



Erica Costa, MS, OTR/L - Occupational Therapy Trainee

LEADERSHIP IN ACTION PLACEMENT:

- Special Medical Service (SMS) is the New Hampshire Title V Program for Children with Special Health Care Needs, which supports a variety of services for children birth to 21 years of age who are either at risk for or have a chronic medical condition, disability or special health care need along with identifying and addressing gaps or needs for these children/ youth and their families
- SMS provides leadership in offering services in the community that are family centered, comprehensive, coordinated, and culturally competent. The focus of SMS is compatible with the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (NH LEND) Program
- The mission of the NH LEND program: Prepare leaders from various professional disciplines to enter the field of maternal and child health by engaging in training in interdisciplinary, family-centered, culturally competent systems of care for youth with developmental disabilities and their families.



PROJECT DESCRIPTION:

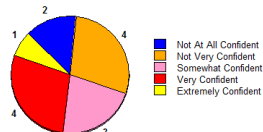
- Survey research investigating practices after a child receives a diagnosis of ASD
- Purpose is to improve the system of care for individuals with ASD and their families
- A follow-up survey for families who had recently received an ASD for their child was developed and distributed to learn about their experiences and needs – these would contribute useful information for planning purposes
- This survey was focused on “what happens after diagnosis” and “what they would like to happen”
- With the guidance and assistance from Rae Sonnenmeier and Liz Collins, I was able to embark on the journey of creating this survey.



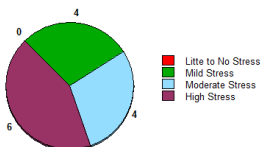
LESSONS LEARNED:

- Leadership requires organization and flexibility
- Leadership involves input from and collaboration with others
- Leadership can involve decision making and modifications, but also requires open-mindedness and adaptability

Confidence Level Post-Diagnosis



Stress Level Post-Diagnosis



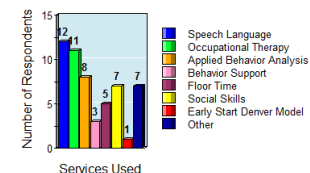
THE PROCESS:

- IRB approval process
- Research and clinic coordinator visits to create drafted survey questions
 - Creation of three surveys and stakeholder input
 - Modifications and finalizing two surveys for mailing
- Clinics identify anonymously which families should receive survey
- Mailing of survey to families with children both over and under 3 with diagnosis of ASD
 - Data retrieval and data analysis

FINDINGS:

- This study involved 15 respondents from families who had children diagnosed with an Autism Spectrum Disorder; 7 were under age 3 and 8 were over age 3 at the time of diagnosis
- 100% of those receiving Early Support and Services (ESS) reported it being helpful and reported their ESS provider being very well trained
- 14/15 respondents reported no information was missing from evaluation (2/15 people reported wishing they knew more about clinic process before clinic day)
- 87% reported services being helpful post-diagnosis
- 29% reported mild stress and 43% reported high stress post-diagnosis

Services Used Post-Diagnosis



References:
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