

A Culturally Sensitive Intervention to Reduce Stigma and Improve Service Access for Somali Children and Adolescents with I/DD and their Families

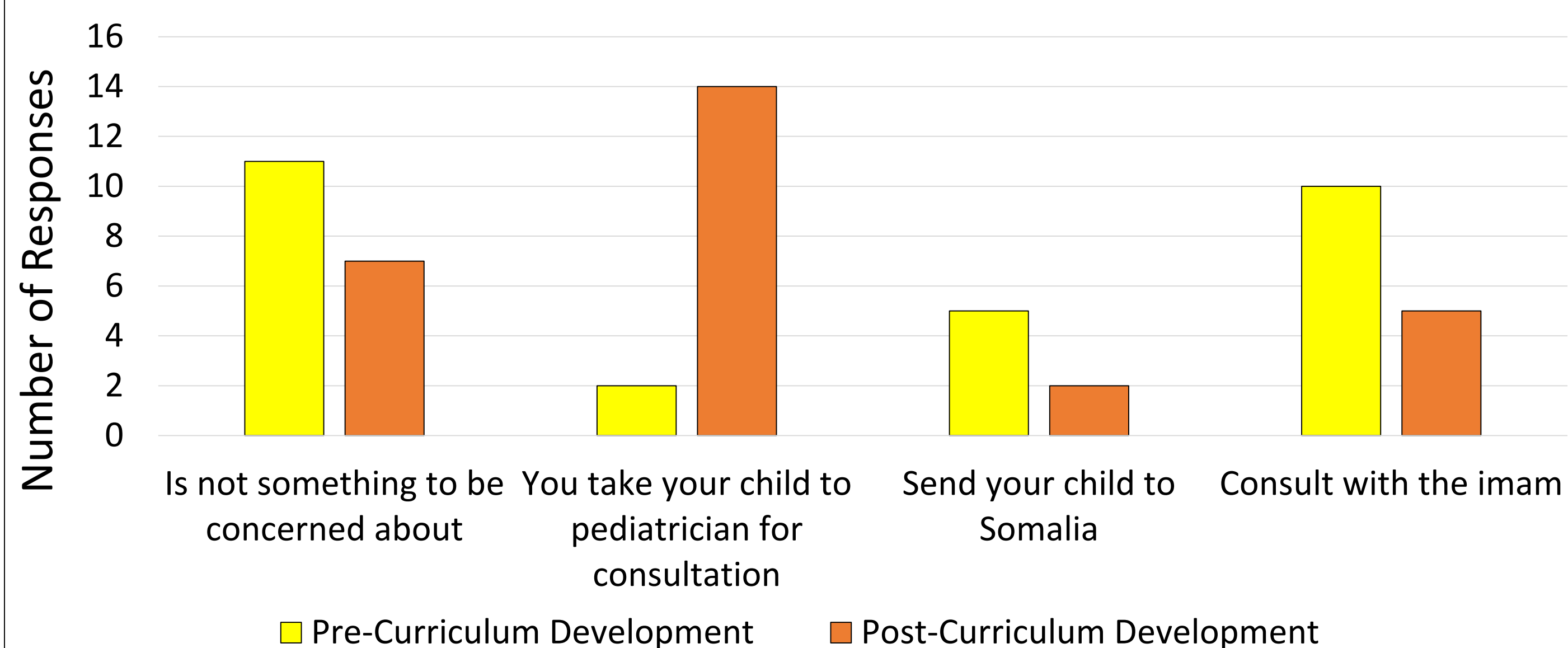
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Problem Perspective

SDC Parent Survey Sample Question

What would you do if your child is almost three and is not talking?



Positive Results of the Intervention

- ❖ The women moved toward acknowledging they are not alone; they no longer felt they should hide their children; they can share their struggle; and they felt less isolation and hopelessness
- ❖ The women felt that fathers delayed accessing services, especially for sons, as they were not accepting the initial diagnosis – fathers were then included in the group meetings and willingly participated
- ❖ Parents realized that shame/guilt/stigma prevented their accepting their child’s diagnosis and prevented them from seeking services
- ❖ Parents felt power in connecting to other parents and giving each other emotional support
- ❖ The parent support group is ongoing

Methods/Curriculum

A women’s group from the Somali Development Center developed an I/DD educational curriculum for the Somali community designed to inform parents about child development; to address stigma; and to promote the idea of early intervention for services in health and education.



Curriculum Topics Developed:

- ❖ Tea and Talk - Casual conversation
- ❖ Setting rules for the group (Code of Conduct)
- ❖ Mothers’ Self-Care: Parents are important, Parents have rights
- ❖ Family engagement and being involved
- ❖ Child Development Milestones: How do you know?
- ❖ Accepting the Situation: Discussion of Stigma
- ❖ Let’s Get Organized: Care maps, binders, problem-solving
- ❖ Communicating to schools, doctors, and community programs

Challenges in Starting the Intervention

- ❖ Creating a safe space for women to talk openly
- ❖ Facilitating a useful and productive meeting
- ❖ Finding the first woman in the group to share her I/DD story
- ❖ Giving time for women to feel comfortable about I/DD
- ❖ Understanding that therapies in I/DD are unique to each child

Future Directions

- ❖ Transfer group leadership to other group members over time
- ❖ Create groups in other locations
- ❖ Facilitate further education of the parent leaders about I/DD, services, leadership and advocacy
- ❖ Sustain the curriculum at SDC with LEND Fellows involvement

Policy Recommendations

- ❖ Health education and services can be accessible and inclusive if they respect the Somali custom of being an oral rather than a written culture
- ❖ Grandmothers and extended family members hold behind the scenes power in determining health service compliance and should be included
- ❖ Trauma-informed services may be essential to mitigating Somali civil war and refugee experiences

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