Collaborating for Change NH-ME LEND/NMPHI

Description

• The NH-ME LEND/NMPHI (New Mainers Public Health Initiative) parent advocacy training project was created out of a desire from Somali families of children with Autism to have information to support and advocate for their children.

• Connected to the New Mainers Public Health Initiative, 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 supporting implementation of the training sessions.

Training Description

Initial stages – Topics for the training series determined by co-leadership mentors, Hibo Omer and Marnie Morneault, informed by a variety of sources.

Listening Sessions – Richly gathered the experiences and personal “stories” of the families as they interacted with the early intervention and special education system. Topics in the training series shifted from looking at “what” we delivered to looking at “how” we delivered the content by incorporating parent stories as a thread that wove throughout the entire training series.

Parent Advocacy Training Sessions 1-5 – Each session delivered 1-2 topics based on parent input.

Evolving/Follow-Up Phase – Periodic meetings to support individual and ongoing needs of the parents. Parents continue to be the decision-makers about the “what” that they need for the group, and we continue to support the “how.”

Lessons Learned

Changes were made throughout the project that integrated both parent feedback and shifts that the co-leadership mentors agreed to make after discussing each session. Changes included involving parents in a culturally sensitive way from planning to implementation, establishing group norms, establishing a mutual understanding for the interpretative role, and adding a cultural broker role to link the training to the personal stories of the families.

Training series topics included:

• What Is Special Education?
• Advance Written Notice
• Least Restrictive Environment
• Consent for Evaluation
• Written Notice
• IEP
• Resources to Problem Solving
Challenges Between the Special Education System and Parents/Children of Diversity

**Special Education System** – created to support the United States education system, founded on early European settlers’ culture, which can cause a divide for parents of diverse descent.

**Individual Child** – brings their own unique needs and responses to the supports provided within the special education system, which can be challenging to incorporate within the context of the system.

**Teachers** – implement special education through understanding and cultural beliefs of the system. Challenges can arise because of the potential differences in understanding of the system as well as cultural beliefs of the system the teachers may have.

**Parents** – Team practices can inhibit parental collaboration and participation. Additionally, parents struggles with the nuances and the complexity of the system (e.g., laws and expectations of parent roles).

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**Parents of children with language and cultural barriers can experience additional obstacles participating in the special education system.**

**Language** – Printed materials can be presented in a non-home language, interpretation paid for by school-can be a conflict slanted towards school. Interpreters can feel obligated to respond “in favor” of the school (employer/contractor). Parents can feel a sense of distrust and lack of full participation due to this dynamic.

**Cultural** – system is not founded on, nor implemented based on family’s cultural beliefs.

Collectively, this dynamic generated more restrictive placements for children in our project, caused disagreements about the quantity of services that children received, parent’s reported their children were not making progress on their IEP goals (often goals were continued for more than one year), and parents sought less inclusive settings for their children, due to a desire for more progress on their child’s IEP goals. This is depicted in the box to the right of the circles visual shown above.

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