Educational & Developmental Intervention Services (EDIS) Personnel Development

KIT

Keeping In Touch

JULY 2016

Inside this edition

"Supporting Families of Young Children with Feeding Challenges."

Resource Article

Families with babies and toddlers who have been hospitalized and received medical feeding support, may view the idea of being discharged from the hospital, coming home with the child, and taking on the feeding responsibilities as daunting. But when the level of communication between the medical facility, parents, and community-based providers is high, successful feeding in the child's natural environment can be achieved. In her article, "Early Feeding Intervention: Transitioning from acute care to early intervention," VanDahm outlines strategies to enhance this process.

Feeding issues are not uncommon for children in the general population. In fact, estimates of 25 to 40% of young children have feeding challenges and this estimate increases to 85% for children with developmental disabilities (Bernard-Bonnin, 2006; Manikam & Perman, 2000). Dysphagia, Aspiration, and Feeding Disorders are among the most common terms used to refer to feeding issues. Children with feeding issues may be born prematurely, suffer medical conditions (e.g., cerebral palsy, seizure disorder, cleft lip, etc.) that require medications that may affect feeding, or experience failure to thrive.

The role of medical providers addressing children's feeding issues differs from that of community-based providers working with families in their homes. Medical providers often conduct feeding evaluations, make recommendations for and carry out additional testing (such as the Modified Barium Swallow [MBS] or Fiberoptic Endoscopic Evaluation of Swallowing [FEES]). VanDahm explains that these procedures have two purposes, "…to identify or negate the presence of penetration or aspiration, and to identify an appropriate means of intervention to support safer feeding" (p. 12). Medical feeding teams are interdisciplinary in nature and often consist of the child's primary care provider, nursing staff, a dietician to address nutritional needs, a Speech-Language Pathologist to address feeding and swallowing needs, an occupational therapist to address sensory and fine motor needs and of course the child's parents. Even though medical providers work in the same facility, the communication between and among providers and the parents can

Resource Article (continued)

be confusing for parents. Direct communication among and between team members is of paramount importance. Some strategies to facilitate communication within a medical team include:

- Determining the types of supports available to the family (e.g., equipment, access to early intervention programs, home nursing).
- Considering the challenges the family may face (e.g., single parent/limited family support, limited income, transportation and learning barriers).
- Sharing information about the family's supports and challenges to amongst the team.
- Providing written instruction, electronic resources to the family to include the discharge summary.
- Providing contact information for the hospital feeding team as well as contacts within the community.

Medical teams often refer families to community-based services such as visiting nursing programs, Women-Infant-Children, early intervention, schools, etc.). The role of community-based providers in supporting families of children with feeding challenges will differ from that of the medical-based team. Community-based providers help families understand and build their confidence and capacity to implement strategies that can support their child's feeding and monitor their child's feeding status (are they gaining weight, is the feeding going well, etc.). Strategies for helping families transition to feeding their children in natural environments include:

- Review the discharge summary with the family.
- Check-in with families to determine their perceptions and understanding of the feeding concerns, current status of the child, and recommendations made by the team.
- Help families understand and monitor their child's status (medical and feeding).
- Help families move forward with recommendations by considering the stress and trauma they may have experienced throughout the hospitalization and current feeding situation (working through guilt and denial).
- Continue to share information with the hospital feeding team (as necessary updating them on the child's status, seeking out additional support, and encouraging families to following through with appointments).

When medical feeding teams and community-based providers communicate effectively families' confidence and capacity to facilitate their children's successful feeding is improved. This in turn facilitates improved outcomes for children. By meeting families in their natural environments, early intervention providers play an important role in helping families problem solve strategies that are meaningful and doable in families day to day lives.

VanDahm, K. (2010). Early Feeding Intervention: Transitioning from acute care to early intervention. *The ASHA Leader, 15* (7), 12-14.

What do the data say?

What are the eating differences in children with and without autism?

In your work with families you can likely recall several accounts of how children with autism experience greater eating challenges than do their typically developing peers. But what do the data say? To answer this question we look to the research of Provost, Crowe, Osbourn, McClain, and Skipper (2010). Using The Mealtime Survey, developed for their study, the researchers set out to answer the following questions (p. 222):

1. What are the most common mealtime issues of preschool-aged children with ASD?
2. Do children with ASD have significantly different mealtime issues than children with typical development matched for their age, gender, and ethnicity?
3. How soon in early childhood do differences in mealtime issues emerge?

This study included 24 children (3 to 6 years of age) with an autism diagnosis and 24 typically developing 3 to 6 year old children. The children with autism were matched by 6 month age ranges, gender, and ethnicity. The groups included 18 boys and 6 girls. The parents of these children were asked to complete the 49 item Mealtime Survey, organized into four parts (i.e., Early history, Mealtime Environment, Child Likes and Dislikes and Parental Views). The results yielded parental perceptions and reinforced that children with autism experience greater mealtime challenges.

Regarding early history, among the children who were breast fed, 47% of the parents of children with autism reported difficulties while only 20% of the parents of typically developing children reported challenges. The reported eating challenges also comparatively increased for the children with autism as they got older. Fifty-eight percent of the parents of children with autism reported feeding concerns when their children were between 2 and 3 years of age while only 4% of the parents in the typically developing group reported concerns when their children were this age.

Looking closer at food preferences 67% of the children with autism had favored food textures compared to 0% of their typical developing peers in this sample. A greater percentage of children with autism were also reported to have food, color, temperature, and food packaging preferences. Inquiry about mealtime location also showed discrepancies between the children with and without autism. More parents of children with autism reported challenging mealtime behaviors compared to the parents of typically developing children. Among the parents of children with autism 38% reported their child resists sitting at the table compared to 4% of the parents in the typical development group. The percentage differences for *picky eating*, *ritualistic eating*, *eating food in a repetitive manner*, and *having problems with gagging* were 62%, 33%, 38%, and 25% respectively for the children with autism and 12%, 8%, 8%, and 0% respectively for the children without autism. Among the pairs of children with and without autism, significantly more children with autism resisted trying new food, limited intake to favorite textures, and mouthed nonfood items.

The results of this study showed findings similar to research conducted with older children. That is, children with autism experience greater mealtime challenges than do their same age peers without autism. Yet, important to note too is that some parents of children with autism reported no mealtime concerns reinforcing that some children with autism behave similar to same age peers. Being aware of parents concerns about mealtime and the detail of those concerns is an important aspect of intervention, as there is no single profile of meal time concerns. Rather the presence of concerns, if any, is unique to the individual child and family, reinforcing the critical importance of family-centered early intervention.

Provost, B., Crowe, T. K., Osbourn, P. L., McClain, C., & Skipper, B. J. (2010) Mealtime behaviors of preschool children: Comparison of children with autism spectrum disorder and children with typical development. *Physical and Occupational Therapy in Pediatrics, 30*(3), 220-233.

Consultation Corner

From March - August 2016 we are excited to have **Dr. Kay Toomey** as our Consultation Corner expert. This month Dr. Toomey addresses questions about feeding challenges among children with autism.

1. Are there unique issues to children on the Autism Spectrum that makes them so difficult to feed?

There are definitely issues that are unique to children with an Autism Spectrum Disorder (ASD) that contribute to the challenges frequently seen when trying to feed these children. Estimates range from 60% to 90% of children with ASD have some type of feeding problem (Williams, et.al., 2000; Marshall, et.al., 2013). Marshall et.al. (2013) reviewed 44 studies of children with ASD and identified 5 significant patterns in their feeding difficulties: 1. Fear of trying new foods; 2. Rigid routines around mealtimes; 3. Food refusal; 4. Difficulties with texture management; and 5. Disruptive behaviors. The reasons that feeding and eating are so difficult for a child with ASD are primarily related to the differences that these children have in their sensory processing and the way in which children on the spectrum learn new things. However, if you recall from our earlier discussions there are 7 different areas of human function that are involved in the process of eating/feeding; organ systems, muscles, sensory systems, learning, development, nutrition and the environment. While children on the Autism Spectrum struggle most with the sensory and learning areas of human functioning, they unfortunately have differences across ALL of the 7 areas.

Organ Systems: Dr. Timothy Buie, a gastroenterologist reported a prevalence of Gastrointestinal (G.I.) tract symptoms in children on the Autism Spectrum between 9 and 70% in the studies he reviewed (Buie et.al, 2010). The most common symptoms reported included; Chronic abdominal pain, Constipation, Chronic diarrhea and Gastroesophageal Reflux Disease.

Muscles/Tone: Ming et.al. (2007) studied 154 children on the Autism Spectrum and found that 51% of the children had Hypotonia. In addition, Motor Apraxia was present in 34%, especially oral apraxia, but only 9% had presented with Gross Motor Delay. Lane et.al. (2010) reported that a significant number of children on the Autism Spectrum have Postural Instability.

Sensory: We know that these children do not process sensory information correctly, especially in the vestibular and proprioceptive domains (discrimination problems; Schoen, et.al., 2009). They also have differences in their olfactory (smell) perception (under respond; Bennetto, 2007) and in their auditory reactivity (over react; Tan et.al., 2012). They have tactile over reactivity and oral-tactile defensiveness as well (Cermack et.al., 2010). Children on the Autism Spectrum are overly reliant on their visual systems (Kana et.al., 2013) which in turn, negatively impacts their learning.

As a result of all of these over reactions and different experiences with the sensory properties of food, for many children on the Autism Spectrum, eating is an uncomfortable or even painful activity. If every time you sat down to eat, it was similar to you trying to focus while sitting on a one legged stool, and you regularly bit your tongue, or you gagged or vomited every time because the food tasted or felt bad in your mouth, you would eventually learn to stop eating. In addition, you would develop learned avoidance behaviors to anything that signaled this bad experience was going to happen to you.

Consultation Corner (continued)

You can then imagine your relief when you are able to eat your one safe food and nothing bad happens to you (i.e. a "bland and tan" diet food). Even if you are still not sitting with good postural stability, you can at least eat without aversive sensory experiences or pain occurring.

Learning and Development: The learning and developmental differences in children with ASD are well documented (deSchipper et.al., 2016). The important thing to recognize is that because children with ASD over-rely on their visual systems, they have what I refer to as "microscopic learning" when it comes to food. That is, they see every tiny detail of the food AND every other thing in their environment while they are eating. As a result, it is difficult for them to recognize a preferred food if it looks AT ALL different (e.g. the ear of the Teddy Graham is broken off), and/or if someone tries to serve them that food in a different environment (e.g. therapy clinic versus home). For example, a child with ASD may have learned to eat chicken nuggets at school. However, to this child, the chicken nugget is more than just a brown, round, warm breaded piece of pre-chopped white meat. It is all of these sensory features, as well as, the whitish plastic plate that the nugget is served on, which is on top of a gray table top, with fluorescent lights overhead, linoleum under their feet, while sitting on a bench seat with lots of people around them and it is noisy because they are eating it in the school cafeteria. If the parent tries to serve the exact same chicken nugget at home, the child cannot recognize it as their chicken nugget. This is because too many of the visual properties are now different. That small, round, brown, breaded piece of pre-chopped white meat is now on a nice pottery plate on top of a cloth placemat, on top of a wooden table, there is natural light, carpeting under their feet, it is quiet, they sit in a regular chair and there is only one other person present (their parent). Because all of the other "conditioned cues" in the environment are different, this food is no longer their chicken nugget. They can't recognize the food when it is missing all the extra visual pieces.

Additionally, because these children struggle with processing too many visual inputs, you will find that they do what we refer to as "drive by eating". They look at a food just long enough to recognize it, and then they never look at it again while eating it. This means their food needs to look perfect to them to recognize it because they look at it so briefly. In addition, as we eat a food, it changes visually with every bite and we now have to process those new visual inputs. One of the major goals during a feeding with these children, is to help them visually pay attention to the food as they eat so they learn to understand that their favorite food is still their food even if it looks different, or comes on a different plate or is served in a different place.

Nutrition: Restricted dietary variety is the most frequently reported dietary problem in children on the Autism Spectrum, with fruits and vegetables being reported as the least frequently eaten food groups (Marshall et.al, 2013). As a result, between the ages of 3-11 years, Bandini et.al. (2010) found that children on the Autism Spectrum had inadequate intakes of Vitamins A, C and D, Zinc, Calcium and fiber. Fruits and vegetables often have very difficult sensory inputs; they are wet, slimy and many go "gush" and/or they are too sour or too bitter.

Consultation Corner (continued)

Environment: Needless to say, parents of children on the Autism Spectrum are often desperate to get their children to eat anything at all, much less a food that has really solid nutrition to it. In addition, they are frequently also doing everything they can to avoid their child with ASD having a major tantrum. Consequently, parents of children on the Autism Spectrum get stuck in some typical "feeding traps" that can actually contribute to their child eating less and less variety over time. The biggest trap is letting their child "food jag". Remember, a Food Jag is when the child wants to eat the same food prepared the same way over and over again. Another trap is letting the child eat what they want when they want and not having their child on a feeding schedule. Recall, we have discussed the problems with allowing children to graze.

#2 – what are some tips to give to parents of children on the Autism Spectrum to help them teach their children how to eat better?

First, I would encourage you to go back and read your May 2016 KIT newsletter for all of the strategies we discussed to help typically developing children not become "picky eaters" around the age of 2-3 years. These strategies are the same as what you want parents of children on the Autism Spectrum to be trying. HOWEVER, the caveat to this is that the parents will need to further simplify the routines, make the sensory demands of the task even easier, and especially work on avoiding food jagging. In addition, it is key that children on the Autism Spectrum be in Therapies to help improve their communication and their sensory processing. Ideally, children with ASD who are struggling to eat would also be in feeding therapy.

1. **Encourage parents to allow their child to play in the food**, but teach them that it needs to be "play with a purpose" = learning about the food. Parents of many children do not like the mess and will need to be educated regarding the importance of physical exploration of the foods. Parents of children on the Autism Spectrum are also frequently concerned that if they allow their child to play in the food, that will be all the child will do and then their child won't eat. We need to help parents understand that their job in the meal is to allow play that moves the child closer and closer to the mouth. If their child is not moving the food to their mouth, the parent needs to role model putting the food in their own mouth to eat it. Sometimes they can tell their child "you can take a bite now" after the child has explored the food for a while with play. Sometimes they can guide their child's hand with the food to the child's mouth (but no pushing the hand into the mouth!).

2. **Set up a routine that is consistent for every meal.** The routine for a child with ASD should be similar, but also a little bit different that the one we discussed in the May newsletter. This is because children on the Autism Spectrum need extra help to get into the optimal sensory and motor arousal state prior to <u>each</u> meal/snack.

Consultation Corner (continued)

Step 1 = Give them a 10 minute warning and set a timer. Say – "it's time to get ready to eat". Then, engage them in a large motor physical activity (e.g. climbing stairs, carrying heavy objects, jumping jacks, swinging, jumping on a small trampoline, stretching an exercise band, bouncing on a therapy ball, running around the yard etc)

Step 2 = When the timer goes off, Say – "it's time to wash hands" and bring to the sink to wash hands (transition activity)

Step 3 = sit in the chair, and then pass out foods "Family Style" with the parent's help. Sometimes children on the Autism Spectrum can only put their preferred foods on their plate. They will not put a non-preferred food on their plate. However, they will often at least pass a container of that non-preferred food to a parent or sibling. This is how we start them learning about foods.

Step 4 = work on eating and drinking for at least 15 minutes. When the child with ASD attempts to leave the table too early, Say – "oh-oh, it's not Clean Up time. We stay in our chairs until Clean Up time". Then, go get them and bring them back to the table. Say – "we stay in our chair until Clean Up time".

Step 5 = When you judge they have eaten enough and/or can no longer sit, even if no one else is done eating, have the child do the Clean Up from the meal = placing at least one piece of every food served at the meal (whether they ate any of that food or not) into the trash or scraps bowl and then take their plate to the sink (or hand their plate to their parent)

3. **It is critical especially for children with ASD to have the correct seating at a meal.** This often means having to purchase an adjustable wooden chair (e.g. Height Right chair; Stokke Tripp Trapp chair) to make sure this child is in the 90-90-90 position we discussed in an earlier newsletter.

4. **Decrease the oral-motor challenge of the foods being rejected.** As we discussed in the May KIT newsletter, you want to make the foods easier to manage if the child is rejecting it. For some children with ASD, it is better for them if their foods are drier and more meltable. Some children on the Autism Spectrum do better when the foods don't shatter in their mouth and are more of a soft cube. Also, making the food into a stick shape helps them get a grip on the food, and the first edge of the stick is usually inserted into the mouth and onto the back molars (= correct place for chewing).

Consultation Corner (continued)

5. **Decrease and/or change the sensory challenge of the foods being rejected.** Drier and harder foods typically are easier from a sensory standpoint. Wet purees that do not have a shape are very, very difficult for most children with ASD to visually tolerate. Frequently, those children on the spectrum who are actually eating purees, don't ever look at them. When presenting purees, it is helpful to draw the puree out on the serving plate in the shape of a number or letter. If offering something like a lunch meat (wet, wiggly, pinkish), use a cookie cutter on the meat and present the food in a fun shape (e.g. animal, Christmas tree, a car, letter or a number). You could also consider presenting the non-preferred foods in a clear container/dish that the child can then shake or roll. Put wet, cubed food onto cocktail forks or seafood forks so they can pick them up without getting their fingers wet. In addition, this thin fork will help the child directly place that wet, cubed food onto their back molars = the correct place for chewing.

6. Make sure **parents are feeding the children on a schedule of every 2.5 to 3 hours** from start of meal to the start of the next meal.

7. Often, parents of children on the Autism Spectrum tell us that they have to "force feed" the first bite of food. The parents say that this is when their child figures out it's a food they like and they will eat it. **Force feeding the first bite is not a good idea** because the child basically is being taught that they don't eat at the table until someone force feeds them the first bite. The family needs to follow the Routine above (#2 recommendation). Often the child will independently take a bite of the food because of the new routine which breaks up the old pattern.

8. Children on the Autism Spectrum typically have a very restricted food range of only 5-15 foods that they will eat regularly. Ideally, the RULE is still "if your child eats their perfect food today, they can't have it that way again until the day after tomorrow". The GOAL still is that the parents would offer their child a different protein, starch, fruit and vegetable across every meal and snack, across 2 full days. **It is very important for parents of children with ASD to avoid allowing their child to Food Jag**. However, because of their restricted food range, most children with Autism will need to repeat some of their preferred foods every day. What parents need to do if they have to repeat a preferred food 2 days in a row, is to make a very tiny change to that preferred food on Day 2. This change needs to be big enough to notice, but small enough that the child will still eat that food. If the parent makes a change and the child refuses to eat the food, the parent's change was too big. They will then have to go back to the perfect version of the preferred food for a while before trying a different smaller food.

   EXAMPLE: Child currently eats macaroni and cheese by Kraft (straight noodles, orange cheese, blue box). An appropriate first change might be to cut the noodles into ½ in front of the child (and also to have them help you cut them). It would <u>not</u> be appropriate to change the flavor or color of the cheese yet. It would also not be appropriate to go from the straight noodle to a noodle shaped like a cartoon character. That might be a better 2nd change.

9. **Educate parents about needing to offer their children foods over and over, even if they reject them at first.** We discussed in an earlier newsletter that it takes the typically developing child ten times of eating a food before they will consistently consume that food. For children on the Autism Spectrum, they more often need to see a food closer to 20 times before they will even attempt to eat a new

Consultation Corner (continued)

food. Parents of children with ASD frequently give up offering new foods because their child's over reactions. They need to understand the importance of continuing to present the foods even if their child fusses. You as the interventionist, will then need to give the parents strategies to help calm the child if they are fussing.

My personal opinion is that many children on the Autism Spectrum would benefit from being in Feeding Therapy with someone trained in working with these children. To find an SOS trained therapist in your area, you can go to www.sosapproach-conferences.com and look under the Parent Tab (Therapist Referrals).

Kay Toomey, Ph.D.

Bandini, L. et.al. (2010). Food selectivity in children with autism spectrum disorders and typically developing children. *Journal of Pediatrics*, 157, 259 – 264

Bennetto, L., Kuschner, E., & Hyman, S. (2007). *Biological Psychiatry*, 62, 1015-1021.

Buie, T. et. al. (2010). Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASD's. *Pediatrics*, 125, S 19 – S 29.

Cermak, S.A., Curtain, C. & Bandini, L. G. (2010). Food selectivity and sensory sensitivity and children with autism spectrum disorders. *Journal of the American Dietetic Association*, 110, 238 – 246.

de Schipper E, Mahdi S, de Vries P, Granlund M, Holtmann M, Karande S, Almodayfer O, Shulman C, Tonge B, Wong VV, Zwaigenbaum L, Bölte S. (2016). Functioning and disability in autism spectrum disorder: A worldwide survey of experts. *Autism Research*, Jan 8, doi: 10.1002/aur.1592

Kana, R.K., Uddin, L.Q., Kenet, T, Chugani, D. & Muller, R-A. (2014). Brain connectivity in Autism, *Frontiers in Human Neoroscience*, June, dx.doi.org/10.3389/fnhum.2014.00349

Kana RK, Liu Y, Williams DL, Keller TA, Schipul SE, Minshew NJ, Just MA. (2013). The local, global, and neurol aspects of visuospatial processing in autism spectrum disorders. *Neuropsychologia. 51(14),* 2995-3003.

Marshall, J., Hill, J. R., Ziviani, J. & Dodrill, P. (2013). Features of feeding difficulty in children with Autism Spectrum Disorder *International Journal of Speech Language Pathology*, Early Online, 1-8.

Ming, X., Brimacombe, M. & Wagner, G.C. (2007). Prevalence of motor impairment in autism spectrum disorders. *Brain & Development*, *29*, 565 – 570.

Schoen, S. et. al. (2009). Physiologic and behavioral differences in sensory processing: a comparison of children with autism spectrum disorder and sensory modulation disorder. *Frontiers in integrative neuroscience*, doi: 10.3389/neuro.07.029.2009

Tan, Y. et.al. (2012). Auditory abnormalities in children with autism. *Open Journal of Psychiatry*, 2, 33 – 37.

Young, R. L., Baker, A. E. & Angley, M.T. (2010). Sensory processing subtypes and autism: Association with adaptive behavior. *Journal of Autism and Developmental Disorders*, 40, 112 – 122.

Williams, P. G., Dalrymple, N., & Neal, J. (2000). Eating habits of children with autism. *Pediatric Nursing, 26(3),* 259-264.

On the WWW

This month we feature the online Autism Speaks publication “Exploring Feeding Behavior in Autism: A Parent’s Guide.” It can be downloaded or viewed at the following link:

www.autismspeaks.org/sites/default/files/docs/sciencedocs/atn/feeding_guide.pdf

This parent guide helps parent and providers understand the nuances of feeding challenges common in children with autism. The easy to read guide is organized into three parts beginning with what feeding problems are and why children with ASD have them. This informative section is followed by practical pointers of what families can try at home to address feeding issues. The guide wraps up with several frequently asked questions with informative responses.

Continuing Education for KIT Readers

The Comprehensive System of Personnel Development (CSPD) is offering a continuing education opportunity for KIT readers.

In line with the focus on *Supporting Families of Young Children with Feeding Challenges,* readers are invited to receive continuing education contact hours for reading the monthly KIT publications (March through July 2016) and completing a multiple-choice exam about the content covered in these KITs.

KIT readers will receive the exam in August 2016. There is no need to register for the CEUs. Rather, if you are interested complete the exam online at www.edis.army.mil

Upon successful completion of the exam, you will receive a certificate of non-discipline specific continuing education contact hours.

KIT Newsletters are available online at **www.edis.army.mil**

Thank you for your continued interest in the KIT.