was well-received amongst participants. When asked to rate on a five-point scale (five being most positive), participants indicated that the ESP intervention was helpful (3.8) and that the content of the intervention was relevant to them (4.1). When asked about the specific sections of the ESP, participants rated the *things I can do to manage my emotions* (i.e., coping strategies) was most helpful. And two-thirds of participants agreed they would recommend the ESP to another person.

Of 9 participants, five had clinically elevated scores on the PHQ9 or GAD7 at baseline or in the first week of the semester. Of these, three fell below range of concern at week 14. Of the two

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with persistently elevated symptoms, one had already been enrolled in treatment and the other was referred to therapy.

ESP-S: For the six ESP-S students, monitoring questionnaire completion rates were also high (92%). One participant dropped out at week 10 (citing time constraints), but completed the satisfaction survey); one participant had just completed their monitoring period and was in the process of being scheduled at the time of this report. The remaining four of six participants completed outcome questionnaires and visit.

Following creation of the ESP, participants rated their satisfaction with the materials provided and their experience creating their ESP. On a scale from 1 (Very difficult) to 5 (very easy), average rating of ESP creation was at 3.7, with participants reporting an average of 55.8 minutes to create the ESP (range = 10 – 120 minutes). Participants were given a choice of resources to support creation of ESP; of those used, most were rated as “Very Helpful” by all participants. No students asked someone else to help them create their ESP.

The 5 students who had completed the satisfaction survey reported neutral to positive regarding how helpful the self-guided intervention was. Feedback suggested that, for some students, it would have been more helpful to have someone walk them through the process than do it on their own. One student who was already actively engaged in therapy noted that it likely would have been helpful for someone who had not already had professional support in coping strategies. Two students indicated that the act of creating the ESP (and reminders through questionnaires) was helpful (e.g., “created a muscle memory to do it later” and used strategies more because more on their mind).

Of five participants, two had scores in the clinical range of concern of depressive or anxiety symptoms at baseline; both showed some reduction in symptoms by week 14. The remaining three had minimal anxiety at either timepoint.

Take-aways

1. Autistic college students and their parents may not be aware of or know how to access campus mental health resources (e.g., university counseling centers).
 - a. We hope that the *Mental Health Guide for Autistic College Students* will help to promote awareness and access of resources.
2. The ESP intervention may be a useful tool to prepare students to cope with stressors.
 - a. Students generally rated the ESP intervention positively.
 - b. Materials to support creation of the self-guided ESP were useful, though some students may prefer a clinician-guided option over completing the ESP on their own.
3. Recruitment and participation was clearly affected by proactive approaches to supporting mental health must carefully consider timing and effort required of them in order to be accessible.