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A COMPARISON OF FEEDING AND MEALTIME PROBLEMS IN INTELLECTUALLY DISABLED ADULTS WITH AND WITHOUT AUTISM

A Thesis

Submitted to the Graduate Faculty of the Louisiana State University and Agricultural and Mechanical College in partial fulfillment of the requirements for the degree of Master of Arts

In

The Department of Psychology

By Jill C. Fodstad B.S., Georgia Institute of Technology August 2008



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Abstract

Due to the dearth of information categorically describing feeding behaviors in those with autism spectrum disorders, the goal of this research is to examine the nature of feeding difficulties in adults with intellectual disabilities (ID) and Autism Spectrum Disorders (ASD). Feeding and mealtime behavior problems are an area of concern due to their impact on an individual's daily functioning, as well as the potential for causing severe medical conditions (e.g., poor nutrition, choking, aspiration) that may ultimately lead to death. Due to the importance of this topic for proper diagnosis and treatment planning, a better understanding of these behaviors in persons with autism is imperative. Participants comprised one of two groups: ASD and ID (autism or Pervasive Developmental Disorders – Not Otherwise Specified) or ID and no additional Axis I diagnosis other than Pica or Rumination. The aim of the proposed study is to assess whether there are differences in aberrant eating habits between groups through the administration of the Screening Tool for fEeding Problems (STEP). Taking into account any medical conditions that may be underlying feeding problems, descriptive analyses and a MANOVA were used to analyze data. Results indicated that individuals with ASD and ID evinced more refusal related feeding problems whereas those with ID only had more feeding skill difficulties. Implications of these data are discussed.



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Introduction

In 1943, Leo Kanner first described the syndrome that we now associate with autism (Kanner, 1943). Kanner listed problems with food being a definitive characteristic of autism after noting that 6 out of 11 of his clients had some manifestation of eating dysfunction. Current Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR) criteria does not include feeding difficulties as a caveat needed for an autism spectrum disorder (ASD) diagnosis; however, caregiver and clinician reports have continued to note the prevalence of feeding and mealtime problems in these individuals. Similarly, the relation of aberrant eating habits to the core features of ASD has been poorly represented in the literature, despite its apparent importance to efficacious treatment planning. The goal of the present study will be to examine the relation of ASD symptoms, medical variables, feeding skills, and mealtime behavior of adults with varying levels of intellectual disability (ID) with or without ASD (autism and PDD-NOS). A summary of the history of ASD and its symptom characteristics are discussed along with a description of aberrant eating behaviors, assessment of feeding and mealtime behavior, and associated risk factors.



Autism Spectrum Disorders

Autism spectrum disorders (ASD) are defined by the DSM-IV-TR to be a class of Pervasive Developmental Disorders typified by early childhood onset, impairments in social interaction and communication, and restricted or repetitive interests or patterns of behavior. Included within this spectrum are Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified, Childhood Disintegrative Disorder, and Rett's Disorder.

History

When Kanner first described the syndrome that we now associate with autism (Kanner, 1943), he observed 11 children whose abnormal functioning were incongruent from any known psychiatric condition. The behaviors noted as differing markedly and uniquely from anything seen thus far included a profound lack of affect or emotional responsiveness to others, absence or abnormality of language development and speech (e.g., mute, echolalia, pronoun reversal, etc.), an insistence on preservation of sameness in their environment, repetitive and stereotyped play activities, sensory deficits, a lack of imagination, and a high level of visuo-spatial skills and rote memory. He also noted that 6 out of the 11 children had some manifestation of feeding difficulty. The problems he noted included food and drink selectivity, vomiting, food and drink refusal, rumination, pica, and aspiration. Additionally, Kanner noted that the 11 children all seemed to be "endowed with good cognitive potential," but were different from typically developing children in that they possessed "an extreme autistic aloneness that, whenever possible, disregards, ignores, and shuts out anything ... from the outside" (p. 242). The description that Kanner gave in 1943 has subsequently been termed "classic autism" or "Kanner's syndrome" in the literature. While some of the earliest beliefs regarding autism have



been refined through research (i.e., comorbid medical conditions, cognitive functioning impairments, etc.), the core of Kanner's description remains the same; the deficits seen in social interaction and language are the underlying key elements of autism (Sevin, Matson, Coe, Love, Matese, & Benavidez, 1995; Rutter, 1978).

The naming of the disorder Kanner observed as *infantile autism* unfortunately led to confusion between autism and schizophrenia. The word "autism" was first coined by Swiss psychiatrist Eugene Bleuler in 1911. Autism, in its original derivation, means "self." It was in this context that Bleuler used the term to refer to the self-centered thinking and withdrawal into fantasy characteristic of some schizophrenic individuals, particularly true of diagnostic criteria at that time (Stotz-Ingenlath, 2000). Kanner's intention for using the term was to describe the absence in social reciprocity and imagination he saw among his clients more representative of negative symptoms of schizophrenia (Rutter, 1978). Furthermore, Kanner went on to delineate that a defining difference between the two disorders was that autistic behaviors were more notable early in life whereas schizophrenia had a later onset (Eisenberg & Kanner, 1956). It was also noted that autism was separate from schizophrenia due to Kanner's observation that autistic children were unable to form biological connections with people (Kanner, 1971). Unfortunately, autism continued to be synonymous with schizophrenia. Clinicians and researchers referred to the two, along with other childhood syndromes, as childhood schizophrenia or child psychosis (Rutter, 1978). It was not until additional nosological studies were completed that autism began to be seen as a unitary entity within the DSM classification of diseases. Most notably, Rutter's (1972) seminal paper detailing the demarcations (i.e., social, progression of disorder, cognitive development, gender differences, and co-occurrence of epilepsy) between autism and schizophrenia was influential in starting the paradigm shift.



The diagnostic definition of autism has also undergone some changes since its first description in 1943. Kanner's initial description of autism included delays in social, language, and sensory functioning as well as an insistence upon sameness. These deficits, Kanner believed, occurred from the very beginning of life but did not hinder the child's cognitive functioning and intelligence (1943). Later, Kanner would recant the notion of "inborn autistic disturbances" (p. 250) through various observations of autism arising after a period of normal development in the first 1 to 2 years of life. It is with this knowledge that the essential symptoms of autism were reduced to simply aloofness and indifference to others and an elaborate preoccupation with the preservation of sameness (Eisenberg & Kanner, 1956). It was considered that, if these two features were present, the rest of the typical clinical presentation would be present (Wing, 1993). A formal diagnostic criterion for autism was not developed until the 1970s through research by Rutter and colleagues (as cited in Rutter, 1978). The criteria he described for "childhood autism" included three classes of symptoms, including "a profound and general failure to develop social relationships," "language retardation with impaired comprehension, echolalia and pronominal reversal," and "ritualistic of compulsive phenomena" that were present prior to 30 months of age (Rutter, 1978). The current edition of classifying mental disorders, the DSM-IV-TR, uses Rutter's findings as a guide for its definition of the core symptoms of autism: deficits in social interaction, communication, and restricted interests or behavior (APA, 2000).

Core Symptoms

Social Interaction. The first criterion a person must fulfill to receive an autistic disorder diagnosis is a marked qualitative impairment in social interaction (APA, 2000). Early indicators of an abnormality in social skills characteristic of an autistic individual are manifested through



deficits in reciprocity, initiation of interactions, forming attachments, maintenance of eye contact, ability to share in enjoyment or sorrow, empathy, and ability to infer the interests of others (APA, 1994; Rutter, 1971). Furthermore, children with autism have been found to initiate fewer interactions with peers, especially in unstructured settings, and that a decrease in adaptive social skills predicted a smaller quantity of initiations made to others (Hauck, Fein, Waterhouse, & Feinstein, 1995). These children are rarely observed to enjoy engaging in activities with others, but prefer to play by themselves (Volkmar, Carter, Grossman, & Klin, 1997). A study by Travis, Sigman, and Ruskin (2001) suggested that autistic children who were less competent in social norms and expectations were less likely to show empathy and joint attention skills. During adolescence and adulthood, these individuals continue to have difficulties engaging in conversations with others, likely due to a lack of insight into social norms and others' emotional states (Baron-Cohen, 1991; Cohen & Volkmar, 1997). These possible deficits translate into inabilities in initiating conversations, maintaining conversations, and generating spontaneous conversations (Volkmar, Carter, Grossman, & Klin, 1997). Additionally, deficits in social functioning can significantly affect social interactions and interfere with the ability to establish lasting and meaningful friendships (Tantam, 2000).

These deficits in social skills have implications for an individual's opportunity for normalization, comfort and quality of his or her living environment, and success in the community. As a person with ASD ages, social skills become even more important in acclimation to the environment. An adult with autistic disorder who has more skills in his repertoire and displays very few symptoms has a higher probability of being integrated into society and functioning successfully (Lagone, Clees, Oxford, Malone, & Ross, 1995). In contrast, those who also have severe to profound ID may require life-long treatment and may be



unable to live independently in the community. Individuals with mental retardation have been found to be less likely to hold jobs, become married, have children, own homes, and engage in adult education when compared to adults with normal intellectual functioning (Hall, Strydom, Richards & Hardy, Bernal, & Wadsworth., 2005). Various techniques used to train social skills have shown to have some utility; however, the majority of social impairments for individuals with ASD persist throughout their lifetime.

Communication. The second criterion for a diagnosis of ASD is a qualitative impairment in communication. A lack of or delay in the development of speech, inability or impairment in initiating or sustaining conversation, stereotyped or repetitive use of language, or lack of imaginative or imitative play characterizes these symptoms (APA, 2000). In autistic individuals, speech development is usually delayed or absent, and it has been estimated that anywhere from 20 - 50% remain mute or acquire only a small amount of functional speech (Bishop, 2003; Frith, 1989; Mesibov, Adams, & Klinger, 1997; Rutter, 1978). An autistic individual without language may be suspected of being deaf; however, their inability to speak is not characteristic of an individual who is deaf or has a general learning disability. It has been found that a deaf child shows great sensitivity to noise, evidence of auditory memory, and preferences for certain environmental sounds (Klin, 1991). When language does develop in autistic individuals, it is usually abnormal in quality due to features such as pronoun reversal and echolalia (Rutter, 1971; Schuler & Prizant, 1985). Other language idiosyncrasies that have been observed include telegraphic speech (Wing, 1969), difficulty in making inferences (Minshew, Goldstein, Muenz, & Payton, 1992), failure to recognize connotations of words (Happè, 1991), infrequent use of mental state verbs (Tager-Flusberg, 1992), and inflexible and ritualistic language (Tager-Flusberg, 1981). Furthermore, it is often very difficult to hold a satisfactory two-way



conversation with an individual who has ASD. A typical conversation may turn stagnant due to the individual giving stereotyped answers, monologues about a special interest, over-literal understanding of subject matter, and monotonous language (Hewitt, 1998; Rutter, 1978; Frith, 1989; Tantam, 1991).

Restricted Interests or Behavior. The third main diagnostic category for ASD is a restricted, repetitive and stereotyped pattern of behavior. For a diagnosis of autism, the DSM-IV-TR requires one of the following behaviors to be present: an abnormal preoccupation of one or more stereotyped and restricted patterns of interest; an inflexible adherence to specific, nonfunctional routine or rituals; stereotyped and repetitive motor mannerisms; and, persistent preoccupation with parts of objects (APA, 2000). This behavior, first described as an obsessive "insistence on sameness" by Kanner, describes a wide range of behaviors, interests, and activities. Stereotypies are specific to the individual and are often not stable over time, often changing in quantity, quality, and type (Militerni, Bravaccio, Falco, Fico, & Palermo, 2002). Many different topographies of stereotypy have been described in the literature including body rocking, pacing, posturing, vocalizing, sniffing, facial grimacing, nonsocial laughing, manipulating objects, and repetitively moving body parts (LaGrow & Repp, 1984; Lewis & Bodfish, 1998; Rojahn, Matlock, & Tasse, 2000). Engagement in stereotypy has been found to hinder both the acquisition of new skills and the performance of established behaviors (Epstein, Doke, Sajwaj, Sorrell, & Rimmer, 1974; Morrison & Rosales-Ruiz, 1997). For instance, autistic children have been observed to have limited and rigid play patterns due to their stereotypies decreasing their imagination and creativity during play time (Rutter, 1978). Individuals also suffer from a rigid resistance to change. When the environment or their routine is changed, autistic individuals may experience increased levels of anxiety that can be stigmatizing and may



potentially lead to self injurious behavior (Attwood, 2007; Jones, Wint, & Ellis, 1990). For these and other reasons, reducing stereotypy is often a high priority for intervention.

Associated Symptoms: Cognition and Sensory Deficits. Not part of the official diagnosis, impairment in cognitive functioning has been found to co-exist in ASD. The DSM-IV-TR states that mental retardation can be an associated diagnosis which varies from mild to profound (APA, 2000). It has been shown that approximately 75% of those with ASD are intellectually disabled, and an ASD can occur with equal frequency across different levels of ID (APA, 2000; Joseph, Tager-Flusberg, & Lord, 2002). In contrast, other researchers have estimated that co-occurrence ID can be anywhere from 67 - 90% of individuals with autism (Edelson, 2006). It is believed that an autistic child's level of intellectual functioning is related to deficits in language (Lockyer & Rutter, 1970).

Researchers have shown that those with ID typically show a commensurate level of delay across multiple areas relating to cognition. In contrast for those with ASD, intelligence has been found to have heterogeneous levels of impairment across all testable domains (Folstein, 1999). Regardless of overall intelligence, individuals with autism share a common cognitive strength: the Block Design subtest on the Performance Subscale of the Wechsler Intelligence Scales (Siegel, Minshew, & Goldstein, 1996). Further more, autistic individuals have been shown to have a higher Performance IQ than Verbal IQ and a lower Verbal Comprehension than the Perceptual Organization score (Lincoln, Allen, & Kilman, 1995). In ASD children with functional language and with mild ID or above, this discrepancy between verbal and nonverbal abilities will potentially lessen with age (Joseph et al., 2002).

In addition to core symptoms, some children with autism have been found to be hypo- or hypersensitive to certain things (Folstein, 1999; O'Neill & Jones, 1997; Baranek, 2002).



Hyposensitivity refers to a lack of response, or insufficient intensity of response to sensory stimuli (e.g., diminished response to pain, lack of orienting to novel sounds, etc.). Hypersensitivity is an exaggerated behavioral response to sensory stimuli (e.g., aversive reaction to lights, covering ears to sounds, avoidance of touch, etc.). Other common tactile sensitivities include running water or sand through their fingers or aversions to certain types of food (Folstein, 1999; Prior & Ozonoff, 1998). Due to these sensory issues, many individuals with an ASD will refuse to eat certain types of food due to its smell, texture, or taste. These behaviors may lead to a diagnosis of a feeding problem if it impinges upon their health or causes behavioral issues. Other behaviors that have been observed to occur in low functioning individuals include staring at lights or moving fans and flicking their fingers in front of lights or particular objects (Prior & Ozonoff, 1998).



Background

Feeding and mealtime problems were first described in Kanner's earliest discussion of autism (Kanner, 1943). Through his observations, Kanner concluded that these difficulties should be considered a defining characteristic of the disorder. While feeding and mealtime behaviors have not been part of the diagnostic criteria for autism since Kanner, clinicians and parents have continued to suggest that aberrant feeding problems are present in a substantial number of children and individuals with ASD (Ritvo & Freeman, 1978; Raiten & Massaro, 1986). Schwarz (2003) concluded through multiple observations that most of the feeding problems seen in children with ASD can be classified as primarily feeding disorders, including aversive eating behaviors (e.g., food refusal, choking, gagging, and expulsion with no medical basis) and sensory-based feeding problems (e.g., textural aversion to specific kinds of foods, usually involving the refusal of food with greater texture). This was also believed to be related to the etiological differences between feeding problems seen in those with or without ASD. Specifically, feeding difficulties in children without ASD were characterized by being primarily due to an exacerbating medical condition, such as esophageal problems, swallowing disorders, and motor delays (Frazier & Friedman, 1996; Riordan, Iwata, Wohl, & Finney, 1984; Schwarz, 2003; Spender, Stein, Dennis, Reilly, Percy, & Cave, 1996).

Similarly, eating and feeding problems have been found to occur across the entire range of ID. Linscheid (1983) described 10 mealtime problems that were prevalent within this population including tantrums, bizarre food habits, multiple food dislikes, food-texture selectivity, delay or difficulty in chewing, sucking or swallowing, delay in self feeding, pica, excessive overeating, malnutrition through eating very little, and rumination. Later it was



suggested that feeding problems could be parceled into four distinct categories: lack of independent skills, disruptive behavior, eating too much or too little, and selectivity by type of texture (Sisson & Van Hasselt, 1989). A wide variety of different disorders, skill deficits, and excess behaviors are considered to be feeding and mealtime problems within the ID population. Failure to thrive is one such disorder, which is characteristic of children who, due to a serious pediatric ailment, have trouble gaining weight (Harnill, Drizd, Johnson, Reed, Roche & Moore, 1979; Strickler, 1984). Found within formal diagnostic guidelines of the DSM-IV-TR, disorders seen within the ID population include: feeding disorder of infancy or early childhood, which refers to children who persistently fail to eat adequately and gain weight; rumination disorder, characterized by repeated regurgitation and re-chewing of food; and pica, the persistent eating of non-nutritional substances (Girolami & Scott, 2001). While some of these problems are often associated with infants and children (Johnston, 1993; Riordan, et. al, 1984), these problems are also prevalent among adults with ID.

In an extension of the core symptoms, individuals with ASD often have deficits in feeding and mealtime behaviors. While it only seems natural that the problems pertaining to sensory integration, communication, and restricted interests would translate into difficulties eating meals, there have been few studies published that delve into the underlying factors contributing to the behaviors. Similarly, feeding and mealtime problems are an area of growing concern among clinicians with intellectually disabled clients. Although feeding problems are a serious, and oftentimes life-threatening, health concern for individuals with ASD or ID, most of the research has focused on children, primarily without ID. The small amount of literature published on this topic consists primarily of case studies that utilize functional based assessment, which are at best descriptive in nature. This absence of substantial knowledge on these problems



is reflected in the DSM-IV-TR's limited coverage of feeding disorders among those with ID or ASD.

Prevalence

Prevalence figures of feeding and mealtime problems among those with ID or ASD vary considerably across studies. This finding is thought to be largely in part to a lack of formal identification of feeding problems. Estimates of problems occurring among the children with varying levels of ID are approximately 30% (Gouge & Ekvall, 1975; Palmer, Thompson & Linscheid, 1975); however, it has also been suggested that the more severe the ID, the more prevalent the feeding problem (Perske, Clifton, McClean, & Stein, 1977). For children with a developmental disability, such as an ASD, prevalence rates of having a problem with feeding has been as high as 74% (Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998; Field, Garland, & Williams, 2003). Furthermore, children who are functioning within the severe to profound levels of ID have been estimated to have a prevalence rate of mealtime problems as high as 80% (Perske et al, 1977). While most of the research on prevalence figures has been in relation to children, there have been a few studies conducted on adult populations. Across inpatient and community samples, prevalence rate for feeding and mealtime difficulties range from 1 to 64% (Bouras & Drummond, 1992; Matson, Gardner, Coe, and Souvner, 1991; Reid & Ballinger, 1995; Hove, 2007). Overall, these studies have confirmed that feeding problems are a problem across the age range of individuals with ID, but are most notable among those with more profound ID (Matson et. al, 1991).

Researchers have shown that prevalence estimates for feeding problems are higher for those within the severe to profound levels of ID; however, this range of functioning proves to be rather difficult to accurately identify and assess these problems. For instance, individuals who



have deficits in communication or are non-verbal are unable to describe their symptoms (Poulton & Algozzine, 1980). A clinician who is faced with this situation has to rely on caregiver reports and observations to determine the nature of the individual's specific situation. For example, a person may refuse food or eat a small portion of their meal simply because they do not prefer that type of food, but are unable to indicate their dislike. Similarly, an individual may begin to engage in ruminating behavior due to an exacerbation of gastro-esophageal reflux disease (GERD) but have no functional language (e.g., words or gestures) to communicate the increase in discomfort. In these instances it is imperative for a clinician to accurately observe behaviors, identify antecedents, and determine potentially reinforcing consequences for the behavior to formulate the most effective treatment. Other problems within the ID population that may contribute to the high prevalence rate of feeding problems are deficits in motor skills/abilities (Newell, 1997), physical abnormalities (Pulsifer, 1996) and nutritional imbalances (Pace & Toyer, 2000).

Different Types of Feeding and Mealtime Problems

Pica. Pica is a feeding disorder characterized by the repeated consumption of inedible, nonnutritive items (APA, 2000). DSM-IV-TR criteria specify that the behavior must be part of a persistent pattern occurring for at least one month and is at a developmentally inappropriate level. Furthermore, this behavior must not be associated with a culturally sanctioned practice. Pica is a very serious, potentially life threatening, disorder associated with lead poisoning, intestinal blockage, intestinal perforation, intestinal parasites, encephalitis, failure to thrive, and, in the most serious cases, death (Paisey & Whitney, 1989). Common examples of pica within the ID population include the ingestion of cigarette butts, paint chips, fecal matter, paper, dirt, hair, and cloth (Matson & Bamburg, 1999; Stiegler, 2005).



The definition of pica has been extended to account for various aspects of this phenomenon (McLoughlin, 1987). For example, pica may be classified as non-food pica, food pica (e.g., consumption of rotten or frozen food), non-ingestion pica (e.g., mouthing, licking, or sucking inedible objects), or a combination of these pica subtypes. Pica behavior may also be limited to a single substance or may be exhibited across an array of substances. Lastly, there is no single known etiology for pica and, as such, may range from culture, medical and nutritional, environmental, sensory, and psychopathological factors.

Due to there being multiple functions maintaining pica behavior, the most effective clinical management approach remains unclear (Gravestock, 2000). Pica that is automatically maintained has been effectively treated through the use of delivering oral stimulation with items matching the properties of the specific pica item (Piazza, Fischer, Hanley, LeBlanc, Worsell, Lindauer, & Keeney, 1998). Punishment procedures have also been shown to be efficacious in reducing instances of pica in individuals with ID (Duker & Neilsen 1993).

Empirical prevalence data within the population of people with ID range from 9.2% (McAlpine & Singh, 1986) to 25.8% (Danford & Huber, 1982), but anecdotal reports reflect a higher rate, especially when less severe pica behavior is considered (Ali, 2001). Several studies have similarly found associations between autistic disorder and a diagnosis of pica (Gravestock, 2000; Matson & Bamburg, 1999). For example, Kinnell (1985) observed pica in 60% of autistic participants, whereas only 4% of participants diagnosed with Down's syndrome exhibited the behavior. Despite some of these estimates, the incidence of pica continues to be underidentified and undertreated (Ali, 2001; Lofts, Schroeder, & Maier, 1990; McAlpine & Singh, 1986).

Rumination. Rumination refers to the voluntary, chronic regurgitation of stomach contents into the mouth and, usually, the chewing and re-swallowing of the rumitus in a



repetitive cycle during mealtime (Johnston, 1993). According to DSM-IV-TR criteria, this pattern is recurrent for 1 month following a period of normal functioning. For an individual to be diagnosed, rumination must not be due to an associated gastrointestinal or other general medical condition (e.g., esophageal reflux) or occur exclusively with Anorexia Nervosa or Bulimia Nervosa. Similarly, those individuals with mental retardation or pervasive developmental disorder must exhibit a sufficiently severe level of behavior to merit a separate diagnosis. Rumination is a serious condition because it can lead to a multitude of life threatening consequences. In severe cases, it can lead to adverse consequences such as weight loss, esophageal irritation, dental erosion, decreased resistance to disease, aspiration, esophageal cancer, and death (Johnston, Green, Vazin, Winston, & Rawal, 1990; Johnston, 1993).

Initiation of ruminative behaviors by the individual may occur in different ways depending on physical capabilities, repertoire, and skill development. For example, individuals may stimulate their gag reflexes manually, some may rock forward sharply to gain additional force; and others may make no noticeable or consistent outward movements (Johnston, 1993). The rate with which one ruminates is highly variable, and factors such as characteristics of the food consumed and the quantity of food eaten have been found to influence the likelihood that rumination will occur. For example, researchers have found that the rate rumination increases with pureed foods and decreases as the quantity of food consumed increases (Johnston et al., 1990). Other factors that have been found to influence ruminative behavior are the taste of the rumitus and the amount of oropharyngeal stimulation (Rast, Johnston, Ellinger-Allen, & Drum, 1985).

Behavioral procedures can be effective when properly implemented for the treatment of rumination (Conrin, Pennypacker, Johnston, & Rast, 1982). The majority of behavioral



treatment studies for ruminative behavior have used punishment procedures through the use of noxious tastes and odors, such as lemon juice and Tabasco pepper sauce (Hogg, 1982; Starin & Fuqua, 1987). Overcorrection and oral hygiene procedures are two common punishment procedures represented in the literature that have been used to decrease rumination. Overcorrection involves the individual "restoring" the disturbed environment to an improved state (i.e., restitution) and then practicing more appropriate forms of responding (i.e., positive practice) (Azrin & Wesolowski, 1975). Procedures using oral hygiene comprise of verbal reprimands, a period of tooth brushing, and wiping the individual's lips with a Listerine soaked cloth. Overcorrection and oral hygiene have been shown to be effective treatments when applied after an occurrence of vomiting, however, researchers suggest these procedures are only effective when implemented consistently and, thus, can be time intensive (Sing, Manning, & Angell, 1982). Operant procedures, whereby the function of ruminative behavior is assessed and then a treatment is formulated, have been cited as another avenue to treat rumination. Common functions of rumination are attention (e.g., from staff or caregiver), escape from tasks, and self stimulation (Johnston et al., 1990; Johnston, 1993). In cases such as these, common treatments have included manipulating the environment so as to differentially reinforce incompatible behaviors (DRI). Barmann (1980) described a case of a child who engaged in hand mouthing, which served as a self-stimulatory precursor to rumination. A treatment for this case involved providing the individual a means to provide the same oral vibratory sensation, thereby eliminating the sensory function in a way that was incompatible for rumination.

Previous studies have reported the prevalence of rumination in individuals of institutionalized persons with severe to profound ID to be around 5-10% (Johnston & Green, 1992; Rogers, Stratton, Victor, Kennedy & Andres, 1992). This rate is speculated to be elevated



slightly due to the commonality of individuals to be initially diagnosed with rumination only to then be found later to have gastroesophageal reflux (Singh, 1981). Gender differences have been observed to occur (i.e., males having higher prevalence rates than females) as have associations between rumination and autistic disorder (Gravestock, 2000).

Feeding Disorder of Infancy or Early Childhood. Feeding disorder of infancy or early childhood, also referred to as failure to thrive, is characterized by the persistent failure of an infant or child under six years of age to eat adequately, subsequently reflected in the failure to gain weight or significant weight loss over a period of 1 month or more (APA, 2000). Diagnostic criteria further requires that the behavior cannot be associated or explained by any general medical or physiological condition, such as gastrointestinal problems, nervous system abnormalities, or anatomical deformations. In cases where the individual continues to refuse food for a prolonged period of time, the use of invasive feeding tubes, such as naso-gastric or gastronomy tubes, may be implemented in an attempt to sustain daily caloric intake (Riordan et. al, 1984; Shore & Piazza, 1997). This type of intervention is beneficial in that it increases an individual's food intake; however, these invasive methods can be associated with additional health risks and may fail to aid in the development of appropriate and effective eating behavior (Kuhn & Matson, 2004).

Food Selectivity and Food Refusal. Food selectivity and food refusal have long been considered to be a common phenomenon among those with ID by researchers and clinicians (Riordan, et al, 1984). For individuals who have a preference of certain foods (e.g., food of a certain texture), their feeding difficulties are perceived as being of the food selective type (Babbit, Hoch, Coe, Cataldo, Kelly, Stackhouse, & et al., 1994). Food refusal, on the other hand, is a consequence of food selectivity whereby non-preferred foods are rejected during mealtime



(Babbit, et al., 1994). The incidence of complete food refusal is less prevalent than either refusal occurring with food selectivity or than just a food selectivity problem alone. Moreover, the occurrence of a food refusal and selectivity combination is estimated to occur in anywhere from 19 to 43% of people with mental retardation (Kerwin, Ahearn, Eicher, & Burd, 1995; Gravestock, 2000).

What some have termed as the "picky eater" syndrome, food selectivity in its milder form may impose very few serious consequences; however, an individual whose "picky" preference is deemed severe may lead to malnutrition and severe developmental delays. Numerous case studies documenting food selectivity have shown a varied pattern of problematic eating behavior. In these studies there have been reports of selectivity specific to food type (Leibowitz & Holcer, 1974; Shore, Babbitt, Williams, Coe & Snyder, 1998), by the temperature of the food, by foods of particular texture (Johnson & Babbitt, 1993; Luiselli & Gleason, 1987), by the person who feeds them, by particular people present during the meal, by the location of the meal, or a mixed combination of many of these variables (Kuhn & Matson, 2002).

The development and maintenance of food selectivity may be linked to various organic and environmental factors (Riordan, et. al, 1980). Organic factors most commonly associated with interference in food intake include physical obstructions and abnormalities. These can be manifested as various problems such as deformities in oral musculature, food allergies, cleft palate, muscular dystrophy, and paralysis. The environmental factors that are described at the onset of food selectivity include a lack of opportunities for skill development and aversive feeding experiences (Siegel, 1982). Following the onset of food selectivity, reinforcement contingencies have been found to be responsible for the maintenance of the problem behavior (Cooper, Wacker, Brown, McComas, Peck, Drew, & et al., 1995).



Treatments that focus on food refusal and selectivity attempt to increase the amount and variety of foods a person consumes. These treatments can be helpful in mitigating symptoms of malnutrition, decreasing problem behaviors, and increasing food intake. Procedures frequently cited in the literature to aid in lessening food refusal and selectivity usually incorporate multiple components such as different reinforcement strategies (i.e., contingent attention or tangible reinforcement), noncontingent reinforcement escape extinction, antecedent manipulation, and negative reinforcement techniques (Cooper et al, 1995; Hoch, Babbitt, Coe, Krell, & Hackbert, 1994; Ahearn, Kerwin, Eicher, & Lukens, 2001; Patel, Piazza, Martinez, Volkert, & Santana, 2002). What has been presented throughout the literature regarding effective treatment planning for food refusal and selectivity is that to achieve success you must treat each case differently, as there is no "gold standard."

Overweight, Obesity, and Associated Behaviors. Obesity is considered to be a major health threat in the ID population. Estimates of the prevalence of adults with ID being overweight have been found to be higher than in the general, non-ID, population (Emerson, 2005). Furthermore, research has assessed the prevalence to be as high as 25-59% within this subpopulation (Kelly, Rimmer, & Ness, 1986; Rimmer, Braddock, & Fujijura, 1993; Yamaki, 2005). In particular, women, older individuals, and those with mild ID and certain genetic causes of obesity (i.e., Down syndrome, Prader-Willi syndrome) have been found to be more likely to be obese (Fox & Rotatori, 1982; Kelley et. al., 1986). Individuals in the overweight (Body Mass Index \geq 25) and obese (Body Mass Index \geq 30) ranges of body composition have been found to be at an increased risk for numerous health complications (Bray, 1998). Obesity within the ID community has recently been linked to not only behavioral or genetic reasons, but also the environment in which the individual lives. Research comparing various living



arrangements of adults with the same level of ID has shown that those who live in less restrictive settings (i.e., at home with family or independently) are more likely to be obese than those who live in more supervised settings (i.e., developmental centers) (Frey & Rimmer, 1995; Lewis, Lewis, & Leake, 2002). Given that individuals within the ID community already experience health problems at a higher rate than the typical population, the study of weight related issues and associated risks appears all the more urgent.

Beyond describing prevalence rates of obesity in individuals with ID, research in the area of eating behaviors and disorders has been sparse. A few notable studies have dealt with obesity-related behaviors. For instance, overweight individuals with ID, particularly within the profound and severe range, have been found to engage in rapid and continuous consumption of food, or excessive food seeking behavior (Gravestock, 2000). Research related to eating disorder, such as binge eating and anorexia, have similarly been underrepresented within the ID population. Individuals with Prader-Willi syndrome have been found to display binge eating and associated abnormal eating behaviors, partly because of their impaired food satiety response and hypothalamic and endocrine abnormalities (O'Brien & Whitehouse, 1990). Cases of anorexia in individuals with mild to severe ID have been reported, including those with Down's and Turner's syndromes, autism, phenylketonuria, and epilepsy. Some of the incidences reported have been found to co-occur with depression and most of these cases have been remedied through behavioral approaches and psychoactive medications (Gravestock, 2000). Anorexia nervosa in adults with ID has been found to be related to prior dieting; family psychopathology and conflicts; identity, bereavement, and sexuality issues; physical, psychiatric, and behavioral regression; and increased mortality (Clark & Yappa, 1991; Darby, Garfinkel, Vale, Kirwan, & Brown, 1981; Raitasuo, Virtanen, & Raitasuo, 1998.)



Research regarding treatment issues of obesity and its' associated behaviors has been scant in the ID population. Of the few representative studies in this feeding problem, most have revolved around food stealing behavior. Maglieri, DeLeon, Rodriguez-Catter, and Sevin (2000) used a treatment involving a stimulus control procedure and verbal reprimand to reduce food stealing in an adolescent with moderate ID and Prader-Willi syndrome. After establishing a verbal reprimand as a punisher for the behavior, the researchers were able to effectively pair the reprimand with stickers that were then placed on food containers. This resulted in the elimination of food stealing and these results were then successfully generalized to other places (e.g., the refrigerator and a cookie container) that had previously been targets for the individual's covert behavior.

Feeding Skill Problems. Feeding skill deficits are highly prevalent among individuals with ID (Cooper et al., 1995; Kuhn & Matson, 2002; Riordan et al., 1980). When a person is unable to complete basic skills such as utensil use, neatness, table manners, and oral motor skills, the ability to eat properly decreases and the risk for developing a feeding problem increases. The problems associated with poor feeding skills include difficulties swallowing, chewing, and accessing food. When an individual is unable, either from an inability or unwillingness, to complete these tasks for a period of time, consequences may occur including malnutrition and starvation (Kuhn & Matson, 2002). Similarly, if a person is unable to eat at a regular pace (i.e., eating too fast), the risk of choking or aspirating increases dramatically and can cause a potentially life-threatening situation.

In terms of skill deficits related to problematic feeding behavior, behavioral treatment for the development of appropriate mealtime behavior (e.g., appropriate utensil use and chewing behavior) has been implemented with success. Through the use of techniques such as



instructions, prompts, modeling, manual guidance, behavioral rehearsal, and contingent attention, researchers and clinicians have effectively increased behavior among individuals with ID (Sisson & Dixon, 1986). Behavioral techniques have also been shown to be effective in reducing behaviors that interfere with feeding such as mealtime sloppiness (Cipani, 1981) and rapid eating (Favell, McGimsey, & Jones, 1980). In a study by Piazza, Anderson, and Fischer (1993), a treatment package consisting of three-step guided compliance (least-to-most prompting) and social reinforcement contingent on completing a component of self-feeding (e.g., placing the spoon in the mouth), following a verbal or gestural prompt, was shown to be successful at teaching individual to scoop and place food in their mouths.

Assessment of Feeding and Mealtime Problems

In state facilities, the responsibility and treating these problems has primarily been given to a range of disciplines including an occupational therapist, nutritionist, psychologist, and a physician. Identification of a feeding problem also results from staff or caregivers informally alerting health personnel when behaviors have escalated to the point of being a severe health risk or are difficult to manage. Once an individual's ability to eat properly is called into question, it is necessary to conduct an evaluation for the presence of feeding and/or mealtime problems. There has yet to be established a formal identification process for determining the presence or absence of these types of problems; however, certain steps can be taken to ensure a through evaluation is completed including a screen of behavior through the use of rating scales, an interdisciplinary assessment, and multiple observations (Kuhn & Matson, 2004).

The first step in conducting an evaluation of feeding and mealtime behavior skills is to screen for deficits. This can be done through the use of various rating scales that have proven to be useful in the identification of feeding difficulties in individuals with ID. The Diagnostic



Assessment for the Severely Handicapped – II (DASH-II; Matson, 1995) is a scale developed to primarily assess for symptoms of psychopathology among individuals diagnosed as being within the severe to profound range of ID. The 85 items comprising the instrument are divided into 13 diagnostic categories. The DASH-II has 6 items specific to common feeding and mealtime problems including food stealing, vomiting, choking, pica, eating too fast, and not eating enough. Another measure that has been shown to be useful for the identification of feeding problems in people with ID is the Screening Tool of fEeding Problems (STEP; Matson & Kuhn, 2002). This instrument is comprised of 23 items that are subdivided into 5 subscales (i.e., aspiration, feeding problems in persons with ID. The utility of the STEP lies in its ability to pinpoint specific feeding and mealtime problems in a quick and efficient manner. Once a feeding problem behavior has been identified, an evaluation from an interdisciplinary team is the next step to address the problem.

The interdisciplinary portion of the assessment is composed of three important parts: a medical evaluation, a nutritional evaluation, and an occupational therapy evaluation (Kuhn & Matson, 2004; O'Brien, Repp, Williams, & Christopherson, 1991). A comprehensive medical evaluation is an integral component to the feeding assessment. To conduct a thorough assessment, a physician would check the following: the upper gastrointestinal anatomy of the individual to ensure the airway is protected during swallowing; the mucosal lining of the esophagus, stomach, and duodenum to gather information about whether there has been damage due to a medical condition (i.e., espohagitis, GERD); the upper gastro-intestinal tract for evaluating motility; and measuring intra-esophageal pressure, which provides information about peristalsis and esophageal motility (Babbit, Coe, Cataldo, Kelly, Stackhouse & Perman, 1994;



Patti, Diener, Tamburini, Molena & Way, 2001). If the medical evaluation identifies that a feeding problem occurs due to an exacerbating medical condition, the individual can then be given medical treatment specific to that condition (e.g., avoiding highly acidic foods for GERD). Next, a nutritional evaluation should be carried out by a dietician. The information gathered in this phase of the assessment can clarify if there are any issues regarding caloric intake, weight (O'Brien et. al., 1991), food allergies, or digestion and metabolisation of food that may be a contributing factor to feeding and mealtime problems (Kuhn & Matson, 2004). The last step in an interdisciplinary evaluation is to have an occupational therapist assess for the presence or absence of the basic skills necessary for self-feeding: oral-motor skills (e.g., sucking, swallowing, chewing, and tongue control), hand-eye coordination, tactile sensitivity, gross reflexive movements, and oral pharyngeal reflexes (Kuhn & Matson, 2004; O'Brien et. al, 1991).

The last component of a thorough assessment of feeding problems in individuals with ID is to conduct observations and/or descriptive assessments. This step is essential in providing information about the events surrounding the operationally defined behavior displayed during a meal, which can subsequently aid in identifying functional relations (Iwata, Vollmer, & Zarcone, 1990). An initial interview of the caregiver is an important part of the preliminary observational assessment. This can reveal pertinent information about the course of the feeding problem, any prior treatment strategies, food consumed and/or rejected, meal duration, the individual's daily routine, home structure, and environmental-behavior relationships which will aid subsequent observations (Babbitt, et al, 1994). Next, an observation of the individual during mealtime is conducted. Through observing the feeding process, data is collected on the following measures: frequency (i.e., number of refusals, acceptances, food presentations, etc.), duration (i.e., length of time in seat or latency of presentation to consumption), occurrences (i.e., rumination, expulsion,



etc.), and food amount (i.e., quantity consumed, expelled, remaining, etc.) (Kuhn & Matson, 2004; O'Brien et al., 1991). The data collected, once analyzed, can give insight as to the underlying function of the behavior (i.e., escape, attention, tangible, and automatic) and the nature of the antecedents that typically induce the behavior.



Purpose

With recent attention in the media, research into the area of the autism spectrum disorders has seen a recent surge. This interest is much needed. However, the study of intellectual disabled adults with ASD has gone relatively unnoticed with efforts focusing primarily on children. One area within the ASD population that has received very little attention in the adult cohort is feeding and mealtime behaviors. Of the few studies represented in the literature, the majority have been anecdotal (Ahearn, Castine, Nault, & Green, 2001). Researchers have shown that feeding problems are prevalent in the ID community (Matson et. al, 1991). Similarly, problems such as food refusal, pica, rumination, and food selectivity are also associated with autism spectrum disorders (Gravestock, 2000; Munk & Repp, 1994). Given the serious and life-threatening nature of feeding disorders, and the fact that little is known about the etiology of these problems, additional research is needed.

The rationale behind the proposed study is to investigate differences in feeding and mealtime problems across intellectually disabled individuals with and without ASD (autism and PDD-NOS). For this particular proposed study, this complex issue will be broken down into an investigation of prevalence rates and differences between diagnostic groups.

Many believe that individuals with ASD may have a different pattern in the underlying functions contributing to the maintenance of these behaviors due to the deficits associated with the disorder (Schwarz, 2003). With this investigation, it is felt that a preliminary determination of the nature and specific types of feeding disorders occurring within the ID population of ASD adults can be found. By comparing results to ID only adults, the probability of a person's ASD being a mitigating factor for the variables maintaining specific mealtime and feeding problems



will be addressed. Analyses will be conducted to determine the differences in feeding difficulties between ASD and control groups.

This study serves as an investigative analysis that may have important implications towards the care of adults with ASD and ID. The information obtained may be useful to researchers and clinicians who aim to understand the challenges presented by autistic individuals as they pertain to feeding behaviors among those in the ID community. Furthermore, the findings from the study will help to establish priorities for intervention and general treatment planning in the area of feeding and mealtime problems.



Method

Power Analysis

To determine the sample size required to achieve adequate power to produce reliable results, an *a priori* power analysis was conducted. In the behavioral sciences with an *a priori* level of significance (α) of .05, power should be set at .80 (Chase & Tucker, 1976). Using GPOWER, a power analysis computer program (Erdfelder, Faul, & Buchner, 1996), a sample of 58 participants was shown to be necessary to achieve a power of .80, using a medium effect size. Participants

Sixty inpatient adults diagnosed with varying degree of ID served as the participants who resided at a state-run developmental center in southern Louisiana. Diagnoses of intellectual disability were previously determined through evaluations conducted by a licensed psychologist

	ASD and ID $(n = 30)$ n(%)	ID alone $(n = 30)$ n (%)
Age		
18-29	4 (13.3)	2 (6.7)
30-39	3 (10.0)	5 (16.7)
40-49	14 (46.7)	18 (60.0)
50-59	8 (26.7)	1 (3.3)
60-69	1 (3.3)	4 (13.3)
Gender		
Male	21 (70.0)	17 (56.7)
Female	9 (30.0)	13 (43.3)
Ethnicity		
Caucasian	24 (80.0)	3 (10.0)
African-American	3 (10.0)	27 (90.0)
Hispanic	3 (10.0)	
Level of ID		
Profound	23 (76.7)	23 (76.7)
Severe	4 (13.3)	2 (6.7)
Moderate	3 (10.0)	4 (13.3)
Mild		1 (3.3)

 Table 1. Demographic characteristics per diagnostic group.



using the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR; APA, 2000) criteria along with the following measures: standardized measures of intelligence (Stanford Binet-IV or the Leiter), behavioral observations, the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984), and the Matson Evaluation of Social Skills for the Severely Retarded (Matson, 1995). Of these 60 individuals, 46 were assessed to be functioning at the profound level of ID, 6 with severe ID, 7 with moderate ID, and 1 with mild ID. Participants ranged in age from 18 to 69 years old (M = 45.62) and were predominantly Caucasian (85.0 %) (refer to Table 1 for additional demographic information).

Diagnoses of these individuals fell in one of two groups: ASD (Autistic Disorder and PDD-NOS; n = 30) and ID or ID and no Axis I diagnosis (n = 30). Within the ID and ASD group, 10 participants were diagnosed as having Autistic Disorder and 20 with PDD-NOS. The individuals who comprise the ID and ASD group were the experimental group and had previously established ASD diagnoses by a licensed psychologist established via the clinical team process. Inclusion in the control group was met if an individual is diagnosed as having ID only, unless previously diagnosed with Pica or Rumination. Those with ID only were the control group and, therefore, served to delineate differences specific to autism and not to developmental disabilities in general. Individuals who were fed via a gastronomy tube (g-tube) at the time of data collection were excluded, since the g-tube does not allow the control of eating behaviors. Additionally, participants diagnosed with Cerebral Palsy were excluded from this study, since oral motor dysfunction, dysphasia, GERD, and motoric limitations have been linked to nutritional and feeding insufficiency (Reilly, Skuse, Poblete, 1996; Thommessen, Kase, Riis, Heiberg, 1991). Participants were matched with one participant who meets criteria from the remaining group on gender, age, and level of ID. No participant was excluded based on age,



gender, or level of intellectual disability. Approval was given by the Institutional Review Board (IRB).

Measures

STEP. The Screening Tool of fEeding Problems (STEP) is a 23-item instrument created to screen for a number of feeding and mealtime behavior problems evinced by individuals with ID (Matson & Kuhn, 2001). This scale was developed based on record reviews of the relevant assessment and treatment literature by consultation with direct care staff and experts in the field of treating and diagnosing common eating problems. This informant-based measure has five subscales: 1) Aspiration Risk, 2) Selectivity, 3) Feeding Skills, 4) Refusal Related Behavior Problems, and 5) Nutrition Related Behavior Problems. Behaviors on the STEP are measured for both frequency and severity on a scale from 0 - 2. Frequency addresses how often the behavior has occurred during the last month and is rated "0 = not at all, not a problem", "1 =between 1 and 10 times", and "2 = more than 10 times". Severity pertains to the degree to which the behavior has been problematic for the individual and for others during the last month, and is rated as "0 = caused no harm/problems", "1 = caused minimal harm or problems", or "2 =caused serious injury or problems". The STEP has acceptable psychometric properties with cross-rater reliability of r = .71 and a test-retest reliability coefficient of r = .71. Cut-off scores have also been established for the total and factor scores to better identify persons who are at risk for these problems (Matson, Fodstad, & Boisjoli, in press). Criterion validity for items 9 and 18 has been established and has been found to coincide with DSM-IV diagnoses for pica and rumination (Matson & Kuhn, 2001; Kuhn & Matson, 2002).

Medical Record Review. To account for any medical reason that may be an underlying determinant for an individual's feeding disturbance, the records of all participants for the past



12-months were reviewed. The records covered a compilation of medical disciplines including Gastroenterology, Psychology, Nutrition, Occupational Therapy, and Speech Pathology. Both current medical conditions as well as medical conditions that have been resolved in the past 12 months were included in the analysis. The following was documented as either having occurred within the past 12 months or not: gastro-esophageal reflux disease (i.e., GERD; the passage of gastric contents from the stomach into the esophagus), food allergies or intolerance, diabetes, constipation, cardiopulmonary problems, neurological condition, all types of renal disease, and anatomical anomalies (refer to Appendix). For the purposes of this study, constipation was defined as the passage of less than three stools per week or a history of painful passage of large, hard stools. Cardiopulmonary problems were defined as diseases of the cardiac and pulmonary system such as congenital heart disease, atherosclerosis, and asthma. Neurological conditions was defined as any documented neurological problem that has associated implication in feeding and/or eating ability, including seizure disorders, traumatic brain injuries, brain tumors, and brain malformations. Anatomical anomalies was defined as any abnormality of the mouth (e.g., cleft palate), esophagus (e.g., tracheo-esophageal fistula), or stomach (e.g., microgastria or megalogastria).

Procedure

The STEP was administered by the investigator to direct care staff who had been a primary caregiver of the participant for at least 6 months. The investigator was trained on the proper administration and scoring of the instrument according to the procedures listed in the manual. Administration of the assessment was conducted in a quiet area of the participant's home, free from distraction, in a one-to-one interview between the direct care staff and the clinician. A medical review was also completed by the primary investigator for each participant



and included such information as current BMI and if any preexisting conditions such as GERD, food allergies or intolerance, diabetes, constipation, cardiopulmonary problems, renal disease, neurological problems, and anatomical anomalies was present. A thorough review of available medical records from the previous year, in addition to an interview with the individual's nurse case manager, was conducted to account for any major medical condition. All data was collected for both groups within a two-month period.

Research Design

Preliminary analyses were conducted to ensure that participants did not significantly differ on demographic variables by diagnostic group. Participants were matched with respect to gender, ethnicity, age range, and level of ID. A series of Chi-square analyses were conducted and no differences in regards to gender χ^2 (1, N = 60) = 1.15, p > .05, ethnicity χ^2 (2, N = 263) = 3.18, p > .05, age range χ^2 (4, N = 60) = 8.91, p > .05, and level of ID χ^2 (3, N = 60) = 1.81, p > .05 emerged. Additional descriptive analyses were conducted to determine the prevalence of medical conditions that were present problems or had occurred in the past 12 months that may cause an individual to have feeding difficulties. Furthermore, chi-square analyses were conducted to ensure there were no significant differences in these medical conditions between diagnostic groups.

Analyses were conducted to determine the differences between the two groups (ASD and ID or ID only), as measured by the STEP. Scores for the STEP were calculated by summing the frequency of endorsement across participants for each individual item in the scale. This calculation provided a number that reflected all items in one composite score of general feeding problems. The severity scores associated with the items was not taken into account due to the subjective nature of its assignment per direct care staff (Rojhan, Matlock, & Tasse, M., 2000).



A multivariate analysis of variance (MANOVA) was then conducted to examine the total scores for each of the five factors, aspiration risk, selectivity, feeding skills, food refusal, and nutrition amongst diagnostic group. Each item's score was coded as the statement not occurring, occurring between 1 to 10 times, or more than 10 times within the past month. Each individual item was then assigned a 0, 1, or 2 respectively. The item score on all subscales were summed across participants. Each of the empirically derived subscales of the STEP served as the dependent variable, and group membership (ASD and ID or ID only) as the independent variable.

Follow-up item analyses were then conducted to determine the differences in STEP item endorsement between the two groups. A series of one-tailed Kruskal-Wallis tests were conducted with each individual item serving as the dependent variable and group membership (ASD and ID or ID only) as the independent variable. This method of analysis was chosen to make between-group comparisons because of the nonparametric nature of the data. Hypotheses

Based on the existing literature, predictions can be made regarding the outcome of this study. First, there should be significant differences between individuals with and without autism on the STEP. The autism group is expected to evince more feeding behaviors than the non-autism group (Schwarz, 2003; Field, Garland, & Williams, 2003). Due to previously mentioned features associated with ASD, the feeding problems observed within this group should be primarily clustered in the food selectivity and food refusal groups (Schwarz, 2003; Field et al., 2003). This can then be regarded as preliminary evidence that feeding problems in those with ASD are thought to be behaviorally related, whereas feeding problems in those with ID and/or other developmental disabilities are related to medical and physical variables.



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Results

Results from the descriptive analyses for medical problems indicate that no significant differences in regards to gastro-esophageal reflux χ^2 (1, N = 60) = 0, p > .05, food allergies/intolerance χ^2 (1, N = 60) = 0, p > .05, diabetes χ^2 (1, N = 60) = 1.02, p > .05; constipation χ^2 (1, N = 60) = 2.31, p > .05, cardiopulmonary conditions χ^2 (1, N = 60) = 0, p > .05, neurological conditions χ^2 (1, N = 60) = 3.30, p > .05, renal disease χ^2 (1, N = 60) = .58, p > .05, and anatomical anomalies χ^2 (1, N = 60) = .37, p > .05 emerged. Additionally,

Table 2. Medical condition frequency and percentage endorsement per diagnostic group					
Medical Correlate	Total $(n = 60)$	ASD and ID $(n = 30)$	ID only $(n v= 30)$		
	n (%)	n (%)	n (%)		
Gastro-esophageal reflux	22 (36.7)	11 (36.7)	11 (36.7)		
Food allergies/intolerance	2 (3.3)	1 (3.3)	1 (3.3)		
Diabetes	1 (1.7)	1 (3.3)	0		
Constipation	52 (86.7)	24 (80.0)	28 (93.3)		
Delayed gastric emptying	0	0	0		
Cardiopulmonary condition	16 (26.7)	8 (26.7)	8 (26.7)		
Neurological condition	27 (45.0)	10 (33.3)	17 (56.7)		
Renal Disease	8 (13.3)	3 (10.0)	5 (16.7)		
Anatomical anomalies	14 (23.3)	8 (26.7)	6 (20.0)		

there were no significant differences in regards to total feeding problems; however, those with

ASD and ID were noted to evince more feeding problems (M = 4.20; SD = 2.46) than those with

ID only (M = 3.93; SD = 2.18).

A MANOVA was used to assess differences in STEP subscale mean endorsements across

	ASD and	ID (<i>n</i> = 30)	ID only	(n = 30)		
	M	SD	M	SD	F(1,60)	р
Aspiration risk	.07	.25	.20	.48	1.79	.19
Selectivity	.53	.78	.23	.63	2.72	.11
Feeding skills	1.13	1.94	2.47	2.26	6.02	.02 *
Refusal related	1.23	1.22	.43	.68	9.81	.03 *
Nutrition related	1.23	1.59	.67	1.09	2.59	.11

* *p* < .05; ** *p* < .01



diagnostic groups. Results indicated that there were significant differences between groups in relation to feeding skills and refusal related feeding problems. Specifically, those with ASD and ID evinced more refusal related feeding problems and those with ID only had more feeding skill problems.

Follow-up item analyses conducted via Kruskal-Wallis analyses to further delineate the

	Total $(n = 60)$	ASD and ID $(n = 30)$		ID only $(n = 30)$		
	n(%)	n (%)	<i>M</i> rank	n (%)	<i>M</i> rank	χ^2 Value
Problem behaviors during mealtime	17 (28.3)	13 (43.3)	35.0	4 (13.3)	26.0	6.46 **
Is not able to chew	3 (5.0)	0 (0)	29.0	3 (10.0)	32.0	3.10 *
Chokes on food	11 (18.3)	1 (3.3)	26.0	10 (33.3)	35.1	9.00 **
Does not have the ability to swallow	8 (13.3)	2 (6.7)	28.4	6 (20.0)	32.6	2.49 *
Food type selective	10 (16.7)	8 (26.7)	33.4	2 (6.7)	27.6	4.03 *
Swallows without chewing	6 (10.0)	1 (3.3)	28.6	5 (16.7)	32.5	2.76 *
Pushes food away or attempts to leave area when food is presented	15 (25.0)	10 (33.3)	33.5	5 (16.7)	27.5	3.09 *

Table 4. Prevalence, mean rank, and χ^2 for significant STEP items

* *p* < .05; ** *p* < .01

differences in the subscales identified as being more prevalent mealtime problems in either the ASD or ID only group (i.e., food refusal an feeding skills, respectively). The items of the selectivity subscale were also analyzed due to researchers suggesting a significant relationship to ASD symptomatology. An inspection of the items indicates that 7 out of the 23 items (30.4 %) were significantly different at p < .05. Specifically, those with ASD and ID were more likely to engage in problem behavior during mealtime, refuse food, and were more food type selective than those with ID only. Furthermore, those with ID only were found to be more likely to choke



on food or have some other significant eating skill deficit than those with ASD and ID. Overall, the total percentage of endorsement for items was low; however, given the serious nature and outcomes of feeding problems, even very low rates are clinically significant and suggest the need for immediate intervention.



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Discussion

Currently, there is little research that investigates feeding difficulties in adults with ASD who also have ID. Ensuring that these individuals have proper eating habits is of primary importance given the potentially harmful outcomes of poor mealtime skills (Gravestock, 2000; Rurangirwa, Van Naarden Braun, Schendel, & Yeargin-Allsopp, 2006). Feeding problems are serious and frequently occur in the ID population; however, little is known about how ASD symptomatology in the adult cohort might influence the prevalence, type, and nature of these difficulties. The purpose of this study was to be a preliminary investigation into the differences in feeding and mealtime problems across intellectually disabled individuals with and without ASD (autism and PDD-NOS).

Both diagnostic groups (ASD and ID or ID only) evinced feeding and mealtime difficulties. Even though not statistically significant, individuals with ASD and ID, on average, exhibited more feeding difficulties than those with ID only. Individuals with ASD and ID engaged in more food refusal behaviors (i.e., problem behavior increasing during mealtime, pushes food away, or attempt to leave area) than those with ID only. In addition, these individuals were found to have more food selectivity (i.e., food type); however, the overall selectivity subscale was not significantly different that those with ID only. This scale may not be as elevated as hypothesized because of the participants living in a developmental center and, therefore, many have nutritional diet plans which influence what the person is allowed to eat, the texture of the food, etc. due to the comprehensive nature of the services afforded in this type of setting.

The outcome of this study supports researchers who suggest that individuals with an ASD have different and distinct characteristics. Although feeding and mealtime difficulties are



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not a core feature of ASDs, these problems have continued to be documented by clinicians and parents as being serious associated features. The findings from this study suggest that difficulties in eating do persist well into adulthood and should be a major area of concern due to their potentially life-threatening outcomes. Specifically, it was found that adults with ASD and ID were more food selective and engaged in more food refusal behaviors. It is possible that individuals with autism enjoy eating a narrow range of foods, potentially due to their preference for routines and sameness, which would therefore cause learned habituation to familiar foods and rejection of any food that is novel (Birch, 1999; Schreck et al., 2006). More research is needed to elucidate the underpinnings of ASD symptomatology and how they influence overt behaviors, such as eating, food preferences, and refusal or behavior problems. Knowing how ASD core characteristics influence such phenomenon would therefore prove to be beneficial in early detection and successful intervention of feeding and mealtime difficulties.

There were some limitations that may have influenced the outcome of this study. The first limitation of this study was the sample size. While there was enough individuals to achieve acceptable power, additional participants would not only help with bolstering the findings with more information, but would also show if the data from this study are consistent with both cohorts overall. Furthermore, it might have been wise to have collected data on individuals with ID and an Axis I diagnosis other than Pica or Rumination. This second "psychopathology control" group would have been able to further delineate the differences between autism and other ID comorbidities. The second limitation of this study is that the participants all resided in a large developmental center, where many individuals have medical diagnoses hampering them from successful independent community living. In this type of setting, many have pre-



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is somewhat limited. This may account for the selectivity subscale not being significantly different between the two groups.

This was a preliminary investigative analysis to aid in the delineation of differences in feeding and mealtime problems between adults with and without an ASD. Future research should further investigate individual topographies of feeding difficulties (e.g., Pica, Rumination, etc) and the underlying behavioral variables that maintain these problems (i.e., escape, sensory, attention, medical/physical, and tangible). Furthermore, future studies should include adults who do not live in a large residential setting. While the participants in this study are representative of those individuals with ASD who reside in a large residential setting, the applicability to all adults who have ID and autism is questionable. Knowing how this group of problems may differ in etiology for those with and without an ASD would aid in treatment planning and increase the individual's quality of life. In addition, this type of knowledge would add to the growing amount of literature that researchers and clinicians know about ASD.



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Appendix

Medical Checklist

Medical Checklist		
	Currently	Past 12 Months
Gastro-intestinal reflux disease (GERD)		
Food Allergies or Intolerance		
Diabetes		
Constipation		
• Passage of less than 3 stools per week		
 painful passage of large, hard stools 		
• Bowel obstruction		
Delayed Gastric Emptying		
\circ must be diagnosed with scintigraphy showing less than 50%		
emptying at 2 hours		
\circ occurs when food stays in stomach for too long before it goes to		
the small intestine		
Cardiopulmonary Problems		
• Diseases of the cardiac and pulmonary system, including:		
o Asthma		
o anemia		
o arrhythmia		
 atherosclerosis (coronary heart disease) 		
congestive heart failure		
o endocarditis		
• hypertension		
 adult respiratory distress syndrome 		
 pulmonary fibrosis 		
o other:		
Neurological Conditions		
 include only if have documented neurological problems 		
• Seizure Disorder		
Traumatic Brain Injury		
• Brain Tumors		
• Brain malformations		
Cerebral Palsy		
• Bell's Palsy		
• Encephalitis		
Multiple Sclerosis		
Familial Dysautonomia		
Angelman syndrome		
Amyotrophic Lateral Sclerosis (ALS)		
Myasthenia Gravis		
Parkinson's Disease		
• Other:		



	Currently	Past 12 Months
Renal Disease		withins
Chronic Kidney Disease		
 Acute Kidney Disease Acute Kidney Disease 		
• Other:		
Anatomical Anomalies		
 anomalies of the mouth 		
o cleft palate		
◦ cleft lip		
• hemifacial microsomia of the cheek, jaw, or teeth		
 protruding tongue 		
 soft or hard palate 		
o other:		
• anomalies of the esophagus		
 trachesophageal fistula 		
 esophageal rings or webs 		
 esophageal diverticulum 		
o other:		
• anomalies of the stomach		
o microgastria		
 duodenal obstruction 		
• peptic ulcer		
o other:		

Current weight:

Current BMI:



Vita

Jill Fodstad is currently a second year doctoral student in clinical psychology at Louisiana State University (LSU) in Baton Rouge, Louisiana. She received her Bachelor of Science degree in applied psychology from Georgia Institute of Technology in Atlanta, Georgia, in 2004. She graduated *cum laude*. After graduating from Georgia Tech, she worked for several years at the Marcus Institute in Atlanta, Georgia, on both the Neurobehavioral Unit and Feeding Disorders Clinic. This work involved the assessment and treatment of severe behavior problems (i.e., self-injury, aggression, property destruction, etc.) and feeding and mealtime behavior problems in children and adolescents with developmental disabilities. Jill is currently pursuing a doctoral degree in clinical psychology under the supervision of Dr. Johnny L. Matson, specializing in work with individuals with intellectual and developmental disabilities. She has been a coauthor on a number of journal articles and book chapters. Jill also has served as a guest reviewer for several journals in the area of intellectual disabilities, and has served as a consultant for group homes and developmental centers in Louisiana.

