

Advocating for Client Unmet Needs/Gaps in Services for Persons with Feeding and Swallowing Disorders

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Background

- ^ Feeding disorders are a major challenge for persons with disabilities, especially children with disabilities. They can affect a child's language and motor development.¹
- ^ Between 30-80% of children with developmental disabilities have a feeding disorder, and between 10-40% of children without developmental disabilities have a feeding disorder.²
- ^ Feeding and swallowing clinics are specialty clinics operated by an interdisciplinary team to provide assessment and treatment to persons with feeding and swallowing challenges.³
- ^ The West Virginia University Center for Excellence in Disabilities (WVU CED) Feeding and Swallowing Clinic offers interdisciplinary assessments, treatment and recommendations for children from birth to 21 years of age who have feeding disorders.⁴
- ^ Unmet needs are the gaps between recommended services to improve or treat a health issue and actual services received which can be due to lack of available resources or inaccessibility of resources due to poverty, high cost of healthcare, or high transportation cost, among others.⁵
- ^ Unmet needs imply a worsening effect on the health of the affected persons as they cannot receive the required treatment.⁵

Description of the program

A mixed methods approach was used for this evaluation research: A questionnaire with open- and closed-ended and Likert scale questions was administered through a telephone survey during the fall 2017 semester

- ^ Convenience sampling was used to select participants affiliated with the Feeding and Swallowing Clinic:
 - Past and present staff members
 - Mentors
 - Faculty
 - Seven participants completed the survey

Findings

- ^ Respondents agreed unanimously the clinic excels at providing diagnostic services
- ^ There was universal agreement the clinic lacks resources for follow up services
 - Occupational therapy
 - Physical therapy
 - Behavioral and support services
- ^ 71.4% (n=5) agreed that lack of transportation was a problem for most clients
- ^ 71.4% (n=5) agreed that lack of financial resources was a problem for clients
- ^ 85.7% (n=6) agreed that families often mention having feeding-related problems with the school their child attends
- ^ 85.7% (n=6) reported that families often have problems with the child's school related to their child's developmental needs
- ^ 71.4% (n=5) agreed that missing work to bring a child to clinic is a problem for clients

- ⤴ All respondents reported that the lack of professionals in the state to provide referral and follow up services was the greatest challenge facing both clients and the Feeding and Swallowing Clinic professionals

Objective

- ⤴ To evaluate the WVU CED Feeding and Swallowing Clinic and clients' unmet needs in accessing the services of the Clinic.
- ⤴ To gauge how clients' unmet needs pose as a challenge to assessing or implementing treatment strategies.

Limitations

This study would have been strengthened by surveying Feeding and Swallowing Clinic clients directly, but time limitations made it difficult to extensively survey clients in this study. Additionally, since the investigator had worked directly with clinic clients there was concern about the possibility of client response bias.

Recommendations and Conclusions

This investigation revealed that the Feeding and Swallowing Clinic provides excellent diagnostic services, but lacks resources for providing speech, occupational, physical therapy and behavioral and support services that would allow clients to carry out clinic recommendations. The following recommendations are offered as a result:

- ⤴ Advocate for additional resources to support speech, occupational and physical therapy service delivery at the WVU CED.
- ⤴ Explore the delivery of some therapies online, e.g., speech therapy.
- ⤴ Seek funding for a qualified staffer, e.g., social worker, to work under the supervision of the WVU CED's Feeding and Swallowing Clinic team to provide follow up services for clinic clients.
- ⤴ Advocate for Birth to Three services to be expanded to cover children up to the age of five, when they can start school.
- ⤴ Advocate for the implementation of a certification program that qualifies people to provide speech and occupational therapy services in schools with supervision from a professional speech or occupational therapist.

References

¹Le Grange, D., Swanson, S. A., Crow, S. J., & Merikangas, K. R. (2012). Eating disorder not otherwise specified presentation in the U.S. population. *International Journal of Eating Disorders*, 45 (5), 711-718.77.

²Bruns, D. A., & Thompson, S. D. (2012). *Feeding Challenges in young children. Strategies and specialized interventions for success.* Baltimore, MD: Brookes Publishing.

³Van- Riper, C. L., & Wallace, L.S. (2010). Position of the American Dietetic Association: Providing nutrition services for people with developmental disabilities and special health care needs. *Journal of the American Dietetic Association*, 110 (2), 296-307.

⁴<http://nutrition.cedwvu.org/feeding-swallowing-clinic/>. Retrieved September 26, 2017.

⁵Carrillo, J. E., Carrillo, V.A., Perez, H.R, Salas-Lopez, D., Natale-Pereira, A., & Byron, A.T.

(2011). Defining and targeting health care access barriers. *Journal of Health Care for the Poor and Underserved*, 22 (2),562-75.

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