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# The Caregiver as the Agent of Change in Children with Autism

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THE CAREGIVER AS THE AGENT OF CHANGE IN CHILDREN WITH  
AUTISM

by

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A Research Paper  
Submitted in Partial Fulfillment of the Requirements for  
the  
Master of Science Degree

Department of Communication Disorders and Sciences  
in the Graduate School  
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## Introduction

The correlation between feeding problems and autism has been prevalent since the initial diagnostic criteria of autism spectrum disorders (ASD) were established. In 1943, Kanner included feeding difficulties in the description of ASD, (Twachtman-Reilly, Amaral, & Zebrowski, 2008) yet feeding difficulties are not currently included in the diagnostic criteria although numerous children with autism still present with many feeding challenges. According to Ahearn (2001), research has suggested that 30-80 percent of children with developmental disabilities (e.g. autism) present with feeding problems. Recently research has begun to focus on the assessment and intervention of feeding problems in this population. A study by Schreck, William and Smith (2004) compared the eating behaviors of children with autism to typically developing children. Parents of 298 typically developing children and 138 children with autism filled out the *Children's Eating Behavior Inventory* and the *Food Preference Inventory*. Results indicated that children with autism do indeed have more feeding problems than typically developing children. The children with autism tended to eat a limited amount of food compared to typically developing peers (Schreck et al., 2004).

While the etiology of feeding difficulties in children with ASD is unknown, Twachtman-Reilly, Amaral, and Zebrowski, (2008) divide possible factors of feeding difficulties into physiological and behaviorally based issues. Physiological issues include sensory perception issues (i.e. hypersensitivity and hyposensitivity) as well as gastrointestinal (GI) issues. Generally, these children exhibit problems with the texture and flavor of foods, possibly attributed to sensory perception issues. Ahearn (2001) notes that feeding difficulties have been linked to GI problems. Although there are not any data regarding the percentage of children with ASD with concurrent GI problems, this may be a contributing factor to their feeding troubles. Behavioral concerns include repetitive and ritualistic behavior, executive functioning difficulty, fear and anxiety, and social and language skills (Twachtman-Reilly, et al. 2008). The repetitive and ritualistic behavior found in children with autism may contribute to the specific manners in which they expect meals and food to be delivered (i.e. specific brands, specific colors of food, specific food categories) to them. This is also true with the mental flexibility and planning aspects of executive functioning skills; children with autism enjoy routines and often do not have the mental

flexibility to cope with changes in the routine. When that routine is disrupted, by changing food offerings or meal set-up, undesired behaviors are often exhibited (Twachtman-Reilly et al., 2008).

Intervention for feeding disorders in children with autism includes both sensory integration techniques and behavioral techniques, with the latter the most popular choice (Twachtman-Reilly, et al. 2008). Commonly, a trained behavior analyst or speech-language pathologist provides intervention for a child that presents with feeding difficulties. While this type of intervention has been proven effective, (Freeman and Piazza, 1998; Laud, Girolami, Boscoe, Gulotta 2009; Patel and Piazza, 2001) it is vital to recognize the importance of the caregiver in feeding interventions. With this in mind, additional research has begun to investigate the caregiver as the agent of change. While trained therapists administer most feeding intervention, parents of children with autism can effectively provide behavioral intervention, including preference assessments and functional analysis, to their child who presents with feeding difficulties.

### **Preference Assessment**

A preference assessment determines which items or edibles are most reinforcing to a child. This assessment is a vital component to behavioral therapy as most assume that if the child has access to or works towards a highly reinforcing item or edible, the child's inappropriate behavior will decrease. There are three forms of preference assessments, forced choice/paired stimulus (FC/PS), multiple stimulus presentations with replacement (MSW), and multiple stimulus presentations without replacement (MSWO) (Lanner, Nichols, Field, Hanson, and Zane, 2009). Lanner and colleagues describe the procedures for each type that include during the paired stimulus assessment, the evaluator presents the child with two items and the child picks one. The process continues, presenting two items at a time, for each possible pair. Calculations of the child's choices determine the rank order of items chosen. During the MSW approach, the items are in the child's sight at all times. The child is required to pick one, has access to it, and then it is replaced in the child's site again. The items are rearranged after every trial. The MSWO approach is the same as the MSW approach with the exception that the chosen item is not returned to the table after the child chooses it. The earlier chosen

items are more reinforcing to the child than the later chosen items (Lanner et al., 2009).

Currently research is limited in the use of a caregiver in preference assessment, although Najdowski and colleagues (2010) trained the mothers of children with feeding problems to administer a preference assessment. The mothers received training to administer the preference assessment in order to evaluate non-preferred and preferred foods, as well as foods for generalization probes. They received training with written instructions and verbal explanation. All three mothers in the study were able to perform the preference assessment with 100% accuracy without additional guidance (beyond the initial training). The results of the preference assessment determined which foods would be reinforcers and which foods became targeted in treatment (Najdowski et al., 2010).

### **Functional Assessment**

The goal of a functional assessment is to observe, identify, and evaluate environmental variables that lead to problem behavior (Peterson, Berb, and Horner, 2002). Generally, behaviors occur to gain attention, to gain access to an item or edible, to escape an undesirable situation, or for self-stimulation. Once the environmental factors are identified interventions applied in order to

reduce or eliminate problem behavior. In 2003, Najdowski, Wallace, Doney, and Ghezzi, evaluated the effectiveness of parental implemented functional analysis related to their child's food refusal. Najdowski replicated this study in 2008 with more participants to examine the integrity of the parental-guided functional analysis (Najdowski et al., 2008).

In the 2008 study, six children, five with autism and one typically developing, and their mothers participated in a feeding study. Each child demonstrated food selectivity based on type (Najdowski et al., 2008). The mothers participated in a one-hour training that consisted of the trained therapist reading and modeling the correct procedure and in combination with role-play by the mothers.

The functional analysis component consisted of four separate treatment conditions. In the control condition, the mother presented the child with a plate of preferred foods and sat beside him or her. The mother provided non-contingent attention on a set 30-second interval schedule and there were no consequences for inappropriate behavior (Najdowski et al., 2008). In the no-interaction condition, the child received a plate of non-preferred food and left alone. There were no demands or consequences placed on the child. During the attention condition, the child was

presented with a plate of non-preferred food, while the mother said, "I've got a lot of dishes to do" and went to clean the dishes. There were not any demands placed on the child, but when inappropriate mealtime behavior (IMB) occurred the mother gave the child vocal attention (Najdowski et al., 2008). In the demand condition, the mother sat with the child and went through a three-step prompting procedure: telling the child to "take a bite," bringing the bite in the direction of the child's mouth, and putting the bite in the child's mouth. Inappropriate mealtime behavior occurred with all children when the mothers tried to put the bite in the child's mouth. If the child consumed the bite, the mothers provided praise to the child and the food was removed for 30 seconds.

Through observation and data-collection, researchers found that mothers implemented the functional analysis with a mean of 98% across the conditions (Najdowski, et al., 2008). Research also indicated that all of the children exhibited IMB and was greatest for all children during the demand condition, possibly indicating that escape was functioning as a reinforcer during mealtime (Najdowski et al., 2008). These results indicate that mothers can complete a functional assessment with high accuracy and procedural integrity.

## **Caregiver Conducted Therapy**

### **Training in the Clinical Setting**

In 2001, Anderson and McMillan evaluated the use of the caregiver as the agent of change while implementing escape extinction and differential reinforcement of acceptance (DRA). The study involved Rick, a five-year-old boy with pervasive developmental disorder and mental retardation and his parents. Rick did not consume fruits and that became the focus of the feeding intervention. During the baseline phase, the parents received no instruction of any kind. The parents then participated in training in escape extinction and DRA with written and verbal instructions, modeling and role-playing. The parents placed a bite of food in front of Rick's mouth until he accepted, defined as allowing the bit of food to be placed in his mouth (Anderson & McMillin, 2001). When Rick accepted the food, his parents provided immediate praise and access to a preferred food time in the form of a drink of milk. Instead of representing an expelled bite, the parents presented a bite of preferred food.

The meals in the next phase consisted of one fruit and one preferred food from the baseline phase (e.g. mashed potatoes, yogurt, and applesauce) (Anderson & McMillen, 2001). For the initial meals of the treatment Rick was

only required to intake one bit of fruit per meal (Anderson & McMillin, 2001). Once Rick reduced disruption by 60% from the baseline measures for two consecutive meals, two more bites were required. Rick's parents often increased the bite requirement before the met criterion and at the 18<sup>th</sup> treatment meal, began to serve him the entire jar of baby food. After nineteen treatment meals, reversal to baseline occurred for three meals. At this point, the parents acted in the same manner as in the initial baseline procedures. Seven final meals were implemented using escape extinction and differential reinforcement (Anderson & McMillen, 2001).

Results from Anderson and McMillen (2001) indicated two findings: a) the combination of escape extinction and differential reinforcement is effective in treating feeding problems and b) parents demonstrate effective implementation intervention techniques with their own child in a natural environment. While the intervention was effective, it is important to recognize that the caregivers were not accurately using the intervention procedures until the fifth session. Further research should investigate the efficacy of training parents more accurately before implementing feeding intervention at a meal.

McCartney, Anderson and English (2005), implemented a similar parent-training program because they believed that parents could implement escape extinction in an effective manner and be satisfied with the training process. Caregivers of three children with autism and one typically developing child participated in the training program. The age of the children ranged from eighteen months to seven years old and each child presented with severe food selectivity. Intervention consisted of four phases: baseline (parent-fed), clinic sessions while fed by a therapist, clinic session while fed by a caregiver, and home-based sessions while fed by a caregiver. During the baseline procedure, trained researchers observed caregivers feeding the child at a typical meal. To determine non-preferred foods, therapists also conducted baseline sessions on three occasions using two non-preferred foods and one preferred food presented ten times. Foods rejected 80% of the presentations were determined non-preferred (McCarthy et al., 2005) and included in the study (two per child). Once non-preferred foods were established, therapists implemented the intervention procedure. The child was prompted to take a bite, if the bite was not accepted the bite was placed in the child's mouth at any point that the mouth was open. The child received praise

on an accepted bite and given a bite of a preferred food (McCarthy et al., 2005). Initially the child only needed to accept one bite per meal, but as criterion was met the demand increased by one bite per meal. Introduction of the second non-preferred food occurred once the child accepted eight bites at one meal. Also at this time, the caregiver became the feeding therapist (McCarthy et al., 2005).

McCarthy et al. (2005) reported training occurred via videotaped meals conducted by trained therapists, and from observing actual meals from inside and outside the therapy room. Therapists reviewed the intervention procedures before each caregiver implemented meal and after each meal, caregivers received feedback and guidance. Once the caregiver implemented the intervention process of escape extinction correctly and the child accepted eight bites of both non-preferred foods within 20 seconds and without expulsions, the home-based phase could begin.

The home-based phase was identical to clinical phases in procedure but differed in environment (McCarthy et al., 2005). A trained therapist was in the home for all sessions, but always out of sight during the meal. This allowed for feedback immediately following the completion of the intervention. Intervention was complete when the child accepted eight bites for both foods. Caregivers

received guidance to continue the intervention independently, but not instructed when to begin new foods.

McCarthy et al. (2005) reported successful decrease in food selectivity for all children. Follow up reports demonstrated willingness by each child to accept novel foods without intervention and to eat meals without expulsions of foods or problem behaviors (McCarthy et al., 2005). In a survey to evaluate the caregiver's satisfaction with the intervention, caregivers noted that problem behavior decreased and they were very satisfied with the intervention. Caregivers did report lingering association of mealtimes with stress. It would be important to investigate the importance of parental stress at mealtimes and relationship between stress and feeding behaviors. It would also be beneficial to investigate the validity of parental intervention in the home only, rather than training in the clinic first.

### **Training in the Home**

In 2010, Najdowski and colleagues implemented differential reinforcement in combination with non-removal of the spoon (escape extinction) and demand fading. The goal of the study was to evaluate the effectiveness of this procedure for caregivers implementing the intervention in the home only. Caregivers of two children with autism and

one typically developing child participated in the study. Assessments indicated that each child's behaviors maintained by negative reinforcement, particularly escape. Sessions took place in the home for one meal per day.

Parent training consisted of baseline, treatment, generalization, and follow-up procedures. Procedures included training parents regarding how to take data in each situation and the protocol for the behavioral intervention comprising of non-removal of the spoon, differential reinforcement and demand fading (Najdowski et al., 2010). Similar to McCarthy et al. (2005), training occurred through a variety of manners including written instructions, modeling, role-play, and immediate feedback in the session.

During the baseline portion, mothers presented their child with a bite, and told them if they took a bite of non-preferred food, they could have a bite of preferred food. If the child did not take a bite or was disruptive, the child escaped the meal for thirty seconds (Najdowski et al., 2010). The next phase was a combination of differential reinforcement, non-removal of the spoon, and demand fading. The child was initially required to accept, but not necessarily swallow, one bite of non-preferred food over three consecutive sessions. Upon meeting these

criteria, the child was then required to accept and swallow one bite of non-preferred food for three consecutive sessions. Bite requirements increased by 150% from the preceding bite requirement and included an equal number of bites from three non-preferred foods (Najdowski et al., 2010). As the demand for non-preferred food bites increased, reinforcement bites of preferred foods thinned so that the child had the same number of bites of food at every meal. For example, if the child was required to have fifteen bites of non-preferred food and the terminal bite number was twenty, the child ate five bites of preferred food per meal (Najdowski et al., 2010). Once the child reach the terminal bite number in non-preferred food, the child received a dessert (Najdowski et al., 2010).

Results indicated that the mothers were successful in increasing intake of non-preferred foods and decreasing undesired mealtime behaviors by implementing differential reinforcement in combination with non-removal of the spoon and demand fading (Najdowski et al., 2010). All three children were accepting and swallowing 100% of presented bites by the thirteenth session (Najdowski et al., 2010). Upon follow-up at two, four, six, and twelve weeks, the children were still swallowing 100% of presented bites.

The results reported by Najdowski and colleagues (2010) provide valuable information in determining the effectiveness of parental intervention conducted entirely in the home setting. Providing treatment in the home, conducted by the caregiver, is very cost-effective. Professionals do not need to be on hand to supervise all interactions, saving the family and the professional's time and money (Najdowski et al., 2010). Providing therapy in the home may also lead to better maintenance and generalization by the child.

#### **Non-removal of the Meal**

While non-removal of the spoon appears to be quite effective in feeding therapy, some may view the procedure as "forcing the child to eat" (Tarbox, Schiff, & Najdowski, 2010, P. 224). To an unknown person, keeping a spoon in front of a child's mouth for up to thirty minutes can seem quite forceful and aggressive. This led Tarbox et al. (2010), to investigate a therapy approach that involved non-removal of the plate instead of non-removal of the spoon. The rationale being that this approach, not allowing the child to leave the table until the plate is clear, tends to be a more common practice in households. Non-removal of the meal may be a form of escape extinction, as it prevents the child from leaving the table. If the child

escapes only after completing the meal, this is a negative reinforcement of eating. Activities that are only available to the child after the meal may be positively reinforcing, which turn the meal into a positively reinforcing experience for the child (Tarbox et al., 2010).

The study took place at the kitchen table, in the home of a three-year old boy with autism (Tarbox et al., 2010). The boy demonstrated severe food selectivity, adding stress during mealtimes and on his caregivers. His mother was the sole implementer of all intervention strategies. Meals were cooked at home without any regard to the boy's food selectivity. He received his meal with the following statement,

Ed, this is what's for dinner/lunch. You cannot have anything else. If you eat your whole meal, then you can go play. If you don't eat, then you just have to sit here. If you are not done with your meal by bedtime, then you will need to eat it for breakfast the next morning" (Tarbox et al., 2010, p. 228).

During the first four meals, a consultant was available to prompt and praise the mother for correct implementation. After thirteen meals, a reversal to baseline took place for one meal, where the mother simply told Ed that he could eat

his meal if he wanted to. Intervention phase returned for the last ten meals.

Results found that Ed was eating 100% of presented meals after the second intervention meal and the duration of meals decreased over time (Tarbox et al., 2010). These results infer that the less intrusive intervention of non-removal of the meal can improve a child's consumption of meals. The mother successfully implemented all interventions in her child's treatment, lending more evidence to support parental guided interventions. It is important to consider that this study involved only one child, who did not have inappropriate mealtime behaviors. Non-removal of the meal may be a less intrusive approach that works with children who are simply selective eaters but without behavior problems (Tarbox et al., 2010). Future research should investigate this procedure on children with a range of behavioral difficulties to gauge the success non-removal of the meal compared to non-removal of the spoon.

### **Comparison of Types of Caregiver Training**

Tarbox and colleagues (2010) did not elaborate on the type of parent training used to assist the mother in the feeding intervention of her child, however, Mueller, Piazza, Moore, and Kelley (2003) examined the types of

feeding protocols that are the most effective and efficient in training parents. In a two-part study, Mueller et al., (2003) first evaluated treatment integrity of a multi-component method to train parents and second evaluated the treatment package of the first study to find out which parts alone could be effective. Evaluated parts included: (a) verbal instructions plus modeling, (b) verbal instructions plus rehearsal, and (c) verbal instructions alone (Mueller et al., 2003).

In study one, three parents of two children participated. The mother and father of one child used differential reinforcement and non-removal of the spoon, and the father of the child used non-contingent reinforcement with non-removal of the spoon (Mueller et al., 2003). During the baseline, parents participated in training with written instructions only and had as much time as needed to look them over, but did not have access to them once the baseline procedure began. After baseline, parents received a multi-component package that included verbal instructions consisting of a trained therapist reading and explaining the written protocol, modeling consisting of two therapists role-playing the child and adult in the feeding situation, and rehearsal, which enabled the parents to act as the therapist and the trained

therapist acted as the child (Mueller et al., 2003). Once training was completed, parents received no feedback; and if the parents had questions, they referred back to the written instructions they first received during the baseline procedure (Mueller et al., 2003). The father of the second child also received feedback following feeding sessions 21-30, relating to what he was doing wrong and how to correct his therapy. The father of the first child participated in a follow-up one month after the completion of the training.

Results of study one found that after written instructions, parents implemented the procedures with 0-60% accuracy (Mueller et al., 2003). After the training package, accuracy levels increased to 93.9% and 88.8%, while the father of the second child ranged from 43-93% accurate. He expressed that he believed that he did not need to implement all of the components of the therapy because his child was doing well and data of acceptance and inappropriate behavior supported his opinion. All parents were able to implement the procedures, but it is uncertain which parts of the training package were responsible for the effectiveness, (Mueller et al., 2003).

In study two, six parents were trained to implement differential reinforcement and non-removal of the spoon

(Mueller et al., 2003). Again, for the baseline procedure, all parents received written instruction only. After the baseline treatment, all parents received verbal instructions before receiving the remaining components of their individual treatment package. Parents four and five received verbal instructions and modeling; parents six and seven received verbal instructions and rehearsal; and parents eight and nine received verbal instructions only (Muellar et al., 2003). The training for each component was identical to those in the first study. Four of the parents received follow-up probes between six days and three months post training.

After the written instructions parent four demonstrated 0% accuracy and parent five demonstrated accuracy between 20-50%, following verbal instruction and modeling, both parents were performing at an acceptable accuracy. Parents six & seven demonstrated low accuracy after written instruction only, but improved to 80%-100% accuracy after verbal instructions and rehearsal. After only written instructions and the first verbal instructions, parents eight & nine demonstrated accuracy between 0% and 70%. Following the second verbal instruction, both parents were performing at an acceptable accuracy. These results indicate that modeling and

rehearsal were effective after written instruction (Mueller et al., 2003). Verbal instruction was not effective after one time; but following a second application, verbal instruction proved to be effective in training parents to accurately implement the training procedure (Mueller et al., 2003). Researchers do not understand why repeating the verbal instructions increases treatment accuracy, but Mueller et al. (2003) hypothesized that two components are necessary to become proficient in the training process. Regardless of method, the two components allowed for repetition of the material, giving the parents more access to the material, thus increasing accuracy in implementing the procedure. Further research should investigate the integrity of this hypothesis on a variety of parents with children exhibiting a range in severity of feeding difficulties.

### **Conclusion**

It is evident from the above research that it is possible to train parents and caregivers to use preference assessments, functional analysis, and behavioral therapy to treat feeding disorders in their children with autism. Missing from this research is a comprehensive program that could be distributed to numerous therapists that would become a universal training program. While it is noted

that parents can implement parts of a comprehensive program, it would be wise to develop a complete in-home training program. Ideally, this program would save time and money for all that are involved with the care of children with autism who exhibit feeding difficulties, although, it can be difficult to make a single program that fits the feeding difficulties of every child. Once a researched-based program is developed, it will immediately affect the lives of these families. Feeding therapy implemented in the home, delivered by the child's caregivers, can only lead to promising results.

Research has come a long way in regards to feeding therapy. The impact of this research will become a tremendous asset to any behavior analyst or speech-language pathologist, as they can aid the caregiver in facilitating feeding with their child. Imagine the relief that a caregiver will feel when they realize that they can help their child succeed in feeding. The caregiver has a sense of responsibility in the treatment of the child. From treatment by a therapist in a clinical setting, to treatment by the caregiver in the home setting, feeding therapy has changed dramatically in recent years.

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