

UW LEND Trainee – Leadership Project Proposal 2023-2024

Program: Occupational Therapy

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Project Title:

Creating a Guide for Educators to Support and Improve the Middle and High School Experience for Teens with Autism Spectrum Disorder

Describe the Need: The autistic community has identified suicide prevention as a top priority, yet there is an evidence gap about how best to intervene to reduce suicide risk in autistic individuals. Many risk factors exist including a perceived lack of social support and unmet support needs, the co-occurrence of depression and anxiety, camouflaging or masking, receiving a late diagnosis, being female, and experiencing autistic burnout (Cassidy et al., 2019; Hedley et al., 2017, 2018; Kirby et al., 2019; Raymaker et al., 2020). One step toward improving quality of life and mental health for autistic individuals is to ask about their lived experiences as a middle school and high school student. What was working for them and what got in the way of having successful and satisfying school experiences?

Brief Description of Proposed Project: This project idea was inspired by a guide titled "Understanding Me: An Individual with FASD", created to help educators learn about and better connect with their students with FASD in the classroom. This guide is useful for thinking about and creating individual success strategies that meet students where they are at. A team of two or more LEND trainees will use this guide as a jumping-off point to create a guide to support teens with ASD in the school setting. LEND trainees will collaborate with key stakeholders (i.e., individuals with ASD and their family members) to gather data about the lived experience of being a student/family member with ASD in middle and high school. The LEND trainee team will develop a guide for educators that builds on the strengths and priorities of this community. A strong emphasis will be on creating strategies to improve social support and address the unmet needs of middle and high school students with ASD.

Project Goal and/or Desired Outcome:

- Identify needs and gaps in the school system specific to lack of social support and unmet support needs of teens with ASD.
- Find out what was helpful or supportive for teens in the school environment.
- Identify existing strengths of students with ASD and determine how these strengths can be leveraged.

- Identify strategies and accommodations that can be implemented in a school setting, to support meaningful participation and social engagement with peers.
 One important focus will be to reduce chronic life stress and prevent the mismatch of expectations and abilities without adequate supports (autistic burnout).
- Design an "Understanding Me Guide" for educators and peers that can be completed by students with ASD

Proposed Roles/Responsibilities of the UW LEND Trainee(s): *Include number of trainees desired*

- Review any current literature on this topic (including the articles provided in the reference list)
- Participate in UW LEND seminars on topics of developmental disability, adolescent transition, and any other relevant topic.
- Review the "Understanding Me: An Individual with FASD" guide (attached pdf).
- Partner with Autistic individuals to identify unmet support needs in their school experience and design a guide for educators (and possibly peers).
- Collaborate with Misty Pruner, OTR/L, and other providers at CTU/LEND.
- Consider observing in the Child Development Clinic on a day (when a teen is coming in for a comprehensive evaluation), or the UW Medicine Adult Autism Clinic or a community program that is serving adults with I/DD/autism.

List Any Desired Trainee Prior Experiences or Skills:

• Special interest in teens with ASD and the school experience

References

https://www.fasdsuccess.com/understandingmefasdguide

https://www.seattlechildrens.org/healthcare-professionals/education/grand-rounds/online/suicide-prevention-intervention-individuals-autism-spectrum/

https://www.stephstwogirls.co.uk/2018/05/autism-and-pda-positives.html (Positives of Autism)

https://www.instagram.com/neurodivergent_lou/?hl=en (21-year-old Autistic Instagram Influencer)

Hedley, D., Uljarević, M., Cameron, L., Halder, S., Richdale, A., & Dissanayake, C. (2017). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism*, *21*(8), 929-941.

Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2017). Brief report: social support, depression and suicidal ideation in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*, 3669-3677.

Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A 20-year study of suicide death in a statewide autism population. *Autism Research*, 12(4), 658-666.

Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., ... & Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in adulthood*, *2*(2), 132-143.

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., ... & Mandell, D. S. (2020). "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism*, *24*(4), 919-930.