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## Assessment of Parents Educational Needs and the Availability of Resources for Feeding Children with Intellectual and Developmental Disabilities

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ASSESSMENT OF PARENTS EDUCATIONAL NEEDS AND THE AVAILABILITY  
OF RESOURCES FOR FEEDING CHILDREN WITH INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES

by

Laurel Welborne

A Thesis

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Science

Major: Clinical Nutrition

The University of Memphis

December 2013

## **ABSTRACT**

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Assessment of Parents Educational Needs and the Availability of Resources for Feeding Children with Intellectual and Developmental Disabilities. Major Professor: Dr. Terra B. Smith, Ph.D., R.D.

The purpose of this research was to assess educational needs of parents of children with intellectual and developmental disabilities (IDD) and define the availability of resources for children with IDD who experience feeding disorders in Shelby County. Participants were primary caregivers of a child between three and 18 years with IDD who experience a feeding disorder. A questionnaire of quantitative and qualitative responses was distributed to members of the Special Education Parent Teacher Alliance of Shelby County and Support and Training for Exceptional Parents in Tennessee. The questionnaire reached 665 potential participants. Eight participants responded to the survey. The majority of the participants do not believe Shelby County is meeting needs in providing accessible services for feeding disorders. Conclusively, Shelby County may not be providing accessible services for children with IDD and feeding disorders. However the response rate was limited therefore more research should be completed analyzing the community's needs.

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# CHAPTER 1

## INTRODUCTION

Feeding disorders, or any problem that may decrease the nutritional intake of a person, can affect up to 80% of children with Intellectual and Developmental Disabilities (IDD).<sup>1</sup> Add this on to the wide range of struggles, both physical and psychological, that these children experience, and their quality of life can greatly decrease.<sup>1</sup> Eating for nourishment is a primary life function and when this basic necessity cannot be met, further medical conditions and detrimental psychosocial developments, as well as failure-to-thrive (FTT) (child plotting less than the 5<sup>th</sup> percentile) become the outcomes for these children.<sup>2</sup> More often than not, parents do not understand proper technique in treating these disorders and it can lead to increased stress for them and their child. Access to a community-based feeding program may provide critical education for the parents and caregivers who care for children with IDD.

To understand the critical need for a form of training for the caregiver, the seriousness of feeding disorders and how they affect caregiver and child must be discussed. Less severe disorders include selectivity of certain foods, food refusal, tantrums during feeding times, disruptive behaviors and self-inflicting of harm.<sup>2</sup> Progression of these abnormalities during feeding time can lead to an excess or deficiency of certain nutrients which may cause other issues in the physical development of the child.<sup>3-5</sup> Moreover, great stress on both the caregiver and child is experienced. When attempting to provide a comfortable and safe environment for their child, backtracking and watching them struggle creates frustration. More severe feeding disorders include overeating, under-eating, or delays of development for chewing and

swallowing.<sup>2,6</sup> Aspiration of and choking on food could lead to increased illness, increased hospital expenses and furthermore, poor growth and malnutrition of the child.<sup>2</sup> The effects of one feeding disorder may have cascading negative effects in many areas of development. Potentially, if just one disorder was corrected or improved such as oral - motor skills, child and caregiver quality of life improves greatly.

As previously mentioned, the mental and emotional well-being of a parent or caregiver can be critical in the successful development and growth of a child with IDD.<sup>7</sup> When caregivers do not have the available help for the significant disorders, an increase in stress, anxiety and depression may occur.<sup>1</sup> A primary function of a parent is to nurture, teach and love their child. Stress placed on eating situations may create rifts in the important bonds between parent and child. When interventions for feeding disorders are available, they are often directed towards the child and the child's behavior<sup>1</sup>; however it is important to consider an intervention for the parents and caregivers so that they too can grow and develop their skills, and further understand the needs of their child and how to meet them. By doing so, the stress may be relieved and caregivers are provided lifelong tools that can be employed when resistance is met later on. Adults can then adapt to situations as the child continues to develop.

Addressing these issues may decrease long-term medical costs for the families as well as decrease the number of children with IDD in the FTT category. In 2001, a study was completed indicating that 80% of families with children with special health care needs pay out-of-pocket for the necessary services.<sup>8</sup> The needs of these families must be met through available and accessible venues such as community feeding clinics or programs staffed with professional speech and language therapists, occupational and

physical therapists, behavior analysts, nutritionists and social workers and made available to working families. Community help needs to be affordable; when a child has been diagnosed with IDD, there is a relatively high cost of caring for them depending on where the family lives and the coverage of their insurance.<sup>8,9</sup> Well-rounded care in this manner can only provide positive outcomes for both child and caregiver. The obstacles here are the availability and accessibility of these community projects.

An important aspect of the research will be to assess if there is any form of help currently available and if that help provides the assistance these caregivers need. Questionnaires can be important in detailing the services currently available, the needs and desires of the stakeholders, and evaluating the requirement or the success of an intervention. Questionnaires can provide direct opinion from the stakeholders based on answers received for multiple response questions and fill in the blank responses. They are a low-risk, non-invasive way of finding out personal information and personal beliefs or needs of a population. The purpose of this study is to distribute questionnaires to assess the needs of caregivers who have a child with IDD and feeding disorders in Shelby County, Tennessee. The mean household income of Memphis, TN in 2011 was \$46,102 and the percentage of residents below the poverty line was 20.1%<sup>10</sup>, indicating families from Shelby County may not have the financial resources needed to provide services for their child with IDD. The results of this study will inform future research in the development of community clinics or programs that can be affordable to these parents and caregivers. Utilizing a questionnaire compiled of mixed quantitative and qualitative questions may provide answers to these demands:

1. Can these parents find sufficient help to educate and aid them in fighting the battle of providing adequate nutrition for their child?
2. Do these families have the resources available to tackle the issue of feeding problems?
3. If there are resources available, are they financially accessible for already struggling families?

To support this research it is critical to understand the prevalence and severity of feeding disorders in this population, the nutrition and health implications they may have, the resulting consequences for caregivers and the importance of community-based interventions in supporting change. A comprehensive discussion of a variety of feeding disorders and the impact it has on both a child with IDD and the caregiver will set the background for understanding whether help available through community options can impact those affected by feeding disorders.

## **CHAPTER 2**

### **LITERATURE REVIEW**

In order to completely understand the complications of a feeding problem in children with IDD, a comprehensive look at the background of this problem is necessary. Information on examples of non-organic and organic feeding disorders, effects the feeding problems have on nutritional intake and growth of the child, and how caregivers and parents are affected by these feeding problems will provide a solid framework for this demographic and why they may be searching for help. Discussing the use of questionnaires to develop community-based interventions will further support the need for the completion of this research in defining if there is a need for an intervention in this area.

#### **2.1 Types of Feeding Disorders**

Often, the feeding disorders of those with Intellectual and Developmental Disabilities (IDD) are grouped into two separate classes: non-organic and organic disorders.<sup>1</sup> The first class, non-organic, includes behavioral issues and are markedly less life-threatening than organic disorders, but influential in affecting the nutritional intake and overall environment of the feeding time. The second class of feeding disorders is grouped into organic disorders meaning the physical and medical barriers to receiving food. These disorders include skill problems that relate to muscle coordination like chewing and swallowing, and dysphagia related to poor oral-motor function.<sup>1</sup> This section will address these disorders and the effects they have on children with IDD.

### **2.1.1 Non-organic (behavioral) feeding disorders**

Gal and colleagues<sup>2</sup> found that regardless of severity of the intellectual disorder, extremely common feeding problems are behavior related. These behavioral issues can include stealing food both before and after meals, stealing from others during meals, eating very little or too much, eating inedible foods (Pica), food dislikes, and food refusal.<sup>2</sup> One or more of these problems can result in the child receiving too much or too little macronutrients. Paralleling these results, young toddlers with Down syndrome exhibit food selectivity and refusal in regards to textures and presentation, food pocketing in the buccal cavities, and removal or expulsion of food.<sup>6</sup>

Furthermore, several studies following children on the Autism Spectrum Disorder (ASD) found mild and severe cases of selective eating based on how the food was presented, the utensils needed for consumption, selection by food categories and consuming only pureed foods or foods made into a specific texture.<sup>11</sup> Ahearn and colleagues<sup>12</sup> found that children presenting with ASD had several issues with food refusal and several occurrences were with foods that had been consumed before with no problems, indicating the food refusal and selectivity is not necessarily related to the food presented, more of the learned behaviors of the child. These behaviors could lead to decreased nutrient intake.<sup>13</sup>

### **2.1.2 Organic (Physical and Medical) feeding disorders**

Organic feeding disorders can be observed in up to 80% of children with severe disabilities.<sup>2</sup> Moreover, in children with Down syndrome, the selectivity based on textures has some basis in physical oral-motor coordination. The pocketing of foods, the inability to swallow certain textures, and the bite of the child being inadequately

sustained or controlled leading to regurgitation or loss of food can impact the amount of food consumed.<sup>6</sup>

Additionally, swallowing disorders and co-morbidities can greatly affect the child's health status. Children who have severe feeding disorders such as dysphagia, vomiting, gastroesophageal reflux and rumination are at risk for aspiration, suffocation or pneumonia.<sup>2</sup> Binkley and colleagues<sup>14</sup> conducted a study testing children with poor oral-motor skills for potentially harmful bacteria in the oral biofilms in their mouths. The study confirmed that children with IDD have a higher percentage of *S. pneumoniae*, MRSA, and *C. albicans* in their oral biofilms and were nine times more likely to be diagnosed at a later time with pneumonia, sinusitis, bronchitis or an upper respiratory tract infection from aspiration of food particles that may contain these organisms.<sup>14</sup> This information suggests that children with these feeding problems need to have specialized methods for feeding in order to avoid the development of other illnesses. In addition, children with mild behavior problems, IDD, or ASD had mean numbers of co-morbidities (other medical problems which included metabolic dysfunctional disorders, gastrointestinal problems, cardiovascular issues, allergies, etc) of 2.89, 4.82, and 5.13 co-morbidities, respectively, indicating that multiple co-morbidities may play a role in the difficulties of meal times with these children.<sup>15</sup>

## **2.2 Nutritional Status of Children with Feeding Disorders**

The growth and development of a child with a feeding disorder can be greatly impacted depending on the types of food and the amount of food the child consumes or refuses. The nutritional intake, more specifically the child eating too much or too little, of certain food groups or of food in general can cause health problems. Selective eating or

the inability to chew or swallow a variety of textures can limit the variety of the child's diet and thus decrease the nutrient intake<sup>2</sup>, which can then affect the child's growth.

### **2.2.1 Nutritional intake**

Nutritional status of children with IDD can be severely impacted with the presence of a feeding disorder. For example, the nutrient intake of children with ASD is significantly less compared to children without ASD, and the children with autism tend to consume a much narrower variety of foods.<sup>11,13</sup> One young child with ASD was found to have serious vitamin A and vitamin D deficiencies presenting in a limp, periorbital swelling, xerophthalmia (inability to produce sufficient tears for eyes) and several other symptoms which were due to consuming a diet of only French fries and water for many years.<sup>3</sup> Although this is an extreme case, macro and micronutrients are vital for the growth and development of children; re-introducing this child to a varied diet including the vitamin A and D needs resolved the presenting problems.<sup>12</sup> Pica, the consumption of non-nutritive substances, can also pose life-threatening issues in children with severe developmental disabilities; it can be associated with lead poisoning, blockage of the intestines, parasites, and overall, FTT in younger children due to the lack of nutritional value in the items being consumed.<sup>2</sup>

Underweight, overweight and obesity are nutritional problems that may affect children who express feeding disorders such as stealing and hiding food, selective eating and overeating. A study completed with children with ASD ranging from 2 to 11 years found that those aged 2-5 were more likely to be overweight or obese than typically developing children, where as children with ASD ages 6-11 were more likely to be underweight.<sup>4</sup> Similarly, another study completed with Chinese children with ASD

found that in a sample of 111, 31.5% were overweight or obese and 8.1% suffered from acute or chronic undernutrition.<sup>5</sup> Deficiencies in vitamins A and D were found in individuals in both studies due to the food selectivity and limited intake of the children.<sup>4,5</sup> Furthermore, Hediger and colleagues<sup>16</sup> found that children with ASD may have poorer bone density than an age-matched normally developing group of children due to the selective intake of foods.

### **2.2.2 Growth and development**

An important area to be monitored in these children is growth and development and how it is impacted by the nutritional intake. There is a correlation between feeding disorders and height and weight for children with developmental disabilities, which varies according to the affecting disability.<sup>17</sup> Thommessen and colleagues<sup>17</sup> found that children with self-feeding impairment and lack of oral-motor skills were at a higher risk for growth retardation. Some believe that growth retardation is caused by neurological complications, however proper nutrition can impact growth in severely disabled children.<sup>18</sup>

Children who suffer from cerebral palsy tend to have higher instances of malnutrition due to their increased caloric need and gastrointestinal issues.<sup>19</sup> The shorter stature and lower weight of children with cerebral palsy may hide a lack of growth and development to the untrained caregiver's eye and thus the problem may not be identified quickly enough to prevent further issues involved in malnutrition.<sup>20</sup> Campanozzi and colleagues<sup>19</sup> found that 33% of the 21 children in their study suffering from Cerebral palsy and mental retardation had acute malnutrition grade I (>80% weight / <90% height) according to their weight-to-height ratio, and 19% of the children had acute malnutrition

grade II ( $< / = 80\%$  weight/height). Results suggestive of organic feeding disorders (medical problems) may indicate the child requires a trained caregiver able to look for specific signs that may indicate malnutrition to prevent untreatable damage.

### **2.3 Feeding Challenges**

The experience of the parent or caregiver is important in understanding the climate of the feeding experience. Trier and Thomas<sup>21</sup> review on feeding children with IDD introduces interesting points in relation to the caregiver and the perceived notions of their child's feeding disabilities. Research has estimated that feeding a child with a developmental disability may take up to 15 times longer than feeding a child without a developmental disability.<sup>21</sup> Craig and colleagues<sup>22</sup> spoke with mothers of children with disabilities and found that when feeding their child orally, meal times could last anywhere from 5 to 8 hours throughout the day and often spoke of the experience as “a battle”, “war” or “torture”. The negative connotation of these words points to a stressful environment for both parent and child. Parents and caregivers also discussed feeling personally responsible for the nutritional status of their child regardless of the child's feeding disorder.<sup>1,22</sup>

In opposition, another study completed by Reilly and colleagues<sup>23</sup> found that increased length of time is not always spent feeding these children, but perhaps the parents or caregivers perceive it to take longer due to the increased stress associated with meal times. Measuring the actual stress levels of parents and caregivers with children suffering from feeding disorders showed that the levels of stress of a caregiver correlates with the frequency with which the feeding issues occur during mealtimes.<sup>7</sup> The greater number of issues involved during the meal time could mean more stress for the caregiver.

Clinically significant levels of anxiety, depression and stress were found in a study of parents and caregivers who had a child with IDD, potentially creating a road block in the improvement of meal times with the affected children.<sup>1</sup>

### **2.3.1 Parent and caregiver support and feeding disorders**

Support is a common discussion topic in multiple studies and provides insight into the lives of caregivers and their personal needs. Caregivers often discuss coping mechanisms such as having other caregivers experiencing similar situations available to talk to, share struggles and sympathize with.<sup>1,22</sup> Coping strategies were discussed in Jones and colleagues<sup>1</sup> discussion groups with mothers of children with disabilities, signifying that parents and caregivers feel isolated, alone, and are looking for help in dealing with these problems.<sup>1</sup> A lack of support within the home from spouses and other family members could also be a barrier to the success of a meal time.<sup>6</sup> When surgical interventions such as a gastrostomy tube placement were encouraged, parents felt that surgical solutions could be avoided if other options for treatment (such as therapy) were available<sup>22</sup>, suggesting that parents and caregivers might rather implement therapy before taking serious medical measures to provide food for their child. However, the caregivers would need support and information in order to make an informed decision.

### **2.4 Interventions for Feeding Disorders**

Interventions, whether provided through clinics or community-based programs, may be effective in contributing valuable education and applicable skills in combating the struggles of feeding disorders in children with IDD. A variety of beneficial options exist such as enteral feeding through gastric tube placement<sup>20</sup>, physical and behavioral therapy

and group classes<sup>24,25</sup>. The problem for these families may arise in the availability of and access to these treatment interventions in order for them to retain maximum benefit.

#### **2.4.1 Gastric tube placement**

When a child with severe developmental disabilities does suffer from malnutrition or cannot receive adequate calories, gastric tubes are surgically placed.<sup>20</sup> Parents often want to avoid this option for a variety of reasons. Some are unaware of the procedure or apprehensive of what risks it may possess which makes them less likely to want to go that route.<sup>22</sup> Other parents and caregivers feel like it takes away from bonding with the child, making the already complex situation even more complex.<sup>20</sup> If a gastric tube becomes the best option, then parents need to have training and support so they can continue to bond with their child and provide safe energy and nutrients.<sup>22</sup> A gastric tube has the benefit of providing more freedom for the parent and can improve growth and development. In one study of children who had gastric tubes placed, the number of children suffering from malnutrition decreased from 67% pre-tube placement to 5% post-tube placement.<sup>26</sup> Clearly, parents and caregivers need comprehensive information before making medical decisions of this magnitude; information about treatment options could be provided through group classes.

#### **2.4.2 Interdisciplinary team and treatment**

Several studies have been completed indicating a multidisciplinary program is most effective in treating both organic and non-organic feeding disorders in children with IDD.<sup>21,24</sup> Babbitt and colleagues<sup>24</sup> found that after an in-patient stay and attending therapy with a multidisciplinary team, many of the children progressed to higher levels of food textures, some were able to self-feed and many of the children gained weight. Laud

and colleagues<sup>25</sup> found similar positive results. Their study indicated that when a comprehensive approach with speech and occupational therapists, gastroenterologists, pediatricians, nurse practitioners, behavior analysts, and nutritionists were present during the therapy, children were observed to have increased food acceptance and increased total grams of food consumed, as well as resulting in an increased satisfaction score for parents and caregivers.<sup>25</sup> This indicates the therapy can provide positive health-related outcomes for children and positive environmental outcomes for parents and caregivers. Even more specifically, behavioral treatment and modifications within in-patient settings, in community programs or during home based therapy can often provide successful outcomes.<sup>27</sup> Furthermore, research has been completed not just on the behavioral treatment aspect of feeding problems, but on the types of foods presented to the children during therapy. Behavioral therapy can be made more effective if the right foods are presented; by creating a preferred food list for children at differing age levels, children were more likely to accept versus refuse foods thus making treatments more effective.<sup>28</sup>

### **2.4.3 Community- based intervention**

Difficulties arise in creating a community intervention-based treatment plan for children with feeding disorders due to the individual nature of each patient. Treatment goals can change quickly and when caregivers or therapists have different skill levels, meeting these goals can become difficult. Linscheid and colleagues<sup>27</sup> propose that primary difficulties in addressing these feeding disorders fall on the referral process and the ability to work with caregivers, therapists and insurance coverage to provide the correct types of treatment. Recognizing the economic contingencies from the

government and insurance companies is crucial to finding an intervention that can be made available to a wide community base.<sup>24</sup>

Community interventions can be critical in advocating strategies, information and services that prevent dysfunction and promote well-being among a defined community population<sup>29</sup>, in this case, the children and families of children with IDD suffering from feeding disorders. Community interventions can be difficult to employ and require a clear need before the process of developing and implementing interventions can begin.<sup>29</sup> Questionnaires can be an effective method in providing beneficial information about the personal beliefs of participants and direct stakeholders in a given situation. The method is objective with low risk required for the participants, especially if the questionnaire requires no personal identifying information. A community intervention such as increased marketing or development of services can be identified and further adapted to meet the needs of stakeholders through responses from completed questionnaires.

#### **2.4.4 Availability of resources**

Cost of care can be a huge factor in accessing needed services for children with IDD. Depending on the state of residency, the cost of special needs therapy is paid for out of pocket by a majority (around 80%) of these families, excluding those services provided by the schools.<sup>8</sup> When one caregiver must minimize or completely eliminate one job, it decreases income and increases the economic burden.<sup>9</sup> Currently, under the Tennessee Early Intervention System, the services needed to treat problematic feeding disorders such as speech and occupational therapies and nutrition therapy are covered for children with IDD until the age of three if the child is eligible.<sup>30</sup> After this point, Occupational and Speech therapy is covered by the schools, but feeding therapy is not. It

is up to the parents to pay for these services which can be costly unless they qualify for Medicaid/Medicare/TenCare.<sup>30</sup> The mean household income and the percentage of families below the poverty line in Memphis, TN could indicate a lack of available resources for families just above the poverty line and those who are unaware of the continuation of services using Medicare.

## **2.5 Purpose of Research**

This research will determine whether there is a lack of support for families who have children with developmental disorders who experience feeding problems in the Shelby County area of Memphis. The severity of a feeding problem can greatly hinder a child with developmental disabilities and keep them from reaching their growth potential. Due to the shortage of community based programs which can provide a variety of critical services, families are left to struggle and continue to find their own methods of trying to provide beneficial mealtimes for their child. Even when there are available services through Medicare, families may not be aware of these services or know how to access them. Through questionnaires answered by parents and caregivers who struggle to feed their children, the need for a community based feeding clinic or community support systems will be established by indicating the specific needs and how to create available services.

## **CHAPTER 3**

### **METHODS**

#### **3.1 Participants**

Potential participants for recruitment for the completion of the questionnaire are members of the Shelby County regional Special Education Parent Teacher Alliance (SEPTA) group and members of Support and Training for Exceptional Parents in Tennessee (STEP-TN). Both of these groups help parents with education and life skill needs for children with intellectual and developmental disabilities (IDD).

#### **3.2 Inclusion criteria**

In order to ensure the data collected represents the needs of parents and caregivers within the community, these prioritized criteria must be met:

1. Participant has a child with IDD between the ages of 3 and 18.
2. Child has feeding disorder per parent report.
3. Participant is the primary caregiver or parent.

If the member does not have a child with disabilities over the age of three or is not the primary caregiver of the child with disabilities they will not be included in the data collection process.

#### **3.3 Intervention and Data Collection**

A questionnaire was developed with twenty-three questions; a mixture of both multiple choice and free-response answers were included (APPENDIX A). The questionnaire was created for online distribution utilizing Qualtrics Research Software. Participation in the questionnaire was completely voluntary. The questionnaire was

distributed to community members through e-mail and notification on both group websites. The time period for completion of the survey was three months.

### **3.4 Measures and Data Analysis**

The data was analyzed using the Statistical Package for the Social Sciences software (Version 21 for Windows 2012, SPSS Inc, Chicago, IL). The quantitative questions provided frequency and percentages for responses of the parents or caregivers. The qualitative free-response questions provided more personal accounts of the participants' struggles. Common themes of these responses was compiled and reported. Any outlying or important descriptive data was also recorded. Free-responses provided information about any services currently utilized by participants which may offer more information about existing services.

## CHAPTER 4

### RESULTS

The response was limited; the e-mail was sent to 665 parents throughout the Shelby County area and posted on both group website/newsletters. Only nine participants responded and only eight (n = 8) of the questionnaire responses were considered valid (n = number of participants). The majority of the participants responded to all questionnaire sections (n = 6); however some participants elected to skip questions in the section regarding the search for services and the perceived value of quality of services (n = 2).

#### 4.1 Demographics of Participants

Table 1 (APPENDIX D) displays the demographics of the participants. The majority of the children with IDD fell into the 6-12 year age range at 75%. All of the participants were a parent of the child with IDD. The majority (50%) of the participants had a total annual income of over \$100,000. Diagnoses of the participants' children included high functioning Autism (12.5%), Asperger's (12.5%), attention deficit hyperactivity disorder (ADHD) (12.5%), sensory processing/integration disorder (37.5%), obsessive compulsive disorder (OCD) (12.5%), Down syndrome (12.5%), rheumatic fever (12.5%), auditory language processing disorder (12.5%), epilepsy (12.5%), and cerebral palsy (12.5%).

Feeding problems noted by participants included active gag reflex (12.5%), picky eating (50%), food aversions (12.5%), increased perception of textures (25%), reflux (25%), choking on food or saliva (12.5%), and decreased appetite and inability to make decisions on what to eat (12.5%).

## **4.2 Assessment of Personal Skills and Needs**

Table 2 (APPENDIX D) displays the responses of participants of how they view their personal skills treating their child's feeding disorder. All participants reported a problem in feeding or mealtime behavior that has been occurring longer than one year. The feeding disorder or problem has remained "about the same" for 62.5% of the participants, while 37.5% reported the problem was "getting better". Fifty percent of participants reported they felt "somewhat capable" in handling the problem on their own, 25% found themselves to be "very capable", while only 12.5% reported feeling "not capable" of handling the problem. No participants reported having "no strategies" in helping their child or not feeling confident in their strategies in dealing with the problem. An even split between feeling "very confident" (50%) and "somewhat confident" (50%) occurred when discussing current strategies being utilized in dealing with their child's problem.

## **4.3 The Search for Professional Help**

Table 3 (APPENDIX D) outlines the participants' search for professional help in treatment and management of their child's feeding or mealtime problems. Although participants chose not to answer particular questions, the majority (50%) had attempted to find professional help once, while 37.5% had never looked for professional services. Half (50%) of participants said it was "somewhat difficult" to find these services, while 12.5% found it either "somewhat easy" or were "neutral" on the subject. The route of finding services was split evenly between finding services on their own, and having services or professionals recommended or referred by someone else.

Table 4 (APPENDIX D) provides the participants' responses in regards to the assessment of the services obtained. Equal representation (37.5%) was observed in finding the services "helpful" or "neutral" about the participants' experiences receiving services. Only 4 participants answered the survey question regarding the affordability of services. The majority of services obtained were through occupational therapists at 75%. A speech and language pathologist was utilized by 37.5% of participants, while 25% used a behavioral analyst and 0% utilized services from a registered dietitian. Services can often be offered through interdisciplinary teams therefore participants were allowed to answer the question with more than one response, therefore the percentages do not add to a total of 100%.

#### **4.4 Perceived Assessment of Community Services**

The perceived assessment of the community and the services provided in the community are outlined in Table 5 (APPENDIX D). When assessing the participants' belief in how well Shelby County is meeting their needs in this area with services, the responses were wide spread; 12.5% of the participants replied "strongly agree", "agree", or "strongly disagree". The responses "neither agree nor disagree" and "disagree" were each selected by 25% of the participants. The same distribution of responses occurred when assessing the participants feeling of support in this area from Shelby County. The participants that "disagree" that Shelby County is working towards meeting these needs totaled at 37.5%. The other participants' responses were spread across the spectrum. Only 12.5% strongly agreed with that statement, while only 12.5% strongly disagreed with the statement.

When discussing the participants' activity within the community, a majority (75%) of participants knew of other parents or families who also have children with IDD and have feeding disorders, although not every participant answered this question. Only 37.5% of participants responded that they did belong to a support group for children with IDD who also have feeding disorders; the majority (50%) responded that they did not belong to a support group. One participant (12.5%) did not respond to this question.

The final portion of the survey assessing perceived community support allowed participants to respond with personal opinions. Common responses among participants in how they would like Shelby County to help meet their needs included changing how insurance companies cover behavioral and occupational therapies (moving from only 'medically fragile' to 'behavioral' as well). Two participants stated there should be more service providers advertising their expertise, or working with other healthcare professionals towards more referrals. One participant replied that the biggest barrier was financial issues; services are available, but the cost of services is limiting. Another participant replied that traveling several states away monthly in order to receive services for feeding disorders was necessary to meet the needs of their child. All of the participants but one (12.5%) answered this survey question.

## CHAPTER 5

### DISCUSSION

The results from the study are not completely encouraging; based on the results, Shelby County does not seem to be meeting the treatment needs of the families who have children with IDD who also have feeding disorders. The majority of participants were neutral or in disagreement with the statements regarding Shelby County actively working towards or meeting the needs of these families. The response rate for the questionnaire was very low; eight participants completed it and one of those participants did not fully complete the questionnaire. Over 650 parents involved with STEP-TN and SEPTA received the link to the questionnaire through either e-mail or newsletters. One reason the response rate was so low could be the lack of access. If Shelby County residents do not have access to computers, they may not have been able to respond to the questionnaire. This population may not have been adequately reached.

Jones and Bryant-Waugh<sup>1</sup> reported that up to 80% of children with IDD may be affected by a feeding disorder; if each of the 650 parents that received an e-mail had a child with IDD then Shelby County may not follow this statistic or the targeted participants may not have been adequately reached. Perhaps the feeding disorders are not thought to be as stressful or significant to parents and caregivers as Greer and colleagues<sup>7</sup> participants reported. One participant responded by saying that the feeding disorder may take the backseat as far as priority when it comes down to all of the other medical issues the child is experiencing.

The demographics of the participants and their children were widespread. The majority of the children were between 6 and 12 years of age which may suggest that

children may have the biggest problem with feeding disorders during the middle developmental stages of life. This is important to note because Tennessee Early Intervention Services (TEIS) end at the age of three years; the majority of the children of the participants would not be covered under TEIS. All of the participants who responded to the questionnaire were parents. The majority had an annual household income of \$100,000 or more a year which is suggestive that the participants have the ability to find and afford services more readily than other families and pay out of pocket for them as Shattuck and Parish<sup>8</sup> suggested. Furthermore, only one participant reported making less than \$25,000 annually and only two reported making \$26,000-\$50,000 annually. The demographics do not seem to be fully representative of Shelby County whose average household income is \$46, 102<sup>10</sup>.

The diagnoses reported specify that these feeding problems are experienced across a multitude of developmental disabilities with the only repeated diagnoses being autism spectrum disorder and sensory processing/integration disorder. As would likely be expected, because eating is a sensory loaded process, the children with a sensory processing/integration disorder may have more problems and perhaps require more therapy in order to make progress with the feeding disorder. Picky eating was the highest reported issue that occurred with the participants' child meaning that a larger percentage of children would require increased behavior therapy to help with introduction of foods and to overcome picky eating. A variety of other feeding disorders were mentioned supporting the research suggesting feeding disorders are grouped into both organic and non-organic areas<sup>2,6,11,15</sup>.

## 5.1 Assessment of Personal Skills

All of the participants reported having experienced a feeding problem with their child occurring for longer than a year. The majority of the participants reported that the problems they were experiencing had remained about the same since when they began, while the rest of the participants reported that the problem was getting better. No participants reported the problem getting worse. Parents could be handling the less serious feeding disorders (not medically threatening) in their own way, without searching for therapeutic services and thus perceive the problem to be getting better because they are working towards a solution. The literature reviewed suggested that parents were feeling incapable of dealing with the issues without help<sup>1,7</sup> however the research in Shelby County suggests that they feel “capable” or “neutral” about their ability to deal with their child’s feeding disorder. Only one participant reported feeling incapable of dealing with the feeding disorder the child was experiencing. None of the participants felt “unconfident with their current strategies” or felt as if they “did not have strategies” to utilize in dealing with the feeding disorders. These responses may indicate that parents have either found services or have found methods to handle the disorders without services signifying that the disorders may not have been as life-threatening or serious as expected. On the contrary, the participants might just feel as though the strategies they employ are working, however perhaps the participant has just become more comfortable with a “routine” in dealing with the feeding disorder because it has become a long-term problem.

## **5.2 The Search for Professional Help**

More than one of the participants elected to not respond to the questions regarding searching for professional help. Those participants may not have needed services. None of the participants expressed searching for services more than once possibly meaning they were either found on the first try and thus are easily accessible or the parents were immediately discouraged during their initial search. However, the difficulty of finding these services ranged anywhere between “somewhat difficult” to “somewhat easy” indicating there are services available but not readily accessible by families because none of the participants selected “very difficult”. Half of the participants responded that they had searched for these services at least once, indicating there is at the very least, a need for services or better marketing of these services.

The preferred choice for the participants in treating the feeding disorders was through an occupational therapist which assumes that the behavioral issues are difficult to manage by the parents alone. Speech and language pathologists and behavioral analysts were also chosen as the treatment services of choice. Registered dietitians were not selected by participants demonstrating that registered dietitians do not provide the kind of treatment needed or is perceived as valuable services for feeding disorders. The participants indicated the services rendered were “helpful” or “neutral” however these terms were not defined in the questionnaire. Perhaps the participants felt utilizing services was helping the situation but if the question had been more defined, the participant might have been able to describe any changes in meal times, behaviors, foods consumed, etc, and thus quantifying the changes in order to understand if the services really were “helpful”.

Parents seem to be looking for services and overall the services seem to be financially accessible to them, but the problem arises with the actual search for the services. Although the participants were capable of selecting more than one service provider (e.g. use of a multidisciplinary team), none of the participants selected more than one. Trier and Thomas<sup>21</sup>, Babbitt and colleagues<sup>24</sup>, and Laud and colleagues<sup>25</sup> all suggest that a multidisciplinary team is the most effective in treating feeding disorders, however the participants in Shelby County do not report utilizing a multidisciplinary team. Many reasons for this may exist; perhaps the services are not offered together, are too expensive separately, or even not necessary specific to the feeding disorder. If the services rendered by participants were “helpful” or “neutral”, then perhaps a multidisciplinary team treatment was not necessarily required.

### **5.3 Perceived Assessment of Community Services**

In assessing the needs within the community, the researcher first must understand the current community atmosphere and the services available. The participants were widespread in responses regarding the perceived assessment of community services, however the majority falls into the “neither agree nor disagree” category or the “disagree” category when discussing the current ability of Shelby County to meet feeding disorder needs. Even if the participants are mainly neutral on the subject, there is a slight opinion that the community is not meeting the needs of these parents and children due to the “disagree” responses. Because the number of participants is small and there still are participants who “agreed”, perhaps this is indicative of a lack of advertisement for services or a financial difference in participants. Perhaps the services are available however are not readily accessible to some of these families.

The general consensus when discussing improving community services was mainly focusing on referrals from physicians to services indicating that the participants believe there are services available<sup>27</sup>, but would need the referral to find them. Another topic of discussion mentioned by more than one participant included how insurance companies cover the needed services. Contraindicative of these responses, the reported services employed by the participants were found either through personal research or through referrals or recommendations indicating that the referral process is somewhat effective. Not enough information was collected in regards to insurance coverage and means of providing services to support Linscheid and colleagues'<sup>27</sup> proposal that the primary barrier to treating feeding disorders falls on the referral process and insurance coverage<sup>27</sup>, but responses did provide some support for the referral process. Overall, if families are unable to obtain these services due to paying out of pocket or lack of insurance coverage, then the community is not meeting their needs.

#### **5.4 Limitations**

A large limitation to this study was the lack of participation from parents and caregivers within the community. The number of potential participants that were reached through e-mail and newsletters (665 parents of children with IDD) did not provide large numbers of participants, just the opposite (n = 8). The lack of response could be the most important limiting factor of the results. The research supports that there are professionals that provide services for feeding disorders and they are somewhat useful in treating the disorders, however it cannot be suggested that Shelby County is meeting the needs of families of children with IDD experiencing feeding disorders. If the research could be executed for a longer period of time and continue to recruit participants from the

community, it may provide a better perspective on the actual needs and the assessment of the community. If the time frame was not long enough to find the parents who actually cannot find services and struggle in this area, then the research cannot effectively reflect the needs of Shelby County.

Another limitation of the study was the lack of response within the questionnaire. Many questions on the questionnaire were answered by some participants while other questions were not. With such a small sample size, it greatly affects the data and does not provide an accurate representation of the question addressed. The participant may not have felt as though the question pertained to their situation however, any information they may have provided could have been useful. The questionnaire itself was of a short length and did not require much time to complete, though the consent page was a full page of text which might have been unappealing to some potential participants.

E-mail was not a successful method in reaching the targeted participants in this study. Access to a computer, internet or e-mail could provide potential barriers to participation in the questionnaire. In a county with an average 20.1% of residents below the poverty line<sup>10</sup>, there is a chance that participants with limited finances may also have limited access to a computer. Participants in this category may be the families in the most need of services and also may be the least able to afford those services. Responses from potential participants that do not have access to computers, internet or email would have provided critical information to this study.

## **5.5 Future Research**

In the future, conducting the questionnaire in person with the participants may provide a higher response rate. Participants may be more willing to complete the questionnaire if the consent is verbalized and the questions are asked in person, so that clarification can occur if necessary. Expanding upon the questions of the questionnaire itself and making them more descriptive and specific might provide more detailed information to back the information obtained from the initial survey. Asking the participants to clarify their responses and be as unambiguous and objective as possible might change the responses. More questions regarding specific demographics and more in-depth finances could provide information more representative of Shelby County. Defining the terms “helpful”, “capable” or “getting better/worse” in the questions, or asking the participant to describe the outcomes of their actions in dealing with the feeding disorder may give a better background for how serious the disorder may be and how well they are treating it alone. Asking what specific support groups participants are members of supplies a greater potential participant pool or resource for information.

An area of research that would further benefit the study would be to survey doctors in the Memphis area and see how many of them are currently healthcare providers for children with IDD. Furthermore, asking the doctors about the specific feeding disorders the child may experience, the severity of the disorder, how they treat the feeding disorders and who they refer families to (if at all), could provide critical information about the services available. Information from the doctor would be more objective and less subjective than the information provided by the primary caregivers of the child. Perhaps the doctors would be able to shed light on what other medical

problems the children with IDD experience and how that may affect the services referred to and chosen. Discussions with special education teachers or assistants in schools might provide a better understanding of the current situation or severity of feeding disorders in children with IDD, and how they are managed if they are in school.

## **5.6 Conclusions**

The Shelby County community is not meeting the needs of parents with children with IDD who experience feeding disorders. The demographics of the sample does not seem to reflect Memphis, TN and therefore may not provide an accurate idea of the availability and accessibility of resources for children with IDD who experience feeding disorders. The lack of response is the largest limitation in the research and therefore conclusions may not be reflective of the actual needs of the community; more detailed research should be conducted to obtain more substantial information.

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**APPENDIX A**  
**MEALTIME FEEDING PROBLEMS**  
**SURVEY QUESTIONNAIRE**

You are being invited to take part in a research study about community-based services for children with intellectual and developmental disabilities (IDD) who also express a feeding disorder. You have been invited to take part because you have a child with IDD, a feeding disorder and you are the primary parent or caregiver of this child.

The person in charge of this study is Laurel Welborne, a graduate student at the University of Memphis in the Clinical Nutrition department. She is being guided in this research by Dr. Terra Smith. There may be other people on the research team assisting at different times throughout the study.

**PURPOSE**

The purpose of this study is to reach out to parents or caregivers of children with IDD who also express feeding problems. In completing this study, we hope to understand what problems parents face in feeding their child. The research will discover if there are readily available community-based services that can provide information for them on how to address their child's feeding problems, and if so, where these services have been found. If services are difficult to locate or nonexistent, then this research may conclude that more community-based services for children with IDD and feeding disorders need to be developed within the Memphis area.

**BENEFIT**

There is no guarantee that you will receive any benefits from taking part in this study. Your willingness to take part however, may help the Memphis area community understand the needs of parents or caregivers such as yourself, and the needs of your child, and hopefully rise to meet those needs.

If you decide to take part in the study, it should be because you want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. You will not receive any awards for taking part in this study. There are no costs associated with this study.

**PRIVACY OF INFORMATION**

We will make every effort to keep private all research records that identify you to the extent allowed by law. Your information will be combined with information from other people taking part in the study. We may publish the results of this study; however, identifying information will be kept private. We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. All records of information will be locked up at the University of Memphis for five years, and then destroyed.

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.

If you have questions, suggestions, concerns, or complaints about the study, you can contact the investigator, Laurel Welborne at 720-206-4722. If you have any questions about your rights as a volunteer in this research, contact the Institutional Review Board staff at the University of Memphis at 901-678-3074.

- a. I consent
- b. I do not consent

My child is:

- a. 3-5 years old
- b. 6- 12 years old
- c. 13-18 years old

My relation to the child is:

- a. Parent
- b. Grandparent
- c. Other family member
- d. Unrelated caregiver

The child has:

- a. 0 siblings
- b. 1 sibling
- c. 2 siblings
- d. 3 or more siblings

Please circle the range of your total annual family income.

- a. \$25,000 or less per year
- b. \$25,000-50,000 per year
- c. \$50,000-100,000 per year
- d. \$100,000 or more per year

In the box below, please describe any diagnoses related to Intellectual or Developmental Disabilities that your child may have:

In the box below, briefly discuss the feeding or eating problems your child may experience at meal times. What problems are there in regards to food intake and the physical ability to consume food. (E.g. picky eating, food aversion, aspiration of food, rumination of food, etc):

How long has your child been experiencing the problem(s)?

- a. Within the last month
- b. Within the last 6 months
- c. Within the last year
- d. Longer than a year

Is the problem(s) getting better or worse since your child began experiencing them?

- a. Better
- b. About the same
- c. Worse

How capable do you feel in handling any feeding/eating problems your child has?

- a. very capable
- b. Somewhat capable
- c. Neutral
- d. Not capable

How confident do you feel in the current strategies used to handle your child's feeding/eating problems at meal times?

- a. very confident
- b. somewhat confident
- c. not confident
- d. I do not have any strategies

How often have you looked for professional help to handle feeding problems in the last year?

- a. quite often (more than 4 times)
- b. at least once
- c. never

If you did look for professional help, what was the level of difficulty in finding it?

- a. very easy
- b. easy
- c. neutral
- d. difficult
- e. Very difficult

Any services that you were able to locate for the child were {please check all that apply}:

- a. Located yourself
- b. Located through another resource (e.g. organization)
- c. Recommended or referred by someone (e.g. friend, doctor, etc.)

Any services that were obtained for your child were:

- a. Extremely helpful
- b. Helpful
- c. Neutral
- d. Did not help

How affordable were/are these professional services?

- a. Very affordable
- b. Affordable
- c. Not affordable
- d. Could not utilize services because of financial constraints
- e. Not applicable

If you have found professional services, were/are they provided by a:

- a. Speech and Language Pathologist
- b. Occupational Therapist
- c. Registered Dietitian
- d. Behavior analyst
- e. Combination of any of the above
- f. Other

In the box below, please briefly describe any services you were able to locate within the Shelby County area and any resources utilized to find them:

Do you know other parents with children with Intellectual and Developmental Disabilities who also have feeding/eating problems?

- a. yes
- b. no

Do you belong to any support groups for parents or caregivers who have children who have Intellectual and Developmental Disabilities with feeding/eating problems?

- a. yes
- b. no

The community actively meets my needs in this area (services to help with feeding/eating problems):

- a. strongly agree
- b. agree
- c. neither
- d. disagree
- e. strongly disagree

I feel community support from Shelby County for my child in this area:

- a. strongly agree
- b. agree
- c. neither
- d. disagree
- e. strongly disagree

The Shelby County community is working towards making these needs more accessible to me and other families experiencing the same problems:

- a. strongly agree
- b. agree
- c. neither
- d. disagree
- e. strongly disagree

In the box below, please briefly describe how you feel the Shelby County community could better meet your needs for mealtime feeding problems:

**APPENDIX B**  
**EMAIL, NEWSLETTER, FLIER**

Hello, my name is Laurel Welborne and I am a graduate student of Clinical Nutrition at the University of Memphis. I am currently working on some research in the area of feeding disorders and how they affect children with intellectual and developmental disabilities as well as their family members. Mealtime and feeding problems may hinder their ability to eat all of the nutrients they need to grow properly. It can cause a lot of stress on the child and the family as well. I am working towards distributing online surveys for parents or caregivers of children with developmental disabilities to discuss and understand what problems they face during mealtimes, how they deal with them, if they feel as though they have adequate support in dealing with feeding problems, and whether or not they have access to this kind of support within the community. If the programs are already out there, then this research may indicate there needs to be better access to these programs for these families. If the programs are not available then the research may reinforce the need for the development of an educational clinic or support programs for parents within this community and will be further pursued.

If you are:

- A parent or caregiver of a child with Intellectual or Developmental Disabilities
- The child is between the ages of 3 and 18
- The child is having mealtime problems with feeding

And you are interested in participating in this survey, please follow the link below. The survey is 100% anonymous; no personal identifying information will be collected.

[http://memphishealthsport.qualtrics.com/SE/?SID=SV\\_0HheHeobyAkabad](http://memphishealthsport.qualtrics.com/SE/?SID=SV_0HheHeobyAkabad)

If you have any questions about the research that you would like answered prior to taking the survey please contact me at:

E-mail: [lwlb@memphis.edu](mailto:lwlb@memphis.edu)

Cell: 720-206-4722

**APPENDIX C  
IRB APPROVAL**

Hello,

The University of Memphis Institutional Review Board, FWA00006815, has reviewed and approved your submission in accordance with all applicable statuses and regulations as well as ethical principles.

**PI NAME:** Laurel Welborne

**CO-PI:** Dr. James Meindl , Ph. D., BCBA-D and Lee Wallace, Ms, RD, LDN, FADA

**PROJECT TITLE:** Assessment of Parents Educational Needs and the Availability of Resources for Feeding Children with Intellectual and Developmental Disabilities

**FACULTY ADVISOR NAME (if applicable):** Terra Smith

**IRB ID:** #2612

**APPROVAL DATE:** 6/21/2013

**EXPIRATION DATE:** 6/20/2013

**LEVEL OF REVIEW:** Expedited Modification

*Please Note: Modifications do not extend the expiration of the original approval*

**Approval of this project is given with the following obligations:**

- 1. If this IRB approval has an expiration date, an approved renewal must be in effect to continue the project prior to that date. If approval is not obtained, the human consent form(s) and recruiting material(s) are no longer valid and any research activities involving human subjects must stop.**
- 2. When the project is finished or terminated, a completion form must be completed and sent to the board.**
- 3. No change may be made in the approved protocol without prior board approval, whether the approved protocol was reviewed at the Exempt, Expedited or Full Board level.**
- 4. Exempt approval are considered to have no expiration date and no further review is necessary unless the protocol needs modification.**

**Approval of this project is given with the following special obligations:**

Thank you,

**Ronnie Priest, PhD  
Institutional Review Board Chair  
The University of Memphis.**

*Note: Review outcomes will be communicated to the email address on file. This email should be considered an official communication from the UM IRB. Consent Forms are no longer being stamped as well. Please contact the IRB at IRB@memphis.edu if a letter on IRB letterhead is required.*

**APPENDIX D  
TABLES**

**Table 1.** Questions regarding the demographics of participants.

<b>Demographic</b>	<b>n (%)</b>
<b>Child Age</b>	
3-5 years old	1 (12.5%)
6-12 years old	6 (75%)
12-18 years old	1 (12.5%)
<b>Relation to Child</b>	
Parent	8 (100%)
Grandparent	0 (0%)
Other family Member	0 (0%)
Unrelated Caregiver	0 (0%)
<b>Siblings of Child</b>	
0 siblings	3 (37.5%)
1 sibling	3 (37.5%)
2 siblings	1 (12.5%)
3 or more siblings	1 (12.5%)
<b>Annual Income Range</b>	
\$25,000 or less	1 (12.5%)
\$26,000-\$50,000	2 (25%)
\$51,000-\$99,000	0 (0%)
\$100,000 or more	4 (50%)
Did not respond	1 (12.5%)

**Table 2.** Personal assessment of child's feeding problem and parent or caregiver's ability to handle the problem.

<b>Survey Question Topic</b>	
<b>Length of Feeding Problem Existence</b>	<b>n (%)</b>
Within the last month	8 (100%)
Within the last 6 months	0 (0%)
Within the last year	0 (0%)
Longer than a year	0 (0%)
<b>Change in the Problem Since Development</b>	
Problem is better	3 (37.5)
Problem is about the same	5 (62.5%)
Problem is worse	0 (0%)
<b>Capability of Handling Problem</b>	
Very Capable	2 (25%)
Somewhat capable	4 (50%)
Neutral	1 (12.5%)
Not capable	1 (12.5%)
<b>Confidence in Current Strategies for Feeding Problems</b>	
Very confident	4 (50%)
Somewhat confident	4 (50%)
Not confident	0 (0%)
I do not have strategies	0 (0%)

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**Table 3.** Questions regarding the participants search for professional help.

<b>Response</b>	<b>n (%)</b>
<b>Frequency of searching for help*</b>	
Many times (more than four)	0 (0%)
At least once	4 (50%)
Never	3 (37.5%)
<b>Level of difficulty in finding help*</b>	
Very Easy	0 (0%)
Somewhat Easy	1 (12.5%)
Neutral	1 (12.5%)
Somewhat difficult	4 (50%)
Very difficult	0 (0%)
<b>How services were located**</b>	
Located yourself	4 (50%)
Located through another resource	0 (0%)
Recommended or Referred	4 (50%)

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**Table 4.** Participants' assessment of services obtained.

<b>Response</b>	<b>n (%)</b>
<b>Perceived value of quality of services*</b>	
Extremely Helpful	0 (0%)
Helpful	3 (37.5%)
Did not help	0 (0%)
Neutral	3 (37.5%)
<b>Affordability of services*</b>	
Very Affordable	0 (0%)
Affordable	4 (50%)
Could not utilize services due to cost	0 (0%)
Not applicable	0 (0%)
<b>Service providers utilized*</b>	
Speech and Language Pathologist	3 (37.5%)
Occupational Therapist	6 (75%)
Behavioral Analyst	2 (25%)
Registered Dietitian	0 (0%)

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\* Participants were able to select multiple answers or none at all therefore the total does not equal 100%.

**Table 5.** Perceived assessment of community services.\*

	<b>Strongly Agree n (%)</b>	<b>Agree n (%)</b>	<b>Neither Agree or Disagree n (%)</b>	<b>Disagree n (%)</b>	<b>Strongly Disagree n (%)</b>
<b>Shelby County actively meets my needs in treating my child's feeding/eating problems</b>	1 (12.5%)	1 (12.5%)	2 (25%)	2 (25%)	1 (12.5%)
<b>I feel support from Shelby County for my child in this area</b>	1 (12.5%)	1 (12.5%)	2 (25%)	2 (25%)	1 (12.5%)
<b>Shelby County community is working towards making these needs more accessible to me and other families experiencing these problems</b>	1 (12.5%)	1 (12.5%)	1 (12.5%)	3 (37.5%)	1 (12.5%)

\* Not all participants responded to these questions therefore the total does not equal 100%.