

## **Feeding and Swallowing Concerns – Guidance to the Field**

*Michigan Interagency Coordinating Council (MICC)*

*Michigan Department of Education (MDE)*

*Early On<sup>®</sup> Michigan*

### **Did You Know?**

Up to 80 percent of children with disabilities have difficulties with feeding.<sup>1</sup> Feeding related difficulties can lead to nutritional deficits, critical illness, or even death.<sup>2,3,4</sup> This is a significant concern because “children who are not nourished adequately are at risk for not reaching developmental potential in cognitive, motor, and social emotional abilities. These abilities are strongly linked to academic achievement and economic productivity.”<sup>5</sup> Addressing feeding and/or swallowing concerns in young children is complex. It requires coordinated collaboration among healthcare providers, early intervention/*Early On* Michigan and school based services for older children. Early identification and treatment of infants and toddlers with feeding and/or swallowing concerns can have a significant impact on improving outcomes with the child’s feeding and nutritional intake.<sup>6</sup>

### **What Is the Purpose of the Guidance Document?**

Concerns related to feeding and swallowing dysfunction have captured national and state attention as increasing numbers of children in need of intervention have been documented. This is due to increasing survival rates within the pediatric population as medical knowledge and technology have improved. Many of these survivors, however, experience serious medical conditions likely to include feeding and swallowing disorders as a primary or secondary diagnostic criteria.<sup>7,8</sup> While some communities have developed a successful partnership between *Early On* and medical services for addressing feeding concerns,<sup>9</sup> some parents in Michigan report difficulty accessing medical services for their child related to feeding due to confusion of roles between medical providers and *Early On*.<sup>10</sup> Furthermore, *Early On* service providers and *Early On* Coordinators/administrators in Michigan have identified the need for clarification about the roles of *Early On* and medical partners when addressing the needs of infants and toddlers with feeding concerns in addition to a need for further information and training to providers in *Early On* about child feeding and swallowing concerns.<sup>11,12</sup> Thus, the MICC, a Governor-appointed council that advises and assists the MDE with its comprehensive system of early intervention (known as *Early On* in Michigan), charged an Ad Hoc committee to provide guidance and recommendations for support to the field on the role of *Early On* when addressing the needs of infants and toddlers with feeding concerns.

### **What Is *Early On* Michigan?**

*Early On* Michigan provides early intervention services and supports to families of infants and toddlers, birth to three, who are eligible because they have a developmental delay or disability. This includes physical (gross and fine motor), cognitive, communication, adaptive, and social-emotional development. *Early On* is

available statewide, through all 56 intermediate school districts. MDE is the lead agency.

*Early On* services and supports are based on the core principles of early intervention.<sup>13</sup> Specifically, services are:

- Family centered,
- Based on interagency collaboration,
- Based on parent/professional collaboration, and
- Focused on improving child development for learning.

### **What Is the Role of *Early On* with Health Related Issues, Such as Feeding and/or Swallowing Concerns?**

Part C of the Individuals with Disabilities Education Act (IDEA), in Michigan known as *Early On*, was not intended to be a standalone service but a “system that links services together.”<sup>14</sup> When Congress authorized Part C in 1986, the intent was to “facilitate coordination of payment to ensure that all *existing* resources *remained* in place to support the service delivery system for infants and toddlers with developmental delays or disabilities and their families.”<sup>15</sup> Part C was “envisioned by Congress with a primary role of *facilitating* access to resources, services and supports.”<sup>16</sup> Therefore, *Early On* was not meant to be the sole payer or provider of services for children and families and specifically was not intended to take the place of necessary medical services. Hence, a child is entitled to receive services from both *Early On* and medical partners if they qualify.<sup>17</sup>

A key role of *Early On* is to coordinate services and collaborate with valued community partners, such as medical providers, to ensure a child is receiving all eligible services for which he/she is eligible.<sup>18</sup> Collaboration and coordination are vital to early identification of feeding and/or swallowing concerns and access to medical evaluation related to feeding.<sup>19</sup> In addition, the role of *Early On* is to provide strategies, supports, and parent coaching within natural environments to address the developmental/routines-based needs of children with feeding concerns but not to replace any necessary medical services. For example, *Early On* providers are important to the process of identifying signs of possible feeding concerns and referring for appropriate medical evaluations when necessary. Medical partners are important because medical assessments, including fluoroscopic or endoscopic examinations, may be warranted because a feeding observation completed in the home may not be adequate to identify swallowing dysfunction.<sup>20</sup> Therefore, collaboration of and access to both partners is vital to fully supporting infants and toddlers with feeding concerns.

### **Recommendations**

The MICC recommends the following based on Part C of IDEA, best practice research, and surveys of Michigan parents, providers, coordinators, and administrators.<sup>21,22,23,24</sup>

- Free foundational training through *Early On* Training and Technical Assistance available to all *Early On* evaluators, providers, and *Early On* Coordinators on signs of possible feeding difficulties to ensure early identification.
- Advanced training opportunities coordinated through *Early On* Training and Technical Assistance for specialized providers in *Early On*, such as occupational therapists and speech-language pathologists, to gain skills related to addressing feeding and swallowing concerns in infants and toddlers.
- Access to a full array of professionals, for parents and providers, in *Early On* to ensure that multidisciplinary teams include providers whose scope of practice encompasses feeding (e.g., occupational therapists and speech-language pathologists).
- Development of a Learning Community with a focus on feeding and/or swallowing concerns for *Early On* providers to promote on-going problem solving, collaboration, peer to peer mentoring, and training.
- Identification and development of model procedures and practices related to feeding and/or swallowing concerns, including methods of collaboration between medical providers and *Early On* to ensure timely identification and referral.
- State-level outreach and advocacy to families, school districts, medical partners, community agencies, and insurance companies about collaborating to best identify and support infants and toddlers with feeding and/or swallowing concerns.
- Development of an online site for resource list through *Early On* Training and Technical Assistance related to feeding and/or swallowing concerns.

### Conclusion

It is imperative that infants and toddlers with feeding and/or swallowing concerns have access to both *Early On* and medical services to ensure optimal outcomes. Collaboration is a key piece of this process. We know that *Early On* and medical partners who collaborate provide quick and fluid identification, referral, and treatment of feeding difficulties.<sup>25</sup>

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<sup>1</sup> Lefton-Greif, M.A. & Arvedson, J.C. (2007). Pediatric feeding and swallowing disorders: State of health, population trends, and application of the international classification of functioning, disability, and health. *Seminars in Speech and Language*, 28(3), 161-165.

<sup>2</sup> DeLegge, M.H. (2002). Aspiration pneumonia: Incidence, mortality, and at-risk populations. *Journal of Parenteral and Enteral Nutrition*, 26(6), S19-25.

<sup>3</sup> Lefton-Greif & Arvedson, 161-165.

<sup>4</sup> Newman, L.A., Keckley, C., Mario, P.C., & Hamner, A. (2001). Swallowing function and medical diagnoses in infants suspected of dysphagia. *Pediatrics*, 108(6), e106-e109. doi:10.1542/peds.108.6.e106.

<sup>5</sup> Prado, E., & Dewey, K. (2014). Nutrition and brain development in early life. *Nutrition reviews*, 72(4), 267-284.

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<sup>6</sup> Williams, S., Witherspoon, K., Kavsak, P., Patterson, C., & McBlain, J. (2006). Pediatric feeding and swallowing problems: An interdisciplinary team approach. *Journal of Dietetic Practice and Research*, 67(4), 185-190.

<sup>7</sup> Lefton-Grief & Arvedson, 161-165.

<sup>8</sup> Newman, L.A. (2000). Optimal care patterns in pediatric patients with dysphagia. *Seminars in Speech and Language*, 21(4), 281-291.

<sup>9</sup> Stegenga, S.M. (2015). *Children Birth to Age Three with Feeding Difficulties: Systems level perspectives of supports, needs, and interagency collaboration*. (unpublished masters thesis). Grand Valley State University. Allendale, MI.

<sup>10</sup> DuPont, V., Must, J., & West, A. (2014). *Parent perspectives about supports and barriers to feeding intervention: Birth to three population: A pilot study*. (unpublished masters project). Grand Valley State University, Allendale, MI.

<sup>11</sup> Ehardt, R., Van Dommelen, E., & Zimerle, C. (2014). *Preparedness of early intervention service providers regarding feeding intervention*. (unpublished masters project). Grand Valley State University, Allendale, MI.

<sup>12</sup> Stegenga.

<sup>13</sup> *Early On Michigan* (n.d.). Retrieved April 12, 2015 from the Michigan Department of Education website: <http://www.michigan.gov/mde/0,4615,7-140-43092-127141--,00.html>.

<sup>14</sup> Mackey-Andrews, S.D. & Taylor, A. (2007, January). To Fee or Not To Fee: That Is The Question! NECTAC Notes. The National Early Childhood Technical Assistance Center, 22. Retrieved from: <http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCcQFjAA&url=http%3A%2F%2Fectacenter.org%2F~pdfs%2Fpubs%2Fnnotes22.pdf&ei=wiArVYbSL8iINvKqgbAF&usq=AFQjCNG5LkSkR3Dr7EpP8ZPWBS8QpiSxug&sig2=30QjzkcUkFRRdBUJE6th3g&bvm=bv.90491159,d.eXY>.

<sup>15</sup> Mackey-Andrews & Taylor, 22.

<sup>16</sup> Mackey-Andrews & Taylor, 22.

<sup>17</sup> Michigan Department of Community Health (2013, September). FAQ about Medicaid coverage for services in the schools or other providers/clinics/settings. *Provider Information Notice*.

<sup>18</sup> Individuals with Disabilities Education Act (IDEA), §303 (2004).

<sup>19</sup> Stegenga.

<sup>20</sup> Newman, Keckley, Mario, & Hamner, 108(6).

<sup>21</sup> DuPont, Must, & West.

<sup>22</sup> Ehardt, Van Dommelen, & Zimerle.

<sup>23</sup> IDEA.

<sup>24</sup> Stegenga.

<sup>25</sup> Stegenga.