

Serving individuals with severe developmental disabilities (DD) and intellectual developmental disabilities (IDD) helped me navigate the neurodivergent brain and allowed me to disseminate a wealth of knowledge

Andrea Daniella Mata
Project Amistad non-profit, El Paso, TX

My Personal Journey

- Since the age of 16, I have had a learning disability
- My tenacity, hard work ethic, and perseverance enabled me to overcome the challenges of a learning disability
- I worked hard to be an advocate for vulnerable populations
- As an advocate I served as a Peer Support Specialist (PSS) for a non-profit in El Paso, TX named Project Amistad
- Project Amistad's Peer Support Specialist Program works with adults with DD/IDD the border town of El Paso, TX

My role as a PSS

- Empower individuals with DD /IDD and ensure their voice is heard
- Allow the client to brainstorm achievable goals such as financial literacy, confidence, or networking skills
- Serve individuals with DD/IDD in diverse institutional settings including:
 - State Supported Living Centers
 - Nursing Homes
 - Intermediate Care Facilities

Project Amistad Goals

- Change local policy
- Support person-centered planning
- Provide recommendations to institutional settings for policy amendments

What I have personally learned over the years as a PSS

- It takes time to focus and finish tasks
- It is always better to offer help before giving help
- People with neurodivergent brains work and speak differently at times so be patient

My goal

- Help my DD/IDD client increase understanding of their rights
- Provide resources for support, engagement, and education
- Increase communication skills for verbal and non-verbal clients

Success stories of two clients who benefited from the Peer Support Specialist Program with Project Amistad:

Mentee is very independent despite her PTSD and Paranoid Schizophrenia. Mentee was not comfortable with all her sessions and she was experiencing episodes various time when trying to attempt to call her. Mentee was not very open about her family nor her friend's but was open about her love for Nikki Minaj, racial justice, her job, and walking. Mentee really wanted to buy an iPod in the future and plans to use her advocacy skills learned to do so.

Mentee is extremely high functioning and thus is able to work, but not consistently. At the first session the mentee completed the pre-survey and it was evident that the mentee was very confused and not interested in the survey questions. At the end of the program, the mentee was still confused, but this time she expressed her confusion by telling the PSS that she needed to slow down and that she was going too fast to understand.

PSS was proud of this moment because she was speaking up and telling PSS that she was not getting it. This is a great sign of growth! Mentee learned how to speak up, communicate, and PSS was impressed when the mentee started to ask the mentee questions. The questions that the mentee asked were the same questions that the PSS asked the mentee. This is a form of reiteration and the mentee was proud to see that Mentee was learning skills that the PSS was implementing in the training session.

Mentee learned how to speak up for herself, improve her communication skills, and open up about what she enjoys. Mentee is in great hands and PSS believes that she will continue to use her voice to advocate for herself.

Figure 1: Success story

Mentee communicates in her unique ways despite her Profound IDD; Schizophrenia; and Seizure Disorder. Mentee was not comfortable with all her sessions as she does not like to be isolated. She enjoyed being in the presence or company of other people. Mentee hardly spoke about herself. Mentee really wanted to always be doing something with her hands, and I would recommend that she engage more in fidget toys, painting, or ways for her to have some task or role. She enjoyed helping the Emily's take stuff from one table to the next, as she enjoys these small tasks.

At the first session the mentee did not sit down with the PSS for very long and by the end of the session the mentee and PSS built up to a very long session. This progress in the mentees ability to communicate virtually with someone else shows her communication progress. Further mentee followed along to verbal assignments well until she was triggered by something else in the room. Despite the room being loud and hard to hear, the mentee would put her head near the phone and try to speak quietly, showing that her communication skills with technology advanced. At the end of the program, the mentee was able to have longer communication time, improved listening skills, and engaged in the "simon dice" game with the PSS.

PSS was proud of mentees progress because the first meeting was so very different from the last in regards to her active listening skills and ability to focus her attention. Her progress is a great sign of growth. At times the same statements or questions that the mentee asked were the same questions that the PSS asked the mentee. This is a form of reiteration and the mentee was proud to see that mentee was learning new listening skills that the PSS was implementing in the training session.

PSS would recommend that the mentee engage in small tasks and that the workers give her small responsibility jobs within the day center. This will help her growth.

Figure 2: Success story

Permission to share this was obtained from the author by the Michigan Autism Conference on 3.28.22

Things I wish I knew before being a PSS

- Always talk to your client and not to their caregiver or social worker
- Let your client communicate their thoughts, do not interrupt
- Do not always share solutions with your client, instead support their thought process
- Allow your client to express themselves through stories, pictures, or emotions
- Do not rush the process
- Ask for help when needed
- Every person is unique and so is their disability
- If their actions are predictable, they may be preventable

Do's and Don'ts when working with neurodivergence peers

- Do's:
 - Allow for extended time frame
 - Create more ways to communicate effectively
 - Display a welcome and nurturing environment
 - Demonstrate the ability to empathize, listen, and understand
- Don'ts:
 - Punish people for not making deadlines
 - Police their speaking or thinking
 - Make comments or mock their organization
 - Shame others for being different

Reflection

- Understanding that there will never be a standard brain
- Implementing training on neurodiversity has a lasting impact on neurotypical employees. As someone with a neurodivergence brain, working with other neurodivergent clients, helped me gain a new understanding of the way we function and think about everyday issues