

NH-ME Lend Parent Advocacy Autism Training Project Narrative

The *NH-ME Lend Parent Advocacy Training* project was created out of a desire from families of children with Autism to have information to support their children. Connected to the New Mainers Public Health Initiative they completed a short series of training with general information on Autism through the Autism Society of Maine. The University of Maine Center for Community Inclusion and Disability Studies (CCIDS) was engaged to continue with the families to create and deliver training on topics in special education. As part of their role in the NH-ME LEND, CCIDS's scope of project work involved informing and supporting the parents to advocate for their children, with two LEND trainees (April Fournier and Crystal Cron) supporting implementation of the training sessions.

In the initial stages topics for the training were determined by co-leadership mentors, Hibo Omer and Marnie Morneault, and were informed by a variety of sources. Sources included anecdotal data from parents, data from practitioners in the field, as well as building off of the topics that came up in previous training with parents. You can see this reflected in an original formative document, *Session Outline-Autism Trainings and Supporting You as Parents-What is your role?*

After some reflection, Hibo and Marnie took a step back from the original outline and timeframe and added a listening session to the project. The goal of the session was to more richly gather the experiences and personal "stories" of the families as they interacted with the early intervention and special education system. You can see the questions in the document, *Listening Session Questions*. Although the topics and much of the content for the training didn't shift remarkably based on the information collected in the information sessions, how it was presented did. This single decision to collect personal stories began a shift in the project that set the tone for how we would function and move throughout the life of the continuing project. Prior to the listening sessions, the project had been only about what we delivered for content, after the sessions it became equally as important to look at how we delivered the content.

During the listening sessions, we learned many technical lessons about structure that informed the project, including explaining the project they were involved in so they had context and establishing a mutual understanding for the interpretative role. Most importantly, we learned we needed more than an interpreter to repeat what was spoken, we needed a cultural broker. As co-leadership mentors, we were not familiar with this term prior to this project, but we defined it as someone who has a relationship with the families who were present, understood the culture of the families they were speaking for, and who could encourage them to share their stories, safely. It quickly became clear that this role would help us over the humps that we would hit sometimes, unwittingly, and become a bridge between cultures. After the initial listening session, we clearly decided that Hibo would not fall into the interpreter role and that she would strictly stay in the

cultural broker role. After the third session, the group grew enough in comfort to meet even without the cultural broker present during the fourth session.

Adaptively, we learned that the family's stories would be the thread that wove throughout the entire training series. As we discussed each topic during the sessions, we often referenced the family's individual stories they had shared in the initial listening session, to make the information more relevant and real. We delivered the topics over four training sessions, with each session being led by a set of topics and the flexibility to respond to the parent's needs as they arose in the sessions. As we delivered the sessions, we continued to learn through the parents and to integrate both their feedback and the shifts that we as the co-leadership mentors agreed to make after each session. The document *FAST Project Changes Final* shows a timeline of the challenges, discoveries, and changes that we made as we moved through the phases of the project.

The group is currently in an evolving phase. We have ended our training sessions and are meeting periodically to support the individual and ongoing needs of the parents. The parents continue to be the decision-makers about the “what” that they need for the group, and we continue to support the “how.”

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