Testing an advocacy services intervention for Latinx families of transition-aged youth with autism

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1.0 Background

Adult disability services are complicated, fragmented, and difficult to navigate. For parents of individuals with disabilities, it is frustrating to learn different eligibility schemes, apply for services, and actually access appropriate services. It can be especially difficult for Spanish-speaking, Latinx families to access transition services. Given the systemic barriers facing Spanish-speaking Latinx families, they may especially benefit from an advocacy program to help them learn how to access services. Thus, the purpose of this project is to test the feasibility and effectiveness of an advocacy program for Latinx families.

2.0 Rationale and Specific Aims

The purpose of this study is to determine the feasibility and effectiveness of an advocacy program for Latinx families of transition-aged youth with autism. Specifically, we are examining whether the participants feel that the program is acceptable and feasible as well as whether the program increases their advocacy, knowledge, empowerment, and access to services.

3.0 Inclusion/Exclusion Criteria

To be included in the study, the participant must be: over the age of 18, identify as Latinx, have a child with autism who is over the age of 12, speak Spanish, and reside in Illinois.

4.0 Enrollment/Randomization

Upon learning about the program, the participants will click the link to RedCap. The RedCap survey will include the screening questions (see attached). If the participant meets the inclusionary criteria, the participant will then be directed to the consent form. If the participant signs the consent form, they will then be directed to the pre-survey. After completing the pre-survey, the research team will randomize the participant to either receive the advocacy program in the fall of 2023 or the spring of 2024. The research team will notify the participant of their random assignment. We will enroll 50 participants.

5.0 Study Procedures

Upon learning about the program, the participants will click the link to RedCap. The RedCap survey will include the screening questions. If the participant meets the inclusionary criteria, the participant will then be directed to the consent form. If the participant signs the consent form, they will then be directed to the pre-survey. After completing the pre-survey, the research team will randomize the participant to either receive the advocacy program in the fall of 2023 or the spring of 2024. The research team will notify the participant of their random assignment.

During the advocacy program, the participant will complete short formative evaluations at the end of each session. These evaluations will be completed via RedCap. See

attached. At the end of the advocacy program, the participant will receive the summative evaluation (see attached) and post survey link via RedCap (see attached). Six months later, all participants will be asked to complete the follow-up survey (which is identical to the post-survey). Altogether, participation is up to nine months. The follow-up survey will also be administered via RedCap.

6.0 Reporting of Adverse Events or Unanticipated Problems involving Risk to Participants or Others

This is a minimal risk study. We do not expect any adverse events or unanticipated problems. However, if an adverse event or unanticipated problem occurs, it will be immediately reported to the PI. The PI will then notify the IRB immediately (i.e., within 24 hours of learning of the incident).

7.0 Study Withdrawal/Discontinuation

A participant can withdraw from the study at any time. There is no penalty for withdrawing from the stud.

8.0 Statistical Considerations

This study is sufficiently powered to discern effects on knowledge, advocacy, empowerment, and unmet service needs. Inferential statistics will be used to gauge the effect of the advocacy program.

9.0 Privacy/Confidentiality Issues

The advocacy program and data collection will occur in private locations. All data will be electronic and stored on password-protected computers of research team members for this project. Participant identifiers will be stored separately from the coded participant data.

10.0 Follow-up and Record Retention

The study participation should be approximately nine months. Data will be destroyed at the conclusion of the study.