# VALIDATION OF FEEDING HANDICAP INDEX IN CHILDREN WITH AUTISM SPECTRUM DISORDERS AND INTELLECTUAL DISABILITY

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## **Chapter I**

## Introduction

Feeding is a complex motor and sensory activity which gets refined gradually in the developing child. It is a marker for neurologic maturation. Coordinated feedings require sensory-motor integration of several motor and sensory systems. Feeding involves the infant's ability to (1) engage and remain engaged in a physiologically and behaviorally challenging task, (2) organize oral motor movement to achieve long-term functional benefits, (3) coordinate breathing with swallowing to avoid prolonged apnea or aspiration of fluids, and (4) regulate the depth and frequency of breathing to maintain physiologic stability (Thoyre, Shaker, & Pridham, 2005).

Feeding and eating serve a range of biological, psychological and social functions in the life of the developing child. The biological function is clearly the most basic in that the child requires adequate nutrition not only to survive but to thrive physically and mentally (Cooper & Stein, 2006). The psychological functions have received considerable attention. For example, it has been argued that even the timing of the first feed after the infant's delivery is significant: if this occurs soon after the birth while the child is in an alert state, breastfeeding is likely to go particularly well (MacKeith & Wood, 1977). The behaviors of both caregiver and infant during feeding contribute significantly to the overall success of the feeding interaction as well as feeding performance (Meyer, Coll, Lester, Boukydis, McDonough, & Oh, 1994).

Feeding and eating also play an important role in the social life of the child. Meals are usually timed when the family is together and are the focus of family life. Furthermore, much social interaction outside the family occurs during mealtimes and this context therefore serves a wider socializing function. Understanding the typical developmental patterns of feeding in infants and children is essential in determining the presence or absence of any type of disorder. Infants and toddlers must achieve specific milestones before the introduction of solid food items. Achievements in feeding (e.g. suckling, sucking, sucking, chewing, biting, swallowing) takes place in a sequential process (Morris, 1985). After birth the infant needs to learn to coordinate the suck swallow breathe process. During the first three months after birth, the full term infant has a repertoire of reflexes that are able to ensure survival by means of the acquisition of nutrition. These include rooting, mouth opening, biting and lateral tongue movement. In addition, there is a series of protective reflexes (gag, cough and reflex closure of the airway) which ensure that the infant can feed safely (Cooper & Stein, 2006).

There appears to be sensitive period between about 3 and 6 months of age, during which infants are relatively receptive to new gustatory experiences, and sense of familiarity with wide range of tastes and textures introduced at that time may facilitate the process of weaning and enhance the later introduction of a varied mixed diet (Illingworth & Lister, 1964). They also, found that children should be given solids to chew when they are developmentally ready, usually around 6-7 months of age. By the age of 9 months the infant has not only learned more sophisticated methods of using both lips and teeth or gums to remove food from the spoon but now has more refined tongue movements which extends beyond the simple extension and retraction present at 6 months. These skills tend to get more refined by 12 months of age. At some stage during first 12 months cup drinking is introduced to the majority of infants. By 18-24 months infants have acquired the ability to manage a huge variety of tastes and textures and since they have been exposed to a range of foods, can manage an adult diet.

Mastication and deglutition are relatively complex motor behaviors in the repertoire of infant motor activity, and therefore are highly sensitive to neurologic dysfunction. Problems in feeding can arise due to various reasons. Any anatomical and/or physiological defects in the structures active in feeding and swallowing can lead to feeding problems. Feeding disorders are known to be associated with neurologic dysfunction, brain injury, prematurity, cardiac anomalies, liver function problems, gastrointestinal disorders, pulmonary disorders, metabolic disorders, cleft lip and palate, and a variety of other developmental syndromes (Burklow, Phelps, Schults, McConnell & Rudolph, 1998). Dysphagia may occur early and even sometimes seen as an isolated sign of brain injury (Love & Webb, 1992). Lewis (1972) suggested that oral-motor abnormalities can lead to failure to thrive in infancy, and described difficulties with sucking, chewing, swallowing, tongue thrusting, involuntary tonic biting of the spoon or nipple, excessive drooling and an intolerance of the textures of developmentally appropriate food.

Feeding and eating disorders commonly lead to deterioration of overall health and performance of the child as this reduces the amount of vital nutrients reaching the body. These disorders profoundly affect the quality of life of the child, they experience discomfort due to the inconvenience and pain of feeding tube or due to the difficulty in feeding/swallowing, functional problems, social withdrawal, and emotional problems. Autism spectrum disorders (ASD) and Intellectual Disability (ID) are two of the developmental disabilities found to be frequently associated with feeding issues.

Studies have reported that children with ASD have a greater number of feeding problems and eat a more narrow range of food than children without ASD which includes children with developmental disabilities or other atypical development (Schreck, Smith, & Williams, 2004; Dominick, Davis, Lainhart, Tager-Flusberg & Folstein, 2007; Martins, Young, & Robson, 2008; Matson, Fodstad, & Dempsey, 2009; Bandini, Anderson et al. 2010; Badalyan & Schwartz, 2011; Nadon, Feldman, Dunn, & Gisel, 2011). The feeding problems discovered in children with ASD include (1) food selectivity (Cermak, Curtin, & Bandini, 2010), (2) food refusal (Schreck, Smith,& Williams, 2004), and (3) disruptive mealtime behaviors (Provost, Crowe, Osbourn, McClain,& Skipper, 2010).

Williams, Dalrymple, and Neal(2000) observed in their study that 69% of children with ASD had neophobia for food. They also found that 46% had stereotyped behavior circumventing their eating habits. Field, Garland, and Williams (2003)found that 62% of the children with autism had food selectivity by type. Kozlowski, Matson, Belva, and Rieske (2012) assessed 1747 toddlers with ASD for feeding and sleeping difficulties and found greater number of feeding and sleeping difficulties in toddlers with Autistic disorder, followed by PDD-NOS and atypical development.

Children with ASDs may also present with gastroesophageal reflux disorder or chronic constipation, both of which adversely affect feeding (Schwartz, 2003). Other significant challenges present in children with ASDs include resistance to change and ritualistic behaviors surrounding mealtimes. Children with ASDs also present with sensory integrative dysfunction that affects a wide span of the feeding areas, including visual characteristics, smell, touch (hands touching food), movement, feeling of food within the mouth, and taste of foods (Schwartz, 2003; Groher & Crary, 2010). A review article was published by Marshall, Hill, Ziviani, and Dodrill (2014) where they reviewed 44 research articles concerning feeding issues in children with ASD. They reported that confined dietary variety, food neophobia, food denial, restricted diet based on texture, and a tendency towards being overweight were the most often found feeding issues in these children.

Feeding issues in children with ASD can be attributed to their concentration on detail, perseveration, impulsivity, neophobia, sensory impairments, social noncompliance, and biological food intolerance (Cumine, Leach, & Stevenson, 2000). Parental anxiety, reinforcement of negative feeding patterns, and communication deficits have been recommended as additional social reinforces that lead to the sustenance of maladaptive feeding behaviors in these children with ASD (Shaw, Garcia, Thorn, Farley, & Flanagan, 2003). Ahearn, Castine, Nault & Green, (2001) proposed that selective feeding in children with ASD was an expression of their restricted interests and activities.

In children with ID, Linscheid (1983) found ten different kinds of feeding issues viz. 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. Food refusal and rumination are often associated with infants and children with ID (Riordan, Iwata, Finney, Wohl & Stanley, 1984; Johnston, 1993; Parry, 1994). Inadequate self-feeding skill is one more concerning feature which is characterized by (i) inability or unwillingness to take the food to the mouth; (ii) inability to chew the food and (iii) inability to swallow food/liquid (O'Brien, Repp, Williams, & Christophersen, 1991; Cooper, Wacker, McComas, Brown, Peck, Richman, Drew, Frischmeyer, & Millard, 1995). Matson, Gardner, Coe, and Sovner (1991) found vomiting, regurgitation, pica, over eating, eating too fast, food stealing and poor appetite in the participants with ID.

Feeding problems have also been reported in children with Down syndrome which can be associated to low muscle tone, inadequate strength, mobility and range of motion of the oral muscles (Kumin, Goodman,& Councill, 1991), which leads to poor suck, swallow, lip closure and tongue protrusion (Kumin, 1994;Pilcher, 1998) and gastroesophageal reflux (McCurtin, 1997).

In a study done in Iranby Rezaei, Rashedi, Gharib, and Lotfi (2011), a Screening Tool of Feeding Problems (STEP; Matson & Kuhn, 2001) was administered to find feeding problems on 144 individuals with ID (30 with Down syndrome, 30 were autistic, 46 with cerebral palsy and 36 had other disabilities where 32 had mild ID, 80 had moderate ID and 32 cases with severe ID). The results indicated that almost all the subjects had some amount of feeding problems and few of them were at risk of aspiration. They found that 29.16% were at aspiration risk, 73.61% had disability of selectivity, 79.16% had deficit in feeding skills, 63.88% had food refusal related behavior problems and 66.66% exhibited nutrition related behavior problems.

Feeding issues in individuals with ID can be related to several organic and environmental factors (Riordan, Iwata, Finney, Wohl, & Stanley, 1984). Organic factors most frequently linked with interference in food intake include physical obstructions and abnormalities. These can be revealed 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 accountable for the maintenance of the problem behavior (Cooper, Wacker, 1995).

## Need for the study

Rehabilitation of feeding disorders involve understanding the signs and symptoms exhibited by the child, the underlying cause of the symptom, assessment of functional abilities of the child, impact of the disorder on a child and their caregiver/ family and planning and execution of the best suitable rehabilitation strategy to ensure safe feeding. These definitely involve a team of experts because of the interdisciplinary nature of feeding disorders. The success of rehabilitation depends on the positive changes that could be brought about in a client's feeding and the improvements made in the quality of life.

Thus, it becomes important to assess the nature of the feeding disorders and its impact on clients with different disorders and to understand the change in quality of life during and after rehabilitation. It is possible that these problems in feeding faced by the child have a negative impact on the life of the child, which may in turn hinder the progress of the child during intervention. The feeding problems could affect the social and emotional life and he/she could perceive the feeding problems as a big handicap.

Although there are tools to assess the feeding problems in children, the abnormal behaviors exhibited during feeding, oro-motor skills during feeding etc., tools to assess the physical, functional and emotional aspects related to feeding are limited. It was with this intention that a Feeding Handicap Index (FHI, Srushti, 2014) was developed to measure the handicapping effect of feeding problems. The FHI was prepared by collating information from the literature and from the complaints concerning feeding received from the parents of children with communication disorders. FHI includes physical, functional and emotional domains with a total of 38 items with 21 items in the physical domain, 10 in the functional domain and 5 in the emotional domain. This was later standardized on 60 typically developing children and 60

children with cerebral palsy. This was standardized on children with CP since CP is considered as one of the most common cause of congenital neurogenic dysphagia (Chistenson, 1989). Norms were also developed as a part of the development and validation.

FHI was based on the parent/caregiver reports as it is difficult to elicit the information from the children. Since, the parents/caregivers have a first-hand exposure and experience in feeding their child, they are well aware of the child's feeding behaviors and patterns, food related likes and dislikes, communication behavior to indicate hunger or deny food etc., problems faced by the child during feeding if any, mode of food intake, their ability to us the structures in the mouth efficiently for feeding and swallowing etc. consequently, they are the best people to describe their child's feeding problems.

A look into the literature revealed that the children with ID and ASD also exhibited feeding problems and thus it becomes equally important to assess the feeding problems in these children and its impact on the other domains of life such as functional and emotional. Such information will provide valuable input to the speech-language clinician during the treatment of feeding problems in children. The clinician will be aware of the extent of child's feeding problems in greater detail and its impact on different other domains. This would help the speech-language clinicians in prioritizing the goals during therapy depending on which aspect needs immediate attention. Since the FHI has been currently validated only on children with CP (Srushti, 2014), it was planned to extend the utility of the FHI by validating the index on children with ASD and ID. Thus the proposed study aimed at validating the FHI on children with ASD and children with ID.

## Aim of the study

The present study aimed at validation of Feeding Handicap Index on children with Autism Spectrum Disorder and Intellectual disability in the age range of 2-10 years. The specific objectives of the study included:

- 1. To establish the clinical validity measure for FHI in children with ASD and ID.
- 2. To establish the reliability measure of the tool.

## **CHAPTER II**

## **Review of Literature**

Feeding is a complex sensorimotor skill which is essential for human survival. Feeding encompasses the process of obtaining/gathering food, ingesting the food into the mouth, formation of bolus and swallowing. This physical process requires a series of coordinated steps from the voluntary process of oral management to the swallowing reflex and involuntary esophageal peristalsis. At the time of feeding, lips are used to transport liquid and solid and hold the food in the oral cavity during chewing or mastication (Guyton, 1986; Lund, 1987). The lips and cheeks also help the tongue in ensuring the alternate movement of food between the teeth during chewing (Logemann, 1986). Once the food is masticated, the swallowing occurs to transport materials from the oral cavity to the stomach without allowing entry of food particles into the airway. Logemann (1998) defined feeding as placement of the food in mouth; the manipulation of the food in oral cavity prior to the initiation of the swallow including mastication, and the oral stage of swallow when the bolus is propelled backward by the tongue. Normal swallowing can be illustrated in four phases: anticipatory, oral, pharyngeal and esophageal (Logemann, 1998).

## Anticipatory phase

Anticipatory phase begins when we prepare ourselves to have food by sitting down and a pleasant aroma and an attractive presentation stimulate our hunger, and we become physiologically ready to take in food.

## Oral phase

It comprises of two phases i.e. oral preparatory and oral transport. In *oral preparatory phase*, we are ready to eat; we put the food in mouth and close the lips. While drinking, the tongue forms a cupped position and holds the fluid in a liquid bolus, against the front portion of the hard palate. In preparation for swallowing solid foods, the tongue and cheeks move the food to the molar teeth for chewing and mixing with saliva to form a solid bolus. The prepared liquid or solid bolus is held in the mouth by soft palate, which moves forward and down to touch the back of the tongue and close the passage to the pharynx or throat.*Oraltransport* begins, once the bolus is formed. This stage consists of the movement of the bolus from the front to the back of the mouth. When the food substance reaches the anterior faucial arch at the rear of the mouth, the pharyngeal swallow reflex is triggered. Oral transport typically takes about 1 second.

#### Pharyngeal phase

The velum now moves up to meet the rear wall of the pharynx and to prevent the bolus from going into the nasal cavity. The base of the tongue and the pharyngeal wall move toward one another to create the pressure that is needed to project the bolus into the pharynx. The pharynx contracts and squeezes the bolus down. While this is occurring, the hyoid bone rises, bringing the larynx up and forward. The larynx prevents the bolus from entering the trachea, or windpipe, by closing the true and vocal folds and lowering the epiglottis covering the airway. The pharyngeal phase is complete when the cricopharyngeal sphincter opens and the food or liquid moves into the esophagus. The pharyngeal phase occurs very quickly and is usually complete in less than 1 second.

## Esophageal phase

The last stage of the swallowing process occurs when the muscles of the esophagus move the bolus in peristaltic or rhythmic, wavelike contractions from the top of the esophagus into the stomach. This typically takes 8 to 10 seconds in an unimpaired individual.

## **Developmental Milestones Relevant to Normal Feeding**

According to Pridham (1990), feeding skills were found to be very important for the development of infant's capacity for self-regulation throughout the first year of life. The development of feeding and swallowing is the result of a complex interface between the developing nervous system, various physiological systems, and the environmental factors that begin in embryologic and fetal periods and continue through infancy and early childhood. The development of feeding is sustained by neurological maturation and ongoing experiences of a child. It begins with hunger and satiety pattern at the age of 2-3 months. Till the age of 4-6 months, infants receive all the nourishment from breast/nipple feedings. As the child grows, the sucking and swallowing action is followed by biting, chewing, eating from a spoon, drinking from a cup and a straw which are more mature feeding behaviors. These developments occur as the higher cortical centers gain more control (Arvedson& Brodsky, 1993).

The table 2.1 depicts the normal developmental milestones for self-feeding skills from birth to 24 months.

# Table 2.1

Age (months)	Skill level	
0-5	Hand to mouth begins	
2-4	Hand on bottle during feeding	
4	Spoon feeding introduced	
4-6	Cup drinking introduced	
5-6	Both hands to hold the bottle	
5-7	Semi solids from spoon	
6	Cracker to mouth briefly	
6	Lip closure around the spoon	
6	Munching begins- vertical jaw action	
7	Chewing begins- rotary jaw action	
6-8	Liquids suck from cup	
8-9	Assisting with spoon	
9	Cracker to mouth- deliberately reaches for spoon	
9-10	Drinks from the cup held by the caregiver	
10-11	Pincer grasp for finger feeding	
12	Self-feeding by grasping spoon with whole hands	
12	Holds cup with 2 hands; 4-5 consecutive swallows	
12	Holds and tips bottle by self	
15-24	Skills refined for independent self-feeding	

Normal developmental milestones for self-feeding skills (source: Arvedson & Brodsky, 1993)

Stevenson and Allaire (1991) studied the development of feeding and swallowing and they put forth the following findings:

- i. The normal development of feeding and swallowing skills essentially depends on structural integrity i.e. there is an association between anatomic changes taking place and growth in the feeding function.
- During infancy, feeding is reflexive in nature and is under brainstem control. Along with development, these brainstem mediated reactions gradually come under voluntary control.
- iii. During infancy, swallow does not involve voluntary oral-preparatory phase and oral phase while a mature swallow consists of voluntary oral-preparatory phase, voluntary oral phase, and involuntary pharyngeal and esophageal phases.
- iv. Neural control of swallowing entails sensory afferent nerve fibers, motor efferent fibers,
   paired brainstem swallowing centers and supra-bulbar neural inputs. Normal feeding
   development requires the integration of these sensory and motor functions.
- v. Feeding is also affected by person's nature, interpersonal connections, upbringing and culture.
- vi. The major objective of feeding is the attainment of sufficient nutrition required for age adequate growth and development.
- vii. Along with neural and structural development, feeding also depends on learned behaviors which are controlled by oral sensation, fine and gross motor development, and experimental chances.

The major systems that must be present and functional for normal feeding are summarized in the table given below.

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# Table 2.2

Systems/Domains involved in the development of feeding. (Source: Arvedson & Brodsky, 1993; Stevenson & Allaire, 1991)

Systems	Required for
Oromotor function	Sucking, munching, chewing, and movement of the bolus; also needed for speech
Respiratory System	Maintaining normal oxygen exchange, coordinating suck and swallow, coughing to protect airways
Cardiovascular System	Maintaining normal blood pressure and oxygenation of the tissues
Pharyngeal Coordination	Coordinating swallowing and breathing, safely transporting the bolus to the esophagus
Gastrointestinal System	Esophageal transporting of the bolus to the stomach and lower esophageal sphincter to avoid reflux. Gastric emptying to the duodenum and transporting throughout the bowel
Gross Motor	Maintaining head in midline and upright position, sitting stability on the chair

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Fine Motor	Finger feeding, using a spoon, holding a cup	
Expressive Language	Asking for more or saying no	
Nonverbal Communication games	Pointing for food, opening mouth to receive food, gesturing, playing	
Receptive Language	Comprehension of the meaning of words, "food, bottle", understanding of commands.	
Hypothalamus	Controlling hunger and satiety	
Cognitive	Recognizing foods by color, appearance, taste and so on; learning the associations related to feeding; learning to self- serve food.	
Social	Giving positive feedback to the caregiver, eye contact	
Caregiver (socioeconomics)	Providing appropriate amount and type of food	
Caregiver (emotional)	Funneling positive emotional support of a child during the learning process, setting rules and limits	

Feeding development does not occur in isolation. There are many other skills such as cognitive and sensory motor skills that develop simultaneously in the child which would in turn facilitate feeding skills. Averdson and Brodsky (1993) compiled the developments in all the above mentioned areas which have been depicted in the table 2.3 below:

Table 2.3

*Neurodevelopmental milestones relevant to normal feeding* (Source: Arvedson& Brodsky, 1993)

Age (Months)	Cognitive skill	Sensory Motor skill	Feeding skill
Birth to 2	Visual fixation and tracking	Balanced flexor and extensor tone of neck and trunk	1
3 to 4	Visual recognition of parents	Head maintained primarily in midline and aligned with trunk in supported sitting	Parents preferred for oral feedings Upright supported position for spoon feeding
5 to 9	Visual interest in small objects Extended reach and grasp Object permanence Stranger anxiety	Independent sitting Extended reach pincer grasp and grasp	Feedings more frequently in upright position Initiation of finger feeding Parents preferred for feedings
18 to 24	Use of tools Increasing attention and persistence in play activities Independence from parents	Refinement of upper extremity coordination	Use of feeding utensils Prefer to feed self over longer periods of time Imitate others during meals

## **Factors Influencing the Development of Feeding**

Oral feeding skill may be different in different individuals. Feeding is influenced by multiple anatomic, neurophysiologic, environmental, and cultural factors. It is influenced by the levels of alertness, stress, illness, and fatigue as well as actual motor coordination in the oral pharyngeal system. Also, the cultural pattern along with social factors within the family, have an effect on the feeding skills. The transitional feeding phase is the time, when the dietary pattern and preferences are acquired, and many of these preferences are carried over into adulthood (Arvedson & Brodsky, 1993). The aspects of anatomy, embryology, and physiology a human embraces also influence the feeding development. In addition, it is influenced by behavioral and social factors (Miller, 1986).

Feeding is dependent on the neurological maturation of the child. Maturation of the central nervous system (CNS) plays an important role in the acquisition of normal swallowing or feeding skills. Both feeding and swallowing require intact functioning of the central and peripheral nervous systems and the intricate coordination of actions of multiple muscles of the oral cavity, pharynx and esophagus (Miller, 1982). A child's neurodevelopmental status determines the development of feeding and swallowing. Any abnormalities of developing brain or structural or functional deficits in the oral, pharyngeal or esophageal region commonly results in a spectrum of cognitive, communicative, behavioral and motor abnormalities that are often associated with feeding and swallowing disorders. Even a small injury to the developing brain can have a magnified negative effect on the rest of the sequence of the developing brain leading to congenital malformation and other related abnormalities (Lenn, 1991).

## **Pediatric Feeding Disorders**

A pediatric feeding disorder is the inability of a child to consume sufficient calories for optimal growth and development. Sometimes, this inability is associated with swallowing dysfunction. The number of children identified with feeding and swallowing disorders has increased considerably over the past 20 years. Initially, many of the problems were attributed to the child's behavior or inappropriate parental feeding skills. But now, it is known that the origin of most of the childhood feeding disorders is the result of the related medically based conditions, congenital anomalies, developmental delays, sensory processing disorders and environmental factors (Field, Garland& Williams, 2003). Twenty five percent of all children are reported to present with the feeding disorders; with that number increasing to 80% in the population of children with developmentally delay (Manikam & Perman, 2000). Burklow, Phelps, Schultz, McConnell, and Rudolph (1998) and Field, Garland, and Williams (2003) have found that 74% of the children with developmental disabilities exhibit feeding issues. Feeding disorders are known to be associated with neurologic dysfunction, brain injury, prematurity, cardiac anomalies, liver function problems, gastrointestinal disorders, pulmonary disorders, metabolic disorders, autism and a variety of other developmental syndromes (Burklow et al., 1998).

Groher and Crary (2010) identified a few signs of problematic eatingwhich may signal the eating and feeding difficulty. These have been depicted in the table below:

## Table 2.4

## Few signs of problematic eating in young children

## Signs of problematic eating

- Poor weight gain
- Coughing, choking, or gagging during meals
- Vomiting
- History of a traumatic choking incident
- History of eating and breathing coordination problems with ongoing respiratory issues
- Inability to make transition to baby food purees by 10 months
- Inability to accept table food solids by 12 months
- Inability to make transition from breast to bottle to cup by 16 months
- Has not been weaned from baby foods by 16 months
- Aversion or avoidance of all food of specific texture or food groups
- Food range of fewer than 20 foods, especially if foods are being dropped from child's repertoire with no foods replacing those lost
- Crying or arching by the infant at most meals
- Family fighting about food and feeding
- Repeated paternal reports that the child is difficult for everyone to feed
- Paternal history of an eating disorder with a child not meeting weight goals.

Problematic feeding behaviors such as food refusal, disruptive mealtime behaviors, rigidity in the range of preferred foods, suboptimal growth, and failure to meet self-feeding milestones associated with the child's developmental level is a significant challenge for both child and the family (Linscheid, 2006; Arvedson, 2008). Also, Toomey, Nyhoffand Lester (2007) noted that children with physical difficulties often develop behavioral problems after their attempts to eat don't go well, and children with behavioral eating difficulties developed physical disorders after having poor nutrition for a period of time.Autism spectrum disorders (ASD) and Intellectual disability (ID) are two of the developmental disabilities found to be frequently associated with feeding issues.

#### **Autism Spectrum Disorders**

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders that are characterized by deficits in social communication and social interactions, as well as the presence of restricted repetitive and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 2013). These features can be seen at the age of three years and will remain throughout the life (Kamp-Becker, Schröder, Remschmidt,& Bachmann, 2010). ASD can be associated with intellectual deficit and seizure disorder in substantial number of cases and to an extent determined by genetic factors (Rutter, 2005). According to DSM IV TR (2000) classification, ASD comprises of Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (Atypical Autism) and does not include Rett's Disorder.

As per Centers for Disease Control and Prevention (CDC) Report (2014), Autism and Developmental Disabilities Monitoring (ADDM) Network have found the prevalence rate of ASD as 14.7 per 1000 children aged 8 years in United States. Also, about 1 in 42 boys and 1 in

189 girls aged 8 years were found to have ASD in ADDM network.According to Action for Autism India, the prevalence rate of ASD is 1 in 250 in India. (Posserud, Lundervold, Lie, & Gillberg, 2010).

## **Causes of Autism Spectrum Disorder**

Trottier, Srivastava, and Walker (1999) proposed that etiology of ASD is complex in nature and can be because of both genetic and environmental factors. Many researchers suggested that genetics is an important causative factor leading to ASD (El-Fishawy & State, 2010; Caglayan, 2010; Geschwind, 2011). Multifactorial inheritance was found to be the consistently occurring genetic cause and also it has been observed that the risk of having all the siblings of a child with autism was in the range of 3-10% (Chakrabarti & Fombonne, 2001; Icasiano, Hewson, Machet, Cooper & Marshall, 2004; Lauritsen, Pedersen, Mortensen; 2005). Freitag (2007) suggested fragile X syndrome and tuberous sclerosis as potential genetic disorders. Also, genetic hypothesis suggested: (i) familial incidence of autism is higher than that in the general population (more than one case among blood relatives); (ii) more males affected than females; and (iii) a greater proportion of identical twins than ordinary siblings affected. Although no specific gene has been found to cause autism, researchers are looking at several genes that may be responsible for the disorder (Hedge & Maul, 2006).

Environmental factors could be multiple which could lead to ASD. Environmental causes can be categorized into three categories i.e., *pre-natal* (congenital rubella syndrome, teratogen exposure and pesticide exposure), *peri-natal* (low birth weight, premature delivery and birth asphyxia) and *post-natal* (autoimmune diseases, leaky gut syndrome, viral infection, amygdale development failure, oxidative stress, vitamin D deficiency, heavy metal toxicity and controversial MMR Vaccine) factors (Wakefield et al., 1998; Ashwood & van de Water, 2004;

Davidson, Myers, & Weiss, 2004; Schultz, 2005; Kern & Jones, 2006; Kolevzon, Gross & Reichenberg, 2007; Cannell, 2008).

Neurological factors leading to ASD have also been studied. Some evidences suggest that various portions of the brain that control communication, social interaction, and motor skills may not develop normally in people with autism (Sokol & Edwards-Brown, 2004). Some atypical growth in the head circumference has been noted as well. Generally, a smaller head circumference than normal at birth, and an unusually rapid growth later, has been documented (Aylward, Minshew, Field, Spark, & Singh, 2002).

Researchers have not firmly established the causes of autism, pseudo theories of its causation abound, especially in popular press and internet and these theories lack scientific research support. For example, childhood vaccinations (for measles, mumps and rubella), pesticides in food, air pollution, vitamin deficiencies, food allergies, and a yeast infection called candida albicans have all been blamed for autism. A large Danish study involving 537, 303 children failed to confirm a correlation between vaccinations and autism (Madsen, Hviid, Vestergaard, Schendel, Wohlfahrt, Thorsen, Olsen, & Melbye, 2002).

#### **Features of ASD**

The diagnostic criteria for ASD depends on a triad of impairments, where there is a discrepancy between the behavior and the mental age of the child (Wing, 1996; ICD-10; DSM-IV): (1) impaired social skills, delayed, deviant or atypical social development; (2) impaired language and communication (verbal and non-verbal) skills and (3) rigidity of thought and behavior and poor social imagination; ritualistic behavior, reliance on routines, impairment of

imaginative play. The symptoms of autism are typically noticed sometimes during the first three years. The different areas of impairment are described below:

## Social communication

The central challenge in ASD is impaired social communication. This is a broad reaching term, encompassing the true purpose of communication where components of language and socialization merge to allow for social, human interaction. There are different entities of social communication that are affected simultaneously.

## Social orienting and joint attention

For children with ASD, impairments in joint attention and social orienting are found to most strongly distinguish them from disorders as young children. Dawson, Toth, Abbott, Osterling, Munson, Estes, and Liaw (2004), in their study compared 3-4 year old children with ASD to children with developmental delay and typically developing children. They found that children with autism were significantly below the other groups in all domains for measures of social orienting, joint attention, and attention to another's distress. Impairment of joint attention are noted in autism, which includes difficulty following other's visual or gestural focus attention, as well as reduced skills in shifting gaze between people and objects (Wetherby, Prizant, & Hutchinson, 1998; Mundy & Neal, 2001). Klin, Jones, Schultz, Volkmer, and Cohen (2002) using eye tracking technology found that individuals with ASD attended less frequently to a speaker's eyes and more frequently to their mouths.

#### Monitoring emotional states and shared intentions

Researchers have found that people with autism both attend less to others' emotions, particularly distress or discomfort (Dawson et al., 1990) and display positive affect in a shared interaction less frequently (Wetherby, Prizant, & Hutchinson, 1998).

## Social reciprocity

According to DSM-V, a deficit in social emotional reciprocity is described as ranging from an abnormal social approach and failure of normal back and forth conversation through reduced sharing of interest, emotions, and affect and response to lack of initiation of social interaction (APA, 2013). Social emotional reciprocity is at the core of conversational skills, and individuals with autism typically have difficulty initiating communication spontaneously (Wetherby et al., 1998) and are often limited to conversations that are structured and predictable.

## Language skills

Language skills have been cited as a predictor of later social communication outcomes, specifically the presence of expressive language by age five (Rutter, 1970, 2011). These children do not learn language at usual rate, nor do they use whatever they have learned to communicate with others. Language skills include both comprehension and use, and both are affected in ASD, interfering with the ability to communicate and understand the intent of others. Expressive language, however, tends to improve more readily and rapidly than receptive language (Paul & Cohen, 1984). The various components of language are also affected which have been described below.

#### Semantics

Children with autism often remain in the first phase of lexical development, where words are learned slowly and only for significant people, things and events (Carpenter & Tomasello, 2000). These children appear to demonstrate a separation of language function and language form. Though they may understand basic concepts and vocabulary, the appropriate use of these words in multiple and varied communicative situations are impaired. That is, the words may be recalled and retrieved, but the shared commonalities may not be extracted resulting in impaired category formation (Minshew, Meyer, & Goldstein, 2002). There is also more likelihood to learn words that refer to objects than those that refer to concepts, people, or human relations. Nouns are preferred to verbs. Some acquire difficult words more easily than easier words (Park, 1982).

#### Morphology and syntax

Bartolucci, Pierce, and Streiner (1980) found that children with autism produced the fourteen grammatical morphemes (e.g., articles, present progressive -ing, plural *s*) less frequently than their cognitively matched, nondisabled peers, with most errors noted for use of articles (i.e. a., the, an) and verb tenses. Development of syntax and the use of varying sentence forms appeared to be similar to that of peers of equal cognition, with relation to a developmental rather than age level. They generally speak in shorter and simpler sentences. One of the early language problems associated with autism is echolalia. This communication pattern is evident when the echoed response includes what may be the actual answer to a question.

## **Pragmatics**

The area of language found to be the most significantly impaired in children with autism is pragmatics, or the social use language. Communicative intent is typically very restricted, with regulation of another's behavior, as demonstrated through requests and protests, noted to exist more frequently than socially driven communication (e.g., sharing feelings, commenting, requesting permission) (Stone & Caro-Martinez, 1990).

## Speech skills

Generally children with autism speak at a later age and develop speech at a slower rate than children with autism (LeCouteur, Rutter, Lord, Rios, Robertson, Holdgrafer, & McLennan, 1989), with approximately 15% having a speech disorder (Shriberg, Paul, Black, & van Santen, 2011). Approximately 25% of children with autism have been described as having words (at around 12 to 18 months) and losing them. Recent research indicated that as many as 30% of children with ASD were considered to be nonverbal, explained as using few or no words consistently by the age of nine (Anderson, Lord, et al., 2007).

Children with autism have difficulty in producing speech sounds correctly. Their speech may have a sing song or monotonous quality, and they may speak very softly, even whisper, or may speak excessive loudness. Autistic children may produce speech with abnormal intonation.

## Nonverbal Behavior

The DSM-V specifies deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated verbal and nonverbal communication, through abnormalities in eye contact and body language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures (APA, 2013).

## Play skills

According to Libby, Powell, Messer, and Jordon (1998), children with autism engage in less functional play and more sensori-motor play (e.g., oral exploration, spinning). In addition, when functional play develops it tends to be qualitatively different as children are only being able to use objects as function denotes. Finally, symbolic play is often reduced or absent with an inability to engage in object substitutions. Overall, play appears to be rigid, with difficulty noted for changing routines or materials. It can be especially difficult for children with autism to integrate the ideas or themes of a play partner into their own play.

## Cognitive skills

Recent research (Centers for Disease Control and Prevention, 2012), indicated that the majority of children with ASD did not have intellectual disability. According to Sigman, Dissanayake, Arbelle, and Ruskin (1997), children with ASD are not delayed or deviant in spatial knowledge, perceptual organization, or short term memory skills. Rather, primary difficulties are noted for the derivation of abstract information "necessary for sequencing material and in transforming this information into symbolic representations."

## **Behavior problems**

A few autistic children are prone to hurting themselves constantly such as bang their heads against the walls, pull their hair, chew on their fingers, bite their own arms, and scratch their faces. These are deeply disturbed by a change in routine; everything must be the same place, day after day (Hegde, 2010).

## **Types of ASD**

ASD comprises of Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (Atypical Autism)

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# Autism/ Autistic Disorder

Children with Autism have severe and sustained impairments in the social and communication areas and these are present before the age of three years. They might have restricted range of activities and interests. Delayed speech and language is a core feature of autism.

# Asperger's Syndrome (AS)

Children with AS are similar to those with autism in many respects, but there are some differences. Generally, they have much better speech and language skills when compared to classic autism; but the most significant problem associated with AS is a severe impairment in social interaction.

# *Childhood disintegrative disorder (CDD)*

Childhood disintegrative disorder (CDD) is characterized by normal development at least in the first two years of life, followed by deterioration in learned skills. The disorder is usually diagnosed between 3 and 4 years of age. The child's social, verbal, self-help, and motor skills, as well as bowel and bladder control, may all disintegrate. Similar to children with autism, they exhibit preoccupation with certain interests and activities and repetition behaviors, including hand flapping and rocking. The cause of the disorder is still unknown.

# Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

Children are diagnosed with PDD-NOS if they have some feature of ASDs that is affecting their daily life, but do not meet the criteria for a diagnosis of Autism or Asperger's Syndrome.

# **Associated Problems in ASD**

Intellectual disabilities are very frequently associated with ASD and are a part of autism. Poor motor coordination; abnormal postures; increased or decreased sensitivity to such sensory stimuli as cold, heat, noise, and pain; hearing loss and seizures also are more common in children with autism than in those without.Studies have suggested that around 67% to 70.8% of the individuals with ASD have associated mental health disorder (DSM-IV); the presence of an associated psychiatric condition considerably increases the risk of having multiple diagnoses. Simonoff, Pickles, Chandler, Loucas, and Baird (2008) in their study, assessed 112 children in the age range of 10-14 years for child psychiatric disorders; they found that 41% of the children had two or more disorders in addition to ASD.

Studies also suggested that children with ASD are more likely to exhibit associated disorders in comparison to those with intellectual disability or developmental disability (Bryson, 1997; Bryson & Smith, 1998).Ghaziuddin, Weidmer-Mikhail, and Ghaziuddin (1998) found that 50% of the children with ASD had ADHD; other studies have found that 28.2 to 31% of the children with ASD had ADHD (Abramson, Ravan, Wright, Wieduwilt, Wolpert, Donnelly, Pericak Vance, & Cuccaro, 2005; Simonoff et al., 2008). Simonoff et al., (2008) also suggested that anxiety was seen in 40% of the individuals with ASD which could be specific phobias, social anxiety, generalized anxiety, panic disorder and obsessive compulsive disorder (OCD). Gastrointestinal problems are frequently associated with ASD. Kanner (1968) suggested that children with infantile autism have feeding and dietary problems which support the early association of ASD with gastrointestinal problems.

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# Feeding Problems in Children with ASD

Children with ASDs may present with a variety of feeding problems. Many children with ASD have co-occurring feeding problems with reported prevalence rates of 46–89% (Raiten&Massaro,1986; Ledford &Gast 2006; Schmitt, Heiss, & Campbell, 2008; Bandini, et al., 2010; Seiverling, Hendy, & Williams, 2011) in comparison to a rate of 25 % for typically developing children (Manikam&Perman, 2000).

The feeding issues discovered in children with ASD are usually categorized into three types: (1) food selectivity (Bandini et al., 2010; Cermak, et al., 2010), (2) food refusal (Schreck et al., 2004), and (3) disruptive mealtime behaviors (Twachtman-Reilly, Amaral, &Zebrowski, 2008; Provost et al., 2010; Rogers, Magill-Evans, &Rempel, 2012).

Studies have reported that the most common feeding problem seen in children with ASD was food selectivity depending on type, texture and/or presentation of the food that included strong preference for carbohydrates and aversion for fruits and vegetables (Ahearn, Castine, Nault& Green, 2001; Schreck, Smith & Williams, 2004; Williams, Gibbons & Schreck, 2005).

Studies have suggested that children with ASD have a greater number of feeding problems and eat a more narrow range of food than children without ASD which included children with developmental disabilities or other atypical development (Schreck, et al., 2004; Dominick, et al., 2007; Martins, Young, & Robson, 2008; Matson, et al., 2009; Bandini et al. 2010; Badalyan & Schwartz, 2011; Nadon et al., 2011). Field et al., (2003) found that 62% of the children with autism had food selectivity by type. Williams et al., (2000) observed in their study

that 69% of children with ASD had neophobia for food. They also found that 46% had stereotyped behavior circumventing their eating habits.

Ahearn, Castine, Nault, and Green (2001) used a feeding assessment protocol developed by Munk and Repp (1994) on 30 children with autism and PDD-NOS in the age range of 3 to 14 years of age. They were exposed to 12 food items and recording was done for the observation of food acceptance, food expulsion and disruptive behaviors. They found that 50% of the children showed food acceptance signifying food selectivity based on food category and texture.

Martins, Young, and Robson (2008) in their study assessed the feeding and eating behaviors of children with ASD, typically developing siblings of children with ASD and typically developing children with no sibling with disability in the 2-12 years age range by administering a exhaustive questionnaire on the mothers of these children. Results suggested that selective eating was more often found in children with ASD and they exhibited more problematic eating and feeding behavior in comparison to other typically developing children.

Kozlowski, Matson, Belva, and Rieske (2012) assessed 1747 toddlers with ASD for feeding and sleeping difficulties using Baby and Infant Screen for Children with autism Traits-Part 2. They found that greater number of feeding and sleeping difficulties was seen in toddlers with Autistic disorder, followed by PDD-NOS and atypical development.

Baldalyan and Schwartz (2012) compared children with classic autism with their normal siblings and they found that there was a significant difference between the two groups with respect to prevalence of frequent problematic feeding behaviors, including unusual food preferences (e.g., specific food colors, shapes, textures, presentation, or specific arrangement of food on the plate), insistence on eating food with specific utensils/dishes, dislike of new foods,

fear of new foods, poor mealtime social behavior, unusual posturing during meals, and oral motor problems.

Sharp, Jaquess, and Lukens (2013) selected 30 children with ASD in the age range of 3-8 years. The standardized mealtime observation, a food preference inventory, and the Brief Autism Mealtime Behavior Inventory (BAMBI) were administered. They discovered that 14 out of 30 children either accepted or rejected all the bites while rest 16 showed selective patterns of acceptance depending on type and/or texture of the food. As per observation and parent report, vegetables were the most frequently discarded food item by these children. Also, it was observed that the food selectivity was often associated with the problem behaviors.

A review article was published by Marshall, Hill, Ziviani, and Dodrill (2014) where they reviewed 44 research articles concerning the feeding issues in children with ASD. They reported that confined dietary variety, food neophobia, food denial, restricted diet based on texture, and a tendency towards being overweight were the most often found feeding issues in these children.

Children with ASDs may also present with GER(D) or chronic constipation, both of which adversely affect feeding. Other significant challenges present in children with ASDs include resistance to change and ritualistic behaviors surrounding mealtimes. Children with ASDs also present with sensory integrative dysfunction that affects a wide span of the feeding areas, including visual characteristics, smell, touch (hands touching food), movement, feeling of food within the mouth, and taste of foods (Groher & Crary, 2010).

# Factors Causing Feeding Problems in Children with ASD

A number of rationalities have been proposed for the preponderance of feeding issues in children with ASD, including a concentration on detail, perseveration, impulsivity, neophobia,

sensory impairments, social noncompliance, and biological food intolerance (Cumine, Leach, & Stevenson, 2000). Parental anxiety, reinforcement of negative feeding patterns, and communication deficits have been recommended as additional social reinforcers that lead to the sustenance of maladaptive feeding behaviors in these children with ASD (Shaw, Garcia, Thorn, Farley, & Flanagan, 2003). Williams et al., (2000) and Ahearn et al., (2001) proposed that selective feeding in children with ASD was an expression of their restricted interests and activities.

Behavioral problems in these children are also likely to interact with the feeding and mealtime behaviors. The social, communicative and cognitive deficits present in these children can hamper child's early learning of mealtime behaviors. Rigid mealtime routine can be because of the ritualistic and repetitive behaviors and behavioral inflexibility in them.

Sensory issues present in these children can also have an impact on the feeding and mealtime behaviors. Tactile and oral defensiveness are seen often in children with ASD (Kientz & Dunn 1997; Baranek, Boyd, Poe, David, &Watson, 2007; Tomchek & Dunn 2007). The presence of sensory oversensitivity in the oral region can lead to food selectivity in these children with ASD (Williams, et al., 2000; Cermak et al., 2010; Lane, Young, Baker, & Angley, 2010).

Lecavalier (2006) suggested that externalizing disruptive behaviors are frequently associated with children with ASD which may contribute to the feeding and mealtime behavioral problems. Disruptive behaviors like aggression, self-injury, tantrums (Lukens & Linscheid, 2008), throwing out the food, complaining and arguing (Ahearn et al., 2001; Sharp & Jaquess 2009), eating without utensils, refusing to come to the table, and not staying seated have all been discovered by different researchers in the children with ASD (Matson et al., 2009; Volkert & Vaz, 2010). Field et al., (2003) suggested that feeding problems could arise from learned behavior resultant of gastrointestinal problem

Internalizing problems, for example, anxietyand depression have been observed in children with ASD (Kim, Szatmari, Bryson, Streiner, & Wilson, 2004; Twachtman- Reilly, Amaral, &Zebrowski, 2008; Mayes &Calhoun, 2011)have implicated anxiety as a cause offeeding and swallowing difficulty in ASD. Also, they found the tendency for more situation-based anxiety which was related to the higher prevalence of compulsive rituals or avoidance of certain foods.Evans, Canavera, Kleinpeter, Maccubbin, and Taga(2005) also reported of situation-based fears or phobias in children with ASD.

Johnson, Turner, et al., (2014) selected 256 children with ASD in the age range of 2-11 years for their study, where they evaluated the relationships between feeding and mealtime behaviors and social, communication, and cognitive levels as well repetitive and ritualistic behaviors, sensory behaviors, and externalizing and internalizing behaviors. Results indicated the presence of strong association between feeding issues reported by parents and repetitive and ritualistic behaviors, sensory features and externalizing and internalizing behaviors. Poor association was observed between feeding issues and the social, communication and cognitive deficit.

Belmonte, Saxena-Chandhok, Cherian, Muneer, George, and Karanth (2013) administered ComDEALL oro-motor checklist on children with ASD in the age range of 1 year 10 months to 5 years 5months; and found that these children had deficit in oral motor skills.

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They attributed this deficit to the impaired motor impairment resulting from dissociation within motor execution and executive planning and sequencing and/ or affective motivation.

# **Consequences of Feeding Problems in Children with ASD**

Nutritional deficiencies have been reported consequent to the feeding disorder in children with ASD. In a study fifty three children with ASD in age range of 3-11 years were considered who had feeding issues such as narrow food preference and/or food refusal. They found that these feeding issues lead to nutrition deficiency (fiber, vitamin D & E, and calcium)in them (Bandini et al., 2010). In the largest study to date, the nutritional intake of 257 children with ASD revealed the majority of children did not meet recommended intake of fiber, choline, vitamin D and K and potassium (Hyman, Stewart et.al., 2012). Other studies have found poor protein intake, deficiency of B12 and iron in these children (Buie, Campbell, Fuchs, Furuta, Levy, Vandewater, Whitaker et al., 2010; Zimmer, Hart, Manning-Courtney, Murray, Bing, &Summer, 2012). A few case reports have highlighted the medical implications for significant deficiencies in vitamins A, B12, C, D and K and calcium in individuals with ASD (Clark, Rhoden,& Turner, 1993; Uyanik, Dogangun, Kayaalp, Korkmaz, & Dervent, 2006; Pineles, Avery & Liu, 2010).

# **Intellectual Disability**

Another developmental disability in which feeding disorders have been frequently reported is the intellectual disability. Intellectual disability (ID) in children, previously termed mental retardation, are diagnosed when a child (or an adult) experiences limitations in intellectual functioning, deficient social behaviors or skills, and inadequate daily living skills (American Association on Intellectual and Developmental Disabilities, 2008). Limitation may be evident in communication, self-care, home living skills, self-direction, interpersonal behaviors, academic and conceptual learning, and safety (American Psychiatric Association, 2000).

ID is diagnosed when IQs fall below 70. ID is classified as mild when the IQ is in the range of 50 to 70. The deficiencies of children in this category may not become evident until they enter school and their speech and language skills may be delayed and may need intervention. Moderate ID is evident in children with IQs in the range of 35-49; such children may acquire communication skills in the early childhood years, but they may need significant amounts of speech and language intervention. Severe ID is diagnosed in children with IQs below 20-34; speech and language skills and academic learning are severely limited in this group. Children and adults in this group need intensive intervention and perhaps life-long care and supervision.

# **Prevalence of Intellectual Disability**

World health organization have approximated that 10% of the world's population has some form of disability and ID is one of them which affects 1-3% of the human population(WHO, 1989; Curry, Stevenson, et al., 1997).In a study done at Penn State Hershey Children's Hospital (2011), the researchers found that 1-3% of the population is affected by ID, amongst whom only 25% presents with the specific cause. As per APA (2000), ID is more frequent in males when compared to females and the male-to-female ratio is1.5:1. In United States, about 1 in 10 families is affected by ID. In India, ID has been reported from around 1/1000 to 32/1000, depending on the case definition, methodology and population selected (Girimaji & Srinath, 2010). A study was conducted by Bhagya and Ramakrishna (2013), which aimed at determining the prevalence of ID among school going children in Mangalore in Karnataka, India and the distribution of severity of ID and its relationship with age. There were 2,823 children who had different types of disability among which 561 had ID. The prevalence of ID was higher in males compared to females (p<0.001). The prevalence was higher among Hindus and in the age range of 9-12 years. Most of the children had mild ID (48.15%) and severe to profound ID were diagnosed at much earlier age group than compared to mild and moderate degree of ID

# **Etiology of Intellectual Disability**

There are many causative agents leading to ID that can be genetic, environmental or multiple factors. Also, behavioral or social factors, for example, poverty, malnutrition, maternal drugs alcoholism, and severe stimulation deficit are considered to be the causative agents for ID (McLaren & Bryson, 1987). Congenital malformation of the brain and/or any injury to the brain during pre- and post natal period can lead to ID. This condition can be acquired in nature which can be caused by near-drowning, traumatic brain injury and central nervous system malignancy (Campbell, Morgan & Jackson, 2004). Some of the causes have been described below.

# Genetic conditions

Conditions such as fragile X syndrome, neurofibromatosis, tuberous sclerosis, Noonan's syndrome and Cornelia de Lange's syndrome can contribute to ID (Baraitser & Winter, 1996; Jones & Smith, 1997). Some children may have small deletion or duplication of chromosome leading to syndromes like Down (trisomy 21), Klinefelter's (47, XXY), Digeorge, Prader-Willi, Angelman, Williams, Phelan-McDermid (22q13del), Mowat-Wilson syndrome, genetic ciliopathy (Badano, Mitsuma, Beales, & Katsanis, 2006) which are associated with ID.

# Prenatal problems

ID can be the resultant of inadequate development of fetus inside the mother's womb and also can be because of congenital infections such as cytomegalovirus, toxoplasmosis, herpes,syphilis, rubella and human immunodeficiency virus; prolonged maternal fever in the first trimester; exposure to anticonvulsants or alcohol; and untreated maternal phenylketonuria (PKU) (Strømme & Hagberg, 2007). ID can result when complications are associated with premature delivery such as extremely low birth weight or postnatal exposure to lead.

# Perinatal problems

Perinatal causes involve late pregnancy (complications of pregnancy, diseases in mother such as heart and kidney disease and diabetes and placental dysfunction), during delivery (severe prematurity, very low birth weight, birth asphyxia, difficult and/or complicateddelivery and birth trauma), neonatal (first 4weeks of life) (septicaemia, severejaundice, hypoglycemia) (Kolevzon, Gross & Reichenberg, 2007).

# Postnatal problems

Postnatal problems during infancy and childhood include brain infections (tuberculosis, Japanese encephalitis, bacterial meningitis), head injury, chronic lead exposure, severe and prolonged malnutrition and gross understimulation (Leonard & Wen, 2002;Zoghbi, 2003).

# Metabolic disorders

Metabolic disorders are another possible cause of ID. Phenylketonuria, hypothyroidism, (Scriver, 1995), mucopolysaccharidosis, and sphingolipidoses (Dimauro&Moraes, 1993) results in ID.

# Exposure to certain types of disease or toxins

Diseases like whooping cough, measles, or meningitis can cause ID if medical care is delayed or inadequate. Exposure to poisons like lead or mercury may also affect the mental ability (Aicardi, 1998; Daily, Ardinger & Holmes, 2000).

# *Iodine deficiency (cretinism)*

Iodine deficiency affecting approximately 2 billion people worldwide is the leading preventable cause of ID in areas of the developing world where iodine deficiency is endemic. Iodine deficiency also causes goiter, an enlargement of the thyroid gland (Delange, 1994). Lack of adequate availability of iodine from the mother restricts the growth of the brain of the foetus, and leads to a condition called hypothyroidism. Instead of naming it as cretinism, the ID caused by severe iodine deficiency is called mild impairment of intelligence (Gaitan& Dunn, 1992).

# **Malnutrition**

Malnutrition is a common cause of reduced intelligence in parts of the world affected by famine such as Ethiopia (Durkin, Khan, Davidson, Huq, Munir, Rasul&Zaman, 2000; Wines, 2006).

# **Features of Intellectual Disability**

# Speech and language skills

Children and adults with ID experience a variety of communication problems. Greater the degree of disability, greater is the severity of the communicative problems. Children with ID generally do not show abnormal or unique types of language; their language resembles that of younger children. Although progress is slow, the children with ID follow the same sequence of language development as typically developing children. However, a few children who have profound disabilities and are institutionalized may show echolalia and jargon. Some children with ID, especially those with Down syndrome, do not have language skills that match their general intellectual level. Children with mild ID may show only a few errors of articulation, whereas those with moderate and severe ID tend to have the greatest difficulty in learning to

produce speech sounds. Depending on the severity of the ID, the children's oral language may be extremely limited. Children with profound disability may learn only simple words, and they may lack connected speech and conversational skills. The linguistic features can be divided under four categories: *phonological, semantic, morphosyntax and pragmatics*.

# Phonology

Children with ID, particularly with lower levels of IQ, tend to exhibit pronounced articulation deficits (Abbeduto& Rosenberg, 1993). Children with Down syndrome make far more *phonological errors* than other persons with ID matched on mental age (Dodd, 1976) and the errors produced are qualitatively similar to those produced by much younger children matched on language age (Stoel- Gammon, 1980).

# **Semantics**

There are existing evidences suggesting that individuals with ID develop, represent & apply *semantic knowledge* in much the same way as typically developing children (Rosenberg &Abbeduto, 1993). But they have some limitations in accuracy and efficiency of inferential processing; for example, young adults with ID were less able than their mental age matched peers in retrieving the final word of agent-action-object sentences when cues with subject-verb were given. However, when the sentences were presented with picture descriptions, they were able to recall as efficiently as normal peers (Merill& Jackson, 1992).

# Morpho-syntax

Studies suggest that *morphosyntactic development* in individuals with ID largely matches that observed in typically developing; though often does not reach full mastery (Dewart, 1979; Bridges & Smith, 1984). Dewart (1979) found that children with mild ID comprehended active

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sentences as well as mental age matched peers but performed significantly worse on passive voice sentences and this was attributed to an abnormal reliance on word order.

# **Pragmatics**

On viewing the *pragmatic aspects*, it has been reported that individuals with ID do not achieve communication competence with respect to their mental age. In addition to cognitive deficits, individuals with ID are also said to have social risk factors (Beveridge & Conti-Ramsden, 1987). Evidences in early parent-child interaction show the children to take up more passive, non- responsive role in conversations with parents playing the dominant role and schoolgoing children with ID preferably indulge in solitary play; implying deficits in peer- related social confidence.

# Cognitive skills

Individuals with ID have drastically limited cognitive development and produce extreme individual differences in intelligence. Cicchetti and Beeghly (1990) suggested that development in individuals with ID was delayed and not deviant. The performance of children with ID is commensurate with mental age (MA) and a similar sequence of stages is observed to that seen in typically developing children. Also, researchers suggested that an executive deficit could be a common cognitive cause of ID. In individuals with ID, several aspects of attention appear deficient when compared to individuals without ID of same chronological age (Bergen & Mosley, 1994). However, when matched to individuals of equivalent MA, persons with ID performed as well as typically developing individual on attention tasks (Burack, 1990).

# Play behavior

The sequence of object play development in children with Down syndrome (DS) appears highly similar to that observed in typically developing children, at least during the early childhood (Beeghly, Weiss, & Cicchetti, 1989). Although, their ability to engage in pretense emerges at a delayed pace, children with DS appears to progress through the same sequence of decentraion, decontextualization, and integration in their symbolic play development as do typically developing children. In addition, the early pretend play of both children with DS and mental age matched typically developing reflect their social knowledge and did not differentiate children with DS and MA matched typically developing children. In addition to these problems, feeding skills also have been reported to be affected in children with ID.

# Feeding Skills in Children with ID

Feeding problems are frequently found in children and individuals with ID. Around 30% of children with ID were found to have feeding problems (Gouge & Ekvall, 1975; Palmer, Thompson & Linscheid, 1975) and the severity of feeding problems increased as the degree of ID increased (Perske, Clifton, McClean, & Stein, 1977). Around80% children with severe to profound degree of severity were found to have feeding problems (Perske et al., 1977; Matson et. al, 1991). Perske et al., (1977) estimated that as many as 80% of individuals diagnosed with severe and profound intellectual deficit have a serious problem related to feeding.Feeding difficulties are seen in 31-80% of the children with DS (Pipes & Holm, 1980; van Dyke, Lang, Heide, van Duyne & Soucek, 1990; Field, Garland, & Williams, 2003), which frequently persist in their adulthood with the prevalence rate of 25-31% (van Dyke,Peterson,& Hoffman,1990;Hennequin, Allison, Faulks, Orliaguet, & Feine, 2005).

A study by Linscheid (1983) revealed ten different kinds of feeding issues in this population i.e. 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. Sisson and Hasselt (1989) divided feeding issues under four different categories, i.e. lack of independent skills, disruptive behavior, eating too much or too little, and selectivity by type of texture.

Matson et al. (1991) considered 506 adults and children with ID from United States; where 32% of them were with severe ID and 63% of them had profound ID. Feeding issues seen in them was vomiting, regurgitation, pica, over eating, eating too fast, food stealing and poor appetite. According to DSM-IV-TR, feeding disorder of infancy or early childhood is often associated with ID and the feeding issues seen are failure to eat adequately and gain weight; rumination disorder and pica (Girolami & Scott, 2001). Food refusal and rumination are often associated with infant and children with ID and also in adults with ID (Riordan et al., 1984; Johnston, 1993; Parry, 1994). Inadequate self-feeding skill is one more concerning feature which is characterized by (i) inability or unwillingness to take the food to the mouth; (ii) inability to chew the food and (iii) inability to swallow food/liquid (O'Brien, Repp, Williams, & Christophersen, 1991; Cooper et al., 1995). Likewise, Beange, McElduff, and Baker (1995) have suggested that the adults with ID have issues like inappropriate weight gain, failure to thrive, constipation, dysphagia, reflux oesophagitis, malnutrition, and Vitamin D deficiency.

In a study done in Iran, a Screening Tool of feeding Problems (STEP, Matson & Kuhn, 2001) was administered to find feeding problems in 144 individuals with ID (30 with Down syndrome, 30 were autistic, 46 with cerebral palsy and 36 had other disabilities where 32 had mild ID, 80 had moderate ID and 32 cases with severe ID). The results indicated that almost all the subjects had some amount of feeding problems and few of them were at risk of aspiration. They found that 29.16% were at aspiration risk, 73.61% had disability of selectivity, and 79.16%

had deficit in feeding skills, 63.88% had food refusal related behavior problems and 66.66% with nutrition related behavior problems (Rezaei, Rashedi, Gharib, & Lotfi, 2011).

# **Causes and Consequences of Feeding Problems in Children with ID**

The food selectivity in individuals with ID can be related to several organic and environmental factors (Riordan et. al, 1984). Organic factors most frequently linked with interference in food intake include physical obstructions and abnormalities. These can be revealed 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 accountable for the maintenance of the problem behavior (Cooper, et al., 1995).

Researchers suggest that communication deficits or inability to describe their symptoms can be one the reason leading to feeding issues in these individuals. For example, an individual might be refusing the food because he does not like it, but is unable to express it. Also, an individual might have developed ruminating behavior which might have resulted from aggravation of gastro-esophageal reflux disease, but the individual is unable to communicate his discomfort.

Studies have suggested that the individuals with severe ID tend to be underweight; occurrences of food-refusal and self-induced vomiting are often seen and individuals with mild ID tend to be more overweight (Rimmer &Yamaki, 2006; Hove, 2004). Draheim, Stanish, Williams, and Cubbin (2007) studied the dietary intake among the individuals with mild and

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moderate ID living in three different kinds of housing in North America. They administered a screening questionnaire and interviewed subjects assisted by their care providers. The results suggested low intake of fruits and vegetables and high intake of dietary fat among the participants in all housing types, and the authors feared increased risks of chronic diseases among the individuals with ID.

Gravestock (2000) suggested that several individuals with ID have less nutritional diets in comparison to typically developing individuals, and individuals with severe to profound ID have higher rates of under-nutrition. The reason for this may be swallowing difficulties or concurrent problems with their gastrointestinal tract. Kerr, McCulloch, Oliver, et al. (2003) also found that 57% of individuals with ID in their study, had some level of nutritional difficulties. Fodstad (2008) stated that feeding difficulties in individuals with ID affected their daily functioning and caused severe medical conditions (e.g. poor nutrition, choking, and aspiration) which may eventually lead to death.

# **Assessment of Feeding**

Adequate and ongoing assessment of feeding problems is the foundation of any intervention program, and speech-language pathologists play an important role in this. Several assessment tools for the screening and assessment of feeding problems are available such as *Oral Motor/Feeding Rating Scale* (Jelm,1990), to determine the oral motor/feeding patterns and feeding function in individuals who are more than one year age, *Children's Eating Behavior Inventory* (Archer, Rosenbaum,& Streiner,1991), which assesses eating and mealtime problems under two domains i.e., child and parent and family domain, *Behavioral Pediatrics Feeding Assessment Scale-Child behaviors subscale* (Crist, McDonnell, Beck, Gillespie, Barrett, & Mathews, 1994), to determine the child behavior associated with poor nutritional intake,

*Pediatric Assessment scale for severe Feeding Problems* (Crist, Dobbelsteyn, Brousseau,&Napier-Phillips,2004), *The Screening tools of feeding Problems* (STEP, Matson & Kuhn, 2001), About Your Child's Eating- Revised (Davies, Ackerman, Davies, Vannatta, & Noll, 2007), *Montreal Children's Hospital Feeding Scale* (Ramsay, Martel, Porporino, & Zygmuntowicz, 2011) which evaluates oral motor, oral sensory, appetite, maternal concerns, mealtime behaviors, maternal strategies, and family reactions, *Screening Tool of Feeding Problems Applied to Children* (STEP-CHILD; Seiverling, Hendy, & Williams, 2011), *Pediatric Eating Assessment tool* (Pedi-EAT, Thoyre, Pados, et al., 2014) which is a parent reported instrument to find the feeding problems seen in their child etc.

Certain questionnaires have been developed specifically to assess feeding behaviors and patterns in children with ASD. One such tool is the *Brief Autism Mealtime Behavior Inventory* (BAMBI; Lukens & Linscheid, 2008), the main objective of which is to assess mealtime behavior problems in children with autism under three domains: limited variety (8 items), food refusal (5 items) and features of autism (5 items). *Mealtime Behavior Questionnaire* (Berlin et al., 2010) is yet another tool mainly to assess mealtime behavior problems under the following domains: food refusal/ avoidance (12 items), food manipulation (7 items), mealtime aggression/ distress (9 items), and choking/ gagging/vomiting (3 items).

Although there are tools to assess the feeding problems in children, the abnormal behaviours exhibited during feeding, oromotor skills during feeding etc., tools to assess the physical, functional and emotional aspects related to feeding are limited. It is possible that the feeding problems faced by the child have a negative impact on the life of the child, which may in turn hinder the progress of the child during intervention. The feeding problems could affect the social and emotional life and he/she could perceive the feeding problems as a big handicap.

Keeping this in view a Feeding Handicap Index (FHI; Srushti, 2014) was developed that measures the handicapping effect of feeding problems and standardized on children with cerebral palsy in the age range of 2-10 years. Norms were also developed as a part of the development and validation. The FHI was prepared by collating information from the literature and from the complaints concerning feeding received from the parents of children with cerebral palsy. FHI has a total of 38 items with 21 in the physical domain, 10 in the functional domain and 5 in the emotional domain.

A look into the literature revealed that feeding problems are quite common in children with autism spectrum disorder and intellectual disability which may vary according to the type and severity of the problem. Keeping this in view, it was planned to extend the utility of the FHI by validating the index on children with ASD and ID. Thus the proposed study aimed at validating the FHI on children with ID and children with ASD.

# **CHAPTER III**

# Method

The primary aim of the study was the validation of Feeding Handicap Index (FHI) in children with Autism spectrum disorders (ASD) and Intellectual disability (ID) in the age range of 2-10 years. The study was undertaken in the following phases:

Phase I: Clinical validation of the FHI by administering it on children with ASD and ID.

Phase II: Assessment of test-retest reliability

# Phase I: Validation of the FHI by administering it on children with ASD and ID.

The FHI was administered on the parents/caregivers of 61 children with ASD and 59 children with ID in the age range of 2-10 years. The details of the participants have been provided below.

# **Participants**

Sixty one children with Delayed/Inadequate speech and language with Autism/ PDD/ PDD NOS/ High functioning autism/CDD in the age range of 2-10 years were included as participants in the study. In addition fifty nine children with a diagnosis of Delayed/Inadequate speech and language with ID were included. They were diagnosed by a qualified team of professionals including speech-language pathologist, pediatrician, and a clinical psychologist. These children were identified from among those who had reported to the Dept. of Clinical Services, All India Institute of Speech and Hearing, Mysuru and from a few special schools in Mysuru. The children were sub-grouped based on their age. In the group of children with ASD, there were 39 children in lower age group i.e. 2-6 years and 22 children in higher age group i.e. 6-10 years. In the group of children with ID, there were 31 and 28 children in lower and higher age group respectively.

In the ID group, there were 43 children with mild intellectual deficit and 16 with moderate intellectual deficit. In the ASD group, 12 had mild and 6 had moderate intellectual deficit while 43 children did not have any associated intellectual disability. 59 children with ID comprised of 36 males and 23 females and ASD group of 61 comprised of 46 males and 15 females. There were 11 and 4 children in the ID and ASD group respectively with a history of epilepsy. They were under anti-epileptic drugs. In the ID group, 17 children were diagnosed as Down syndrome and 5 children had a few autistic features. All the children included were enrolled into an intervention program.

Since the data for 60 typically developing children (TD group) was already available as a part of the previous study on developing and validating the FHI on children with cerebral palsy (Srushti, 2014), the same data was used for comparison purposes. Hence typically developing children were not included in this study.

# Assessment tools used

- Com-DEALL Checklist for Assessment of Oro-motor skills in Toddlers (Archana & Karanth, 2008)
- 2. Feeding Handicap Index (FHI) (Srushti, 2014)

# Procedure

The participants were selected based on the criteria mentioned above. The testing was carried out in a relatively noise free environment with minimum distraction. Each child was tested individually. A rapport was established with the mother/caregiver. The purpose of the administration was explained. The demographic data was obtained initially. The Com-DEALL oro-motor checklist was administered followed by FHI on the selected children. In addition, the child was given different items to eat and drink to permit a firsthand observation of the feeding skills. The feeding problems faced by the child were noted. The responses obtained from the parents/caregivers were documented based on the rating scale in the index. They were also asked to rate the overall severity of the feeding problem based on the 7 point rating scale.

All ethical standards were met for participant selection and their participation. Prior to testing, a written consent was obtained from the parents of the participants after explaining the purpose of the study. Participants belonging to low, middle and high socio-economic statuses were included which was ascertained using the NIMH socioeconomic status scale developed by Venkatesan (2009). The scale has sections such as occupation and education of the parents, annual family income, property, and per capita income to assess the socioeconomic status of the participants.

# Phase II: Assessment of test-retest reliability

To assess the reliability of the FHI, this was administered again on 10% of the participants of each group after 1 week of their initial responses. Cronbach's alpha test was administered to assess the test-retest reliability.

## Analysis

The scores obtained from each participant in both the groups on FHI and oro-motor checklist were totaled. A total score on both the checklists were obtained.

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# **Statistical analysis**

These scores were averaged across all the participants and fed to the computer for statistical analysis. SPSS version 20 software was used for this purpose. Descriptive statistics was used to obtain mean, median and standard deviation of scores obtained on the FHI and oro-motor checklist for both the groups. Chi square test was used measure to the significance level of each item. Cronbach's alpha was used to determine the test-retest reliability. Mann Whitney U test was used to compare the typical group with the ASD and ID groups and to measure the influence of different independent variables. Spearman's correlation test was used to assess the correlation between scores obtained on the FHI and oro-motor checklist in both the groups. The results obtained have been presented and discussed in the next chapter.

# **CHAPTER IV**

# **Results and Discussion**

The present study aimed at validating the feeding handicap index (FHI) on children with Autism Spectrum disorder (ASD) and intellectual disability (ID). The specific objectives of this study were to compare the performance of the children with ASD and ID with that of the typically developing children on the feeding handicap index, to compare between the lower vs. higher age group of children in both the groups, to find whether a relationship existed between feeding problems and the oro-motor abilities, and to investigate the influence of degree of intellectual deficit on feeding problems in the children in both the groups.

The FHI comprised of a total of 38 items. These items focused on the physical, functional and emotional domains involved in feeding and were divided into three sections. The three sections viz. the physical, functional and emotional domains had 21, 12 and 5 items respectively. A 3 point rating scale was used where 'Never' signified no problem (score: 0), 'Sometimes' signified problem is seen sometimes(score: 1) and 'Always' signified problem is seen always(score: 2). The possible range of total FHI score that can be obtained by a child varied from 0-76 and the possible range for the scores on physical, functional and emotional domains varied from 0-42, 0-24 and 0-10 respectively. The parents/caregivers of the children with ASD and ID also self-rated the overall severity of the feeding problem on a 7 point rating scale at the end of the administration of FHI where a score of 1 suggested normal feeding skills and a score of 7 suggested severely affected feeding skills.

The clinical validity was assessed by administering the index on a total of 120 participants. The participants selected included 61 children with ASD and 59 children with ID in

the age range of 2-10 years. There were 46 males and 15 females in the ASD group and 36 males and 23 females in the ID group. Eleven and four children had a history of epilepsy and were under anti-epileptic drugs in the ID and ASD group respectively. In ID group, there were 17 children with Down syndrome and 5 children with a few autistic features.

The FHI was administered on these participants and the responses obtained from the caregivers were documented using the rating scale. The scores obtained from each participant were totaled to obtain a total FHI score. The total scores on the three different sections were also noted for each participant. The normative scores obtained from 60 typically developing children as a part of the study by Srushti (2014) formed the data of the typical group. These scores were totaled across all the participants, tabulated and subjected to statistical analyses using SPSS software version 20. The following statistical procedures were carried out:

- Descriptive statistics to obtain mean, median and standard deviation for both the groups.
- Chi square test to measure the frequency and significance level of each item.
- Cronbach's alpha to determine the test-retest reliability.
- Mann Whitney U test to compare the typical group and the clinical groups and between ASD and ID groups to measure the influence of different independent variables.
- Spearman' correlation test to assess the correlation between FHI and oro-motor abilities.

The results obtained from all the above statistical measures have been presented and discussed under the following sections:

# I. Clinical validity

# a) ASD group

1. Comparison between the ASD group and the typical group on the FHI score

- 2. Frequency of different responses and comparison between ASD and the typical group on each item of the FHI
- Frequency of parent/caregiver reported severity of feeding problems in the ASD group
- Comparison between the lower (2-6 years) and the higher (6-10 years) age group of children in the ASD group
- Relation between total FHI scores, the scores on the three sections and the degree of intellectual deficit in the ASD group
- 6. Oro-motor skills in children with ASD
- 7. Relation between total FHI score and oro-motor skills in the ASD group

# b) ID group

- 1. Comparison between the ID group and the typical group on the FHI score
- 2. Frequency of different responses and comparison between ID and typical group on each item of the FHI
- 3. Frequency of parent/caregiver reported severity of feeding problems in the ID group
- Comparison between the lower (2-6 years) and the higher (6-10 years) age group of children in the ID group.
- Relation between total FHI scores, the scores on the three sections and the degree of intellectual deficit
- 6. Oro-motor skills in children with ID
- 7. Relation between total FHI score and oro-motor skills in the ID group

# c) Comparison between ID group and ASD group

# II .Test-retest reliability

# Section I: Clinical validity

# a) ASD group

# 1) Comparison between the ASD and the typical group on the FHI score

The ASD group was compared with the typical group for the total FHI scores and FHI section scores (Physical, Functional & Emotional). The mean and standard deviation obtained have been depicted in Table 4.1. On comparison, it was seen that the mean scores (Total FHI and FHI sections) were higher for the clinical group than for the typical group. To check whether a significant difference existed between the two groups, Mann-Whitney test was used. The results revealed that there was a significant difference between the clinical group and the typical group. The /z/ values have been depicted in table 4.1.The mean total FHI scores and the scores obtained across the three sections for the two groups have been depicted graphically in figure 4.1.

# Table 4.1

Mean, standard deviation (SD) and /z/ values of the total FHI score and the section wise scores for the ASD and the typical group

ASD group	Typical group	/z/ value
15.59±9.95	3.53±3.35	7.60*
8.41±6.42	1.68±2.20	7.68*
3.89±3.82	1.35±1.31	4.73*
3.30±3.77	0.56±0.87	4.93*
	15.59±9.95 8.41±6.42 3.89±3.82	$15.59\pm9.95$ $3.53\pm3.35$ $8.41\pm6.42$ $1.68\pm2.20$ $3.89\pm3.82$ $1.35\pm1.31$

Values are given as Mean $\pm$ SD, \*p < 0.01

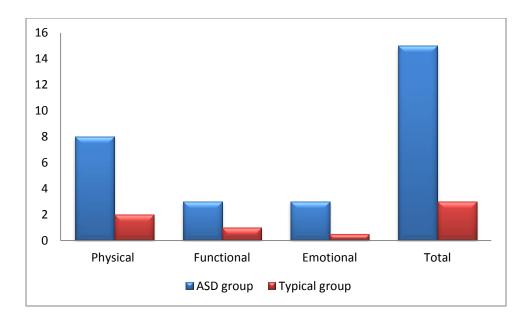


Figure 4.1. Mean FHI score and the scores across the three sections for ASD and typical groups.

In the present study the ASD group obtained significantly higher mean scores, both for the total FHI and for the scores on each section. These results signify that children with ASD exhibited feeding problems. The Physical feeding problems included inadequate chewing; difficulty in eating using finger and spoon, drinking using cup, sucking through a straw, holding the food in mouth; restricted tongue movement and difficulty in rinsing and spitting. They also had inappropriate weight gain, difficulty in swallowing and some of them had nasal regurgitation and vomiting while eating. The Functional feeding problems were eating less amount of food, spillage of food, aversion or avoidance of specific food items, specific position while eating, longer mealtime and need for liquid to swallow the food. The Emotional feeding problems included refusal to open mouth while eating, temper tantrums during feeding and tendency to avoid eating with peer group and/or in social situations. This result is in accord with the studies reported in the literature. Several studies have reported that children with ASD have a greater number of feeding problems and eat a more narrow range of food than children without ASD which includes children with developmental disabilities or other atypical development (Schreck, Smith, & Williams, 2004; Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007; Martins, Young, & Robson, 2008; Matson, Fodstad, & Dempsey, 2009; Bandini et al., 2010; Badalyan& Schwartz, 2011; Nadon, Feldman, Dunn, & Gisel, 2011). Ahearn et al., (2001); Bandini et al., (2008); Sharp et al., (2010) and Marshall et al., (2014) also found restricted food acceptance in these children.

Food refusal and disruptive mealtime behaviors were also reported by Schreck et al., (2004); Twachtman-Reily et al., (2008) and Roger et al., (2012). Marshall et al., (2014) reported that a confined dietary variety, food neophobia, food denial, restricted diet based on texture, and a tendency towards being overweight were the most often found feeding issues in these children. The results of the present study indicated that children with ASD do have problems related to physical, functional and emotional aspects of feeding. This could be attributed to the cognitive, behavioral and sensory deficits present in them. Cumine et al., (2000) also proposed that concentration on detail, perseveration, impulsivity, neophobia, sensory impairments, social noncompliance, and biological food intolerance could lead to feeding problems. Ahearn et al., (2001) proposed that selective feeding in children with ASD was an expression of their restricted interests and activities. Sensory issues present in these children can also have an impact on the feeding and mealtime behaviors. Tactile and oral defensiveness are seen often in children with ASD (Kientz & Dunn, 1997; Baranek, Boyd, Poe, David, &Watson, 2007; Tomchek & Dunn 2007).

# 2) Frequency of different responses and comparison between ASD and typical group on each item of the FHI

The responses obtained from the parents/caregivers under the three response categories viz. 'never', 'sometimes', and 'always' were totaled for different participants in both the groups for each item on the FHI. The frequency of occurrence of the responses for each item for both the groups has been depicted in Table 4.2. To investigate whether significant differences, if any existed in the different aspects of feeding between both the groups for each item, Chi-square test was used.

The results revealed that there was a significant difference on all the items between the two groups except items 1, 2, 6, 8, 11, 19, 21, 28, 31 and 33. The items 3, 4, 5, 7, 10, 13, 14, 15, 24, 25, 27, 29, 35, 37 and 38 were highly significant at 0.001 level, the items 9, 23, 26, 30 and 36 were significant at 0.01 level and the items 12, 16, 17, 18, 20, 22 and 34 were significant at 0.05 level. This suggested that they had the greatest difficulty in chewing, usage of finger and spoon for eating, drinking through straw, usage of tongue to clear the food from gums and cheeks, and rinsing and spiting. They also had inappropriate weight gain, spillage of food while eating, neophobia, aversion to specific food items, smaller and frequent meals, longer mealtime duration, temper tantrum while feeding, dislike towards being dependent while feeding and discomfort to eat in social gathering or peer group. They also had some difficulty in drinking using cup/glass, holding the food in mouth and swallowing solid food. They also had longer swallow time, nasal regurgitation and vomiting. They ate less amount of food, avoided solid food intake, needed specific position while feeding, needed liquid to swallow food, disliked being dependent on others for feeding and avoided eating in social situations.

# Table 4.2

Frequency of responses	for each item in the ASD	and typical groups and the	e results of chi square
i requerie y of responses		and typical groups and the	che square

Item no.		ASD group (61)			Typical group (60)		$-\chi^2$
N	Never	Sometimes	Always	Never	Sometimes	Always	- <i>l</i>
1.	54	3	4	60	0	0	7.31
2.	54	3	4	60	0	0	7.31
3.	41	9	11	56	4	0	15.24***
4.	30	14	17	53	7	0	25.70***
5.	23	9	29	50	10	0	39.03***
6.	55	4	2	54	5	1	0.44
7.	21	8	32	51	9	0	44.55***
8.	58	1	2	55	3	2	1.07
9.	52	3	6	60	0	0	9.56**
10.	39	0	22	56	4	0	29.04***
11.	57	1	2	55	5	0	1.53
12.	55	5	1	60	0	0	6.21*
13.	31	7	23	56	4	0	30.99***
14.	25	3	33	57	3	0	45.48***
15.	47	3	11	48	12	0	16.40***
16.	54	3	4	60	0	0	7.31*
17.	55	3	3	60	0	0	6.21*
18.	59	2	0	51	9	0	5.03*
19.	52	8	1	56	4	0	2.47
20.	56	5	0	45	15	0	6.19*
21.	57	9	2	57	3	0	0.99
22.	50	5	6	57	3	0	6.95*
23.	58	1	1	48	12	0	12.24**
24.	36	15	10	57	3	0	22.74***
25.	15	15	31	60	0	0	72.99***
26.	59	1	1	45	15	0	15.13**
27.	56	2	3	41	19	0	19.08***
28.	58	2	1	55	5	0	2.36
29.	30	15	16	60	0	0	40.99***
30.	51	5	5	60	0	0	10.72**
31.	59	1	1	60	0	0	2.00
32.	60	0	1	41	11	8	20.01***
33.	59	0	1	60	0	0	0.99
34.	35	19	7	45	15	0	0.01*
35.	41	14	6	60	0	0	23.57***
36.	47	3	10	52	8	0	13.52**
37.	34	6	20	59	1	0	31.29***
38.	36	7	18	58	2	0	25.92***

test.

 $* \frac{38.}{p < 0.05, ** p < 0.01, *** p < 0.001}$ 

Also, there was a significant difference between the ASD and the typical group for item number 32 which is 'pinching the nose while feeding'. However the children in the typical group scored higher on this because the parents of the typically developing children reported to use this strategy in order to make their children eat fast, but, the same strategy was not used by the parents of children with ASD.

Studies conducted in the past also suggest that children with ASD exhibited greater eating and mealtime problems in comparison to their age matched typically developing children (Ahearn et al., 2001; Kanner, 1943; Raiten & Massaro, 1986). Also, in a study by Baldalyan and Schwartz (2012), where they compared children with classic autism with their normal siblings, they found that there was a significant difference between the two groups with respect to prevalence of frequent problematic feeding behaviors, including unusual food preferences (e.g., specific food colors, shapes, textures, presentation, or specific arrangement of food on the plate), insistence on eating food with specific utensils/dishes, dislike of new foods, fear of new foods, poor mealtime social behavior, unusual posturing during meals, and oral motor problems.

The parent/caregiver responses obtained from the ASD group also revealed that for item numbers 4, 5, 7, 10, 13, 14, 25, 29, 37 and 38, 16-33(26-54%)children displayed difficulties always and around 8-19(13-31%) children had these difficulty sometimes. These items mainly focused on usage of finger and spoon by the child for eating, drinking using straw, usage of tongue to clear the food particles in the mouth and ability to rinse and spit, neophobia and avoidance of specific food items, longer mealtime, and avoidance of feeding in social situation. Williams, Dalryple, and Neal (2000) also observed in their study that 69% of children with ASD had neophobia for food. Ahearn et al., (2001) found that 50% of the children showed food acceptance signifying food selectivity based on food category and texture. Field, Garland, and

Williams (2003) found that 62% of the children with autism had food selectivity by type. Williams, Gibbons, and Schreck (2005) also found that children with ASD had food selectivity depending on type, texture and/or presentation of the food that included strong preference for carbohydrates and aversion for fruits and vegetables. Martins et al., (2008) in their study assessed the feeding and eating behaviors of children with ASD and found selective eating in them and they exhibited more problematic eating and feeding behavior in comparison to other typically developing children. Cumine, Leach, and Stevenson (2000) have also observed neophobia, sensory impairments, social noncompliance, and biological food intolerance. However these studies do not comment upon the usage of finger and spoon by the child for eating, drinking using straw, usage of tongue to clear the food particles in the mouth and ability to rinse and spit and mealtime duration which were found to be affected in the present study.

For item numbers 3, 15, 24 and 36, around 10-15 (16-24%) children had difficulties always and 8-15(13-24%) children had them sometimes. These items were primarily about difficulty in chewing, inappropriate weight gain, spillage of food by children, and dislike to be dependent on others for feeding. For item numbers, 19, 34 and 35, only 1-7 (1-11%) had these domains affected always and about 8-19(13-31%) had these domains affected sometimes, which mainly focused on presence of gag while eating and refusal to eat and temper tantrums while feeding. Studies conducted in the past have also suggested that the behavioral problems in these children are likely to interact with the feeding and mealtime behaviors. Disruptive behaviors like aggression, self-injury, tantrums (Lukens & Linscheid, 2008), throwing out the food, complaining and arguing (Ahearn et al., 2001; Sharp & Jaquess 2009), eating without utensils, refusing to come to the table, and not staying seated, have all been reported by different researchers (Matson & Fodstad 2009; Volkert &Vaz 2010).

# 3) Frequency of parent/caregiver reported severity of feeding problem in the ASD group

The parents/caregivers of the children with ASD rated the overall severity of the feeding problem of their respective children at the end of the administration of the FHI on a 7 point rating scale where 1 signified normal, 2 and 3 signified mild, 4 and 5 signified moderate and 6 and 7 signified severe. The parent responses obtained from the ASD group revealed that 79.7 % of the parents considered that their children had normal feeding skills. Around 15% of the caregivers felt that their children had mild to moderate level of difficulty in feeding and only 5.1% of them reported severe feeding difficulties in their children. However the FHI scores obtained after administration of the FHI suggested that 68.8% of the children with ASD had feeding issues. Table 4.3 depicts the frequency of parent/caregiver responses on the 7 point rating scale for overall severity of feeding problem in their children.

# Table 4.3

Scale	Frequency	Percentage (%)
4 33 1		
1- Normal	47	79.7
2-	3	5.1
3-	3	5.1
5	5	5.1
4-	1	1.7
5-	2	3.4
5-	2	5.4
6-	0	0
7 0	2	<b>5</b> 1
7- Severe	3	5.1

*Frequency of parent/caregiver reported severity of feeding problem in the ASD group.* 

This result suggested that most of the parents/caregivers of children with ASD were unable to identify the presence of feeding problems in their children or did not consider the feeding issues as a significant problem in their children. They were not very sensitive to the feeding issues present in their children. They were more concerned about their speech and language issues. This can be attributed to the fact that children with ASD did not have much difficulty with swallowing, sucking, biting or chewing which are very obvious problems related to feeding. However, they did present with problems such as food selectivity or refusal, disruptive mealtime behaviors, difficulty in self-feeding and difficulty in rinsing and spitting which were probably considered as a part of their behavioral problems.

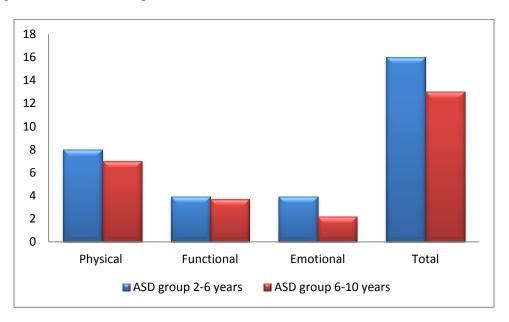
# 4) Comparison between the lower (2-6 years) and the higher (6-10 years) age group of children in both the groups

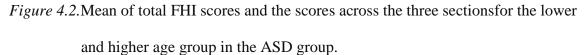
The children in the ASD group and the typical group were divided into two age groups i.e., 2-6 years and 6-10 years to assess if any variations in performance on the FHI existed; since the participants were in the developmental period. The mean and standard deviation values for both the age groups for both the groups were computed using descriptive statistics and have been depicted in table 4.4. In the ASD group, similar mean values were obtained for both lower and higher age groups on FHI (both total FHI score and the section scores). Conversely, higher mean scores were obtained by the lower age group in the typical group. Mann-Whitney test showed that there was a significant difference between the two age groups for the total FHI score and the scores on physical, functional and emotional sections for the typical group, while no significant difference existed between the two age groups in the ASD group. The mean values of the lower and higher age group for the ASD group have been depicted graphically in Figure 4.2.

Mean, standard deviation (SD) and /z/ values of total FHI score and the section scoresfor both lower and higher age group in both the groups.

FHI score	ASD group			Typical group		
	2-6 years	6-10 years	/z/value	2-6 years	6-10 years	/z/ value
Total	16.56±11.05	13.86±7.54	0.32	4.63±3.35	2.43±3.13	3.04*
Physical	8.72±6.65	7.86±6.09	0.66	2.23±2.62	1.13±2.62	2.15*
Functional	3.95±4.24	3.77±3.02	0.93	1.46±0.86	1.23±1.65	1.97*
Emotional	3.90±4.43	2.23±1.79	0.15	0.93±1.04	0.20±0.40	3.04*

Values are given as Mean $\pm$ SD, \*p < 0.01





This result suggested that there was no improvement in feeding skills with development in children with ASD and both lower and higher age groups exhibited similar type and extent of feeding problems. This could be due to the inadequate focus received for these specific problems during the intervention, as the parents of children with ASD are more concerned about the speech, language and behavioral intervention of their children and do not report the same to the speech language pathologist handling their children. They tend to ignore the feeding related problems in their children.

Further it was seen that greater percentage of children (64%) in the higher age group attended greater duration of intervention compared to only 13% in the lower age group. Despite this, it was seen that the higher age group of children had feeding problems similar to that seen in the lower age group. This could be because of the presence of associated intellectual deficit in greater number of children with ASD in the higher age group which could have also influenced the results. Studies have reported that intellectual deficit also can lead to feeding problems (Gouge &Ekvall, 1975; Palmer, Thompson & Linscheid, 1975; Rezaei, et al., 2011).

In the typical group a significant difference between the lower and the higher age group was seen which could be attributed to the development that occurs consequent to maturation of the nervous system. Studies indicate that feeding development takes place in a gradual manner during the early childhood. The maturation in mastication coordination in typically developing children is fully achieved by 6 years of age (Vitti & Basamajian, 1975). Gisel and Patrick (1988) also reported that the time taken for chewing the solid food gets lesser as the child grows older. Further the refinement of independent self-feeding skills occurs only after 2 years of age (Pridham, 1990).

## 5) Relation between total FHI scores, the scores on the three sections and the degree of intellectual deficit in the ASD group.

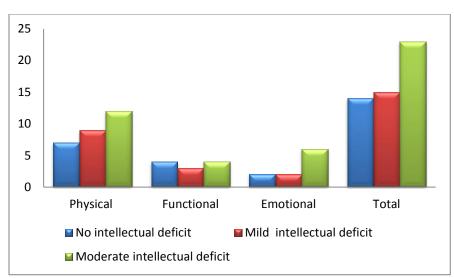
Some of the children with ASD had associated intellectual disability. Based on the degree of retardation, the children with ASD were divided into 3 groups. The first group comprised of 41 (67.2%) children with ASD with no intellectual deficit, 12 (19.6%) with mild intellectual deficit and 6 (9.8%) with moderate intellectual deficit. Table 4.5 depicts the mean and the standard deviation obtained for the FHI scores for each group. On comparing the mean values between groups, it was seen that the overall scores for FHI were highest for children with intellectual deficit rather than the children without intellectual deficit. Also, scores for children with moderate intellectual deficit was greater in comparison to those with mild intellectual deficit. The results of the Mann Whitney test revealed that there was no significant difference across the three groups. The mean values of the ASD group across the degree of intellectual deficit for the total FHI scores and the scores across the three sections have been depicted graphically in Figure 4.3.

The results of this study are in consonance with the findings by Fodstad (2008).He assessed the nature of feeding in adults with ASD with ID (n=30) and only ID (n=30) using Screening Tool for Feeding Problems (STEP) and he found that the individuals with ASD and ID showed more food refusal related feeding problems whereas those with ID only had more deficits in feeding skills. He found that individuals with ASD and ID had problematic behaviors during eating, food refusal and food selectivity while individuals with only ID had choking on food and significant deficit in eating skills. Although, this was not statistically significant, the mean scores for the individuals with ASD and ID were higher which indicated greater feeding issues than those with ID only.

Mean, standard deviation (SD) and /z/ values of the total FHI score and the total section scores across the degree of intellectual deficit in the ASD group

ASD group (n=61)				
No intellectual	Mild intellectual	Moderate		
deficit	deficit	intellectual deficit		
(n=43)	(n=12)	( <b>n=6</b> )		
14.53±9.70	15.58±8.77	23.17±12.23	3.35	
7.49±5.83	9.67±7.30	12.50±7.74	3.45	
4.09±4.36	3.08±1.56	4.00±2.74	0.18	
2.95±2.74	2.83±2.75	6.67±8.71	1.23	
	deficit (n=43) $14.53 \pm 9.70$ $7.49 \pm 5.83$ $4.09 \pm 4.36$	No intellectual         Mild intellectual           deficit         deficit           (n=43)         (n=12) $14.53 \pm 9.70$ $15.58 \pm 8.77$ $7.49 \pm 5.83$ $9.67 \pm 7.30$ $4.09 \pm 4.36$ $3.08 \pm 1.56$	No intellectualMild intellectualModeratedeficitdeficitintellectual deficit(n=43)(n=12)(n=6) $14.53\pm9.70$ $15.58\pm8.77$ $23.17\pm12.23$ $7.49\pm5.83$ $9.67\pm7.30$ $12.50\pm7.74$ $4.09\pm4.36$ $3.08\pm1.56$ $4.00\pm2.74$	

Values are given as Mean±SD,



*Figure 4.3*.Mean values of the total FHI score and the total section scores across the three ASD groups with and without intellectual deficit.

### 6) Oro-motor skills in children with ASD

Com-DEALL Oro-Motor Checklist (Archana & Karanth, 2008) was administered to assess the oro-motor deficits present in the children with ASD. The checklist consisted of four domains i.e. jaw movement, tongue movement, lip movement and speech with a total of 30 questions. Responses were rated on a three point rating scale where '0' signified absent, '1' signified only spontaneously present and '2' signified consistently present. The score of each child was obtained for each domain which was added up to obtain the total oro-motor scores. Higher scores on the Com-DEALL Oro-Motor Checklist indicated better oro-motor skills.

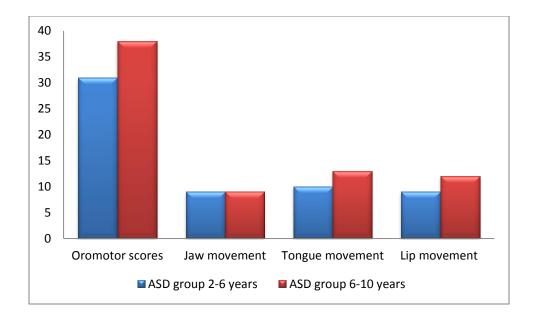
The total oro-motor scores and the individual domain scores (jaw, tongue & lip) were lower in the ASD group (for both the age groups) in comparison to the norms published as a part of the checklist. When the mean scores for the lower and higher age groups were compared, it was seen that there were very minimal differences. The results of Mann Whitney test revealed that no significant difference existed between the two age groups of the ASD group for the oromotor scores. The mean, standard deviation and /z/ values have been depicted in Table 4.6. The performance of both the groups on the oro-motor checklist has been depicted graphically in figure 4.4.

## Table 4.6

Mean, standard deviation (SD) and /z/values for oro-motor checklist for lower and higher age groups within the ASD group.

Oro-motor scores	ASD	/z/ value	
	2-6 years	6-10 years	
Total oro-motor scores	31.29±12.58	38.71±12.29	0.38
Jaw movement	9.39±2.57	9.32±3.06	0.10
Tongue movement	10.97±6.84	13.46±5.47	0.84
Lip movement	9.00±4.67	12.64±3.85	0.77
Values are given as Mean			

Values are given as Mean±SD



*Figure 4.4*.Mean of total ComDEALL scores and the total domain scores for the ASD group across both lower and higher age group

On viewing the oro-motor scores and comparing it with normative scores, it was seen that the tongue movements were affected to the greatest extent, followed by lip movement and then jaw movements. These children had difficulty in tongue elevation and tongue lateralization. With regard to the lip movement, they had difficulty in sucking through straw, blowing, lip rounding and protrusion. This finding suggested that although these children did not have any oro-motor weakness, they tend to have difficulty in executing certain oro-motor movement.

The finding that children with ASD had oro-motor deficits is in consensus with the study by Belmonte, Saxena-Chandhok, Cherian, Muneer, George, and Karanth (2013). They administered ComDEALLoro-motor checklist on children with ASD in the age range of 1 year 10 months to 5 years 5months; and found that these children had deficit in oral motor skills. They attributed this deficit to the impaired motor impairment resulting from dissociation within motor execution and executive planning and sequencing and/ or affective motivation.

### 7) Relation between total FHI score and oro-motor abilities in the ASD group

Spearman correlation test was carried out to assess if there was a correlation between the total FHI score and the oro-motor score for both age groups in children with ASD. The results indicated that there was a strong correlation between FHI and Com-DEALL Oro-Motor Checklist scores for both lower and higher age groups (Spearman's coefficient= -0.62 and -0.64 respectively). There was strong to moderate correlation of jaw, tongue and lip movements with FHI scores for both the age groups as depicted in Table 4.7. This result suggested that impaired oro-motor skills in children with ASD can lead to poor feeding skills. However, the impaired feeding skills also could be due to associated sensory, cognitive, or behavioral deficits present in them. Cumine et al, (2000), Shaw et al. (2002) and Ahearn et al. (2001) reported that the feeding issues in children with ASD could be because of behavioral problems. Field et al., (2003) suggested that feeding problems could arise from learned behavior resultant of gastrointestinal problem. Other researchers have reported that sensory issues can have impact on feeding behavior (Williams et al., 2000; Cermak, et al., 2010; Lane, et al., 2010).

# Correlation between Total FHI score and ComDEALL oro-motor score and its sections for children with ASD

Oro-motor scores	Total FHI Score			
	Lower age group	Higher age group		
	(Correlation coefficient)	(Correlation coefficient)		
Jaw movement	-0.75***	-0.66**		
Tongue movement	-0.52**	-0.62**		
Lip movement	-0.51**	-0.51*		
Total oro-motor score	-0.61***	-0.64**		

\* p< 0.05, \*\* p < 0.01

### b) ID group

## 1) Comparison between the ID and the typical group on the FHI score

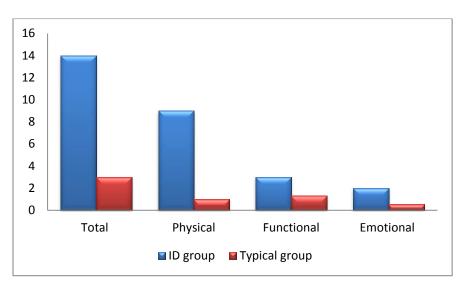
The total FHI scores and FHI section (Physical, Functional & Emotional) scores obtained from ID group was compared with the typical group. The mean and standard deviation obtained have been depicted in Table 4.8. On comparison, it was seen that the mean scores were higher for the ID group than for the typical group. Mann-Whitney test revealed that the ID group had significantly higher scores than the typical group. The /z/ values have been depicted in table 4.8. The mean of the total FHI scores and the scores obtained across the three sections for the two groups has been depicted graphically in figure 4.5.

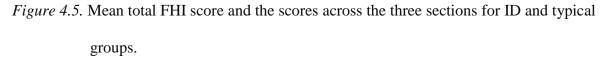
## Table 4.8

Mean, standard deviation (SD) and /z/ values of the total FHI score and section wise scores for the ID and typical group

FHI score	ID group	Typical group	/z/ value
Total	14.76±9.95	3.53±3.35	8.15*
Physical	9.31±6.57	1.68±2.20	7.00*
Functional	3.41±2.97	1.35±1.31	6.01*
Emotional	$2.05 \pm 1.88$	0.56±0.87	5.67*

Values are given as Mean $\pm$ SD, \*p < 0.01





These results signify that children with ID exhibited feeding problems. The *Physical feeding problems* included inadequate sucking, chewing, difficulty in eating using finger and/or spoon, drinking using straw, independent drinking using cup/glass, drooling, difficulty in usage of tongue to clear the food particles in the mouth, inability to rinse and spit, inappropriate weight gain, retention of food in mouth, difficulty in swallowing and choking. *Functional feeding problems* included spillage of food, aversion or avoidance of specific food items, need for specific position while feeding, need for smaller and frequent meal, need to push the food back in the mouth, longer mealtime, usage of liquid to swallow the food and need for specific utensils while eating. *Emotional feeding problems* exhibited were dislike to be dependent on others for feeding, refusal to eat, temper tantrums during feeding and dislike to eat in social situations.

The results of the present study are in consensus with the studies reported in the literature. Around 30% of children with ID were found to have feeding problems (Gouge &Ekvall, 1975; Palmer, Thompson & Linscheid, 1975). Other studies reported that approximately 80% children with severe to profound degree of severity have feeding problems (Perske et al., 1977; Matson et. al, 1991). Many studies reported a range of 31-80% of the children with Down Syndrome having feeding problems (Pipes & Holm, 1980; van Dyke, Lang, Heide, van Duyne & Soucek, 1990; Field, Garland, & Williams, 2003), which frequently persist in their adulthood with the prevalence rate of 25-31% (van Dyke, Peterson & Hoffman,1990; Hennequin, Allison, Faulks, Orliaguet & Feine, 2005).

Linscheid (1983) also found ten different kinds of feeding issues in this population i.e. 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. Sisson and Hasselt (1989) reported of lack of independent skills, disruptive behavior, eating too much or too little, and selectivity by type of texture in these children. O'Brien et al. (1991) and Cooper et al. (1995) also reported inability or unwillingness to take the food to the mouth; inability to chew the food and inability to swallow food/liquid in these children with ID.

## 1) Frequency of different responses and comparison between ID and typical group on each item of the FHI in the ID and the control group

The frequency of occurrence of the responses obtained for each item for both the groups has been depicted in table 4.9. To investigate whether significant differences, if any existed in the different aspects of feeding between both the groups for each item Chi-square test was used, the result of which are also depicted in table 4.9. The results of the test revealed that the items 4, 5, 7, 9, 10, 13, 14, 15, 24, 25, 26, 27, 29, 32 and 35 were highly significant at 0.001 level, the items 3, 12, 17, 23, 30, 31, 36 and 38 were significant at 0.01 level and the items 1, 11, 16, 21, 22, 28, 34 and 37 were significant at 0.05 level. However, there was no significant difference in the items 2, 6, 8, 19, 20 and 33 between both the groups. This suggested that they had the greatest difficulty in usage of finger and spoon for eating to drink from cup, drinking through straw, rinsing and spitting, difficulty in oral phase of swallowing, spillage of food while eating, neophobia, and aversion to specific food items, needed smaller and frequent meals, took longer time to complete the meals and threw temper tantrums while feeding. They also exhibited some difficulty in sucking through straw and biting, had drooling, gaging, vomiting, choking; took longer swallow time and ate less amount of food. They also exhibited refusal to open mouth during feeding and disliked to have food with their peer group.

This result is in accord with the studies reported in the literature. Maston et al. (1991) found feeding issues seen in children with ID which were vomiting, regurgitation, pica, over eating, eating too fast, food stealing and poor appetite. Food refusal and rumination are often associated with infant and children with ID and also in adults with ID (Riordan et al., 1984; Johnston, 1993; Parry, 1994). Inadequate self-feeding skill is also reported which is characterized by (i) inability or unwillingness to take the food to the mouth; (ii) inability to chew the food and (iii) inability to swallow food/liquid (O'Brien, Repp, Williams, & Christophersen, 1991; Cooper et al., 1995). Beange, McElduff, and Baker (1995) have suggested that the adults with ID have issues like inappropriate weight gain, failure to thrive, constipation, dysphagia, reflux oesophagitis, malnutrition, and Vitamin D deficiency.

The parent/caregiver responses obtained from the ID group also revealed that for item numbers 5, 7, 10, 13, 14, 15, and 25, 16-30 (27-50%) children displayed difficulties always and around 3-11 (5-18%) children had these difficulties sometimes. These items mainly focused on usage of spoon by the child for scooping the food as well as independent eating, drinking using straw, usage of tongue to clear the food particles in the mouth and ability to rinse and spit, inappropriate weight gain and avoidance of specific food items. For item numbers, 3, 4, 16, 24, 29 and 36, around 10-15 (17-25%) children had these difficulties always and 4-14 (6-24%) children had them sometimes. These items were primarily about difficulty in chewing, usage of fingers to eat, retention of food in mouth, spillage of food by children, and dislike to be dependent on others for feeding. The item numbers, 9, 34 and 35 were affected in 11-18 (18-30%) children sometimes and only 5-7 (8-11%) were affected always, which mainly focused on inability to drink independently, refusal to eat and temper tantrums while feeding.

Frequency of responses for each item in the ID and typical groups and the results of chi square

test
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Item no.	ID group (59)				Typical group (60)		
	Never	Sometimes	Always	Never	Sometimes	Always	- χ <b>²</b>
1.	53	1	5	60	0	0	6.43*
2.	55	2	2	60	0	0	4.21
3.	43	5	11	56	4	0	12.81**
4.	32	12	15	53	7	0	21.49***
5.	25	7	27	50	10	0	35.86***
6.	49	5	5	54	5	1	2.91
7.	24	7	28	51	9	0	37.96***
8.	53	6	0	55	3	2	3.03
9.	43	11	5	60	0	0	18.79***
10.	37	3	19	56	4	0	23.02***
11.	47	5	7	55	5	0	7.62*
12.	49	4	6	60	0	0	11.11**
13.	27	3	29	56	4	0	39.27***
14.	23	11	25	57	3	0	44.02***
15.	39	1	19	48	12	0	17.45***
16.	44	4	11	60	0	0	5.31*
17.	54	0	5	60	0	0	9.57**
18.	59	0	0	51	9	0	1.54
19.	52	6	1	56	4	0	5.35
20.	52	6	1	45	15	0	2.22
21.	52	6	1	57	3	0	8.79*
22.	49	2	8	57	3	0	8.79*
23.	52	2	5	48	12	0	12.29**
24.	28	18	13	57	3	0	33.61***
25.	27	10	22	60	0	0	44.51***
26.	58	0	1	45	15	0	17.63***
27.	57	1	1	41	19	0	19.80***
28.	55	0	4	55	5	0	8.99*
29.	35	14	10	60	0	0	30.57***
30.	48	4	7	60	0	0	12.33**
31.	51	8	0	60	0	0	8.72**
32.	59	0	0	41	11	8	22.23***
33.	59	0	0	60	0	0	-
34.	37	15	7	45	15	0	7.77*
35.	40	12	7	60	0	0	22.99***
36.	39	7	13	52	8	0	14.92**
37.	52	1	6	59	1	0	6.43*
38.	48	2	9	58	2	0	9.94**

 $\frac{38. \qquad 48 \qquad 2}{* \ p < 0.05, \ ** \ p < 0.01, \ *** \ p < 0.001}$ 

The results of present study are supported by earlier studies. Linscheid (1983) reported of tantrums, bizarre food habits, multiple food dislikes, food texture selectivity, delay or difficulty in chewing, sucking or swallowing, delay in self-feeding etc. in children with ID. Other problems such as inability or unwillingness to take the food to the mouth, inability to chew the food and inability to swallow food/liquid were reported by O'Brien, Repp, Williams, and Christophersen, 1991 and Cooper et al., 1995. Sisson and Hasselt (1989) have reported lack of independent feeding skills, disruptive behavior, eating too much or too little, and selectivity by type of texture in these children. Girolami and Scott (2001) reported of failure to gain weight and other researchers have reported food refusal (Riordan et al., 1984; Johnston, 1993; Parry, 1994). Rezaei et al., (2011) also reported aspiration, food selectivity and food refusal in children with ID and all developmental disabilities including those with Down Syndrome.

These feeding problems can be attributed to the cognitive, communicative, behavioral and or sensory deficits. Cooper et al., (1985) attributed the feeding problem to the behavioral deficits seen in these children. Bhatia, Kabra, and Sapra (2007) studied the behavioral issues in children with Down syndrome and concluded that the behavioral problems in these children interfere with the feeding skills. Siegel (1982) attributed the feeding problems to environmental factors.

### 2) Frequency of parent/caregiver reported severity of feeding problem in the ID group

The parent/caregiver responses obtained from the ID group revealed that 63.9 % of the parents considered that their children had normal feeding skills and the remaining 37.2% felt that their children had mild to moderate level of feeding problems. However, the FHI scores obtained after administration of the FHI suggested that 83% of the children with ID had feeding issues.

Frequency of parent/caregiver reported severity of feeding problem has been depicted in Table 4.10.

#### Table 4.10

Frequency of parent/caregiver reported severity of feeding problem in the ID group

Scale	Frequency	Percentage
1- Normal	39	63.9
2-	6	9.8
3-	9	14.8
4-	5	8.2
5-	2	3.3
6-	0	0
7- Severe	0	0

This result suggested that most of the parents/caregivers of children with ID did not consider the feeding problem as a significant problem in their children. They were not sensitive to the feeding issues present in these children. This can be because the parents of these children are more concerned about their Speech and language, cognitive and behavioral deficits rather than the feeding skills. This also can be attributed to the fact that children with ID did not have much difficulty with swallowing, biting or chewing which are very obvious problems related to feeding. However they did present with problems such as food selectivity or refusal, disruptive mealtime behavioral problems by them. Similar, results were obtained by Malavika (2015) who found that only 5% of parents/caregivers reported that their children with Down syndrome had

moderate degree of feeding problem and the remaining parents/caregivers reported no feeding problems. However the examiner had rated 11% of children with Down syndrome to have moderate degree of feeding problems and 52% of the children to have mild degree of feeding problems. This suggested the parents' lack of awareness of feeding problems faced by their children.

## 3) Comparison between the lower (2-6 years) and the higher (6-10 years) age group of children in both the groups

The children in the ID group were also divided into two age groups i.e., 2-6 years and 6-10 years to assess if any variations in performance on the FHI existed; since the participants were in the developmental period. The mean and standard deviation values for both the age groups for both the groups were computed using descriptive statistics and have been depicted in table 4.11.Similar results were obtained for ID group as in the ASD group. Comparable values were obtained for both lower and higher age groups for the total FHI score and the section scores. Mann Whitney test suggested that there was no significant difference between the two age groups. This result suggested that there was no improvement in feeding skills with the development in children with ID. The mean values of the lower and the higher age group for the ID group have been depicted graphically in figure 4.6.

Mean, standard deviation (SD) and /z/ values of total FHI score and the section scores for both lower and higher age group in both the groups

Subscales	ID group		/z/value	Typical group		/z/ value
	2-6 years	6-10 years	-	2-6 years	6-10 years	-
Total	15.45±8.42	14.00±10.88	1.37	4.63±3.35	2.43±3.13	3.04*
Physical	10.03±6.08	8.50±7.09	1.35	2.23±2.62	1.13±2.62	2.15*
Functional	3.45±2.66	3.36±3.32	0.77	1.46±0.86	1.23±1.65	1.98*
Emotional	1.97±1.85	2.14±1.95	0.28	0.93±1.04	0.20±0.40	3.04*

Values are given as Mean±SD, \*p < 0.01

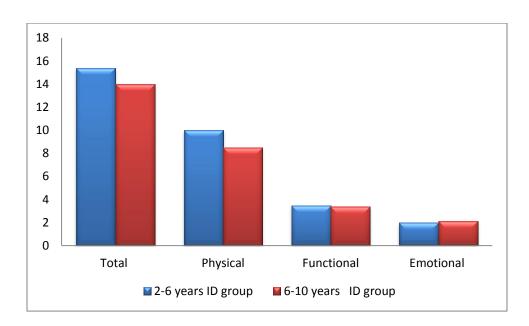


Figure 4.6.Mean of total FHI scores and the scores across the three sections for both

lower and higher age group in the ID group.

This result suggested that there was no improvement in feeding skills with development in children with ID and both lower and higher age groups exhibited similar type and extent of feeding problems. This could be due to the inadequate focus received for these specific problems during the intervention, as the parents of children with ID are more concerned about the speech, language and behavioral intervention of their children and do not report about the feeding problems to the speech language pathologist handling their children. They tend to ignore the feeding related problems in their children.

Further it was seen that greater percentage of children (33%) in the higher age group attended greater duration of intervention compared to only 10% in the lower age group. Despite this, it was seen that the higher age group of children had feeding problems similar to that seen in the lower age group. This could be because of the presence of associated intellectual deficit in greater number of children with ASD in the higher age group which could have also influenced the results. In the lower age group, 84% of them had mild intellectual deficit and 16% with moderate deficit; while, in the higher age group, there were 60% with mild and 40% with moderate intellectual deficit.

In the typical group a significant difference between the lower and the higher age group was seen which could be attributed to the development that occurs consequent to maturation of the nervous system. Studies indicate that feeding development takes place in a gradual manner during the early childhood. The maturation in mastication coordination in typically developing children is fully achieved by 6 years of age (Vitti & Basamajian, 1975). Gisel and Patrick (1988) also reported that the time taken for chewing the solid food gets lesser as the child grows older. Further the refinement of independent self-feeding skills occurs only after 2 years of age (Pridham, 1990).

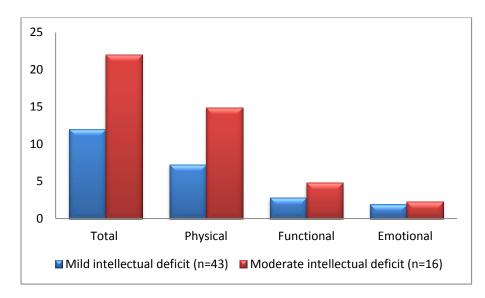
## 4) Relation between total FHI scores, the scores on the three sections and the degree of intellectual deficit in the ID group.

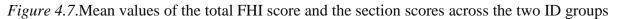
Based on the degree of intellectual deficit, the children with ID were divided into two groups. There were 43 (72.8%) with mild intellectual deficit and 16 (27.1%) with moderate intellectual deficit. Table 4.12 depicts the mean and the standard deviation obtained for the FHI scores for each group. The overall mean FHI score and scores of all sections were higher for the group with moderate intellectual deficit in comparison to the group with mild intellectual deficit. The results of Mann Whitney test suggested that there was a significant difference across the two groups for total score and scores obtained from the physical domain. The mean values of the ID group across the degree of intellectual deficit for the total FHI scores and the scores across the three sections have been depicted graphically in Figure 4.7.

Mean, standard deviation (SD) and /z/ values of the total FHI score and the section scores across the degree of intellectual deficit in the ID group

FHI score	ID grou	ID group (n=59)		
	Mild intellectual	Moderate		
	deficit	intellectual deficit		
	(n=43)	( <b>n=16</b> )		
Total	12.02±7.76	22.13±10.44	3.46*	
Physical	7.21±5.19	14.94±6.70	3.90*	
Functional	2.86±2.51	4.88±3.64	2.26	
Emotional	1.95±1.75	2.31±2.24	0.32	

Values are given as Mean±SD, \*p < 0.01





This result suggested that feeding problems were greater in individuals with greater degree of intellectual deficit. Several studies support this finding. Studies have suggested that around 30% of the children with ID have associated feeding issues which vary with degree of retardation (Gouge & Ekvall, 1975; Palmer, Thompson, & Linscheid, 1975). Also, studies suggest that feeding issues are more prevalent in individuals with severe retardation (Perske, Clifton, McClean, & Stein, 1977). Most of the studies have established that feeding problems are present across the age range of individuals with ID, although they are mainly prominent among those with severe to profound retardation (Perske et al., 1977; Maston et al., 1991).

#### 5) Oro-motor skills in children with ID

The total oro-motor scores, the scores for tongue and lip movement for both the age groups were lower in comparison to the normative scores. The mean scores obtained for both lower and higher age groups for the total oro-motor scores and the domain scores were almost comparable. Mann Whitney test revealed that only lip movement scores were significantly different for both the age groups, while for rest of the domains there was no significant difference between the two age groups. The mean, standard deviation and /z/ values were computed which have been depicted in Table 4.13. The performance of both the age groups on the oro-motor checklist has been depicted graphically in figure 4.8.

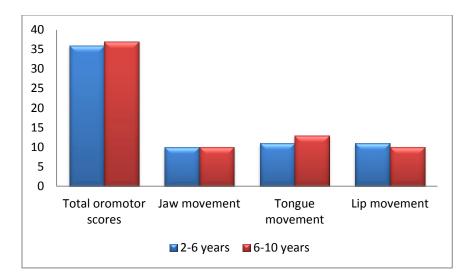
On viewing the oro-motor scores and comparing it with normative scores, it was seen that that tongue movements were affected to the greatest extent, followed by lip movement. The scores for jaw movements were comparable to the normative scores. These children had difficulty in tongue elevation and tongue lateralization. Also, with regard to the lip movement they had difficulty in sucking, blowing, lip rounding and protrusion. Children with Down syndrome had associated oro-motor weakness and they had difficulty in executing the movements. Moreover, between the two age groups, the lip movement was significantly different with the higher age group having poorer scores. This could be attributed to the fact that there were greater number of children with moderate intellectual deficits in the higher age group in comparison to the lower.

Table 4.13

Mean, standard deviation (SD) and /z/ values for oro-motor checklist for lower and higher age groups within the ID group

Oro-motor scores	ID g	/z/value	
_	2-6 years	6-10 years	
Total oro-motor scores	36.36±13.74	37.59±15.22	2.11
Jaw movement	10.38±2.46	10.41±2.44	0.38
Tongue movement	11.41±6.03	13.05±6.55	1.26
Lip movement	11.10±4.64	10.36±5.28	3.04*

Values are given as Mean $\pm$ SD, \*p < 0.01



*Figure 4.8*.Mean of total Com-DEALL scores and the domain scores for ID group across both lower and higher age group.

The results obtained indicated that lip and tongue movement were affected in children with ID. This finding is in consensus with the studies reported in literature. Wuang, Wang, Huang, and Su (2008) considered 233 early school-age children with mild intellectual disabilities (ID) aged 7 to 8 years for their study and found that children with mild ID had weaker fine motor skills than gross motor skills. Spender, Stein, Dennis, Reilly, Percy, and Cave (1996) found that oral motor skills are often affected in individuals with Down's syndrome mainly jaw and tongue movements leading to feeding difficulties.

#### 6) Relation between total FHI score and oro-motor abilities in the ID group

Spearman correlation test indicated that there was a moderate correlation between FHI and total oro-motor scores for both lower and higher age groups (Spearman's coefficient= -0.59 and -0.53 respectively). There was strong correlation of jaw movements with FHI scores both the age groups as depicted in Table 4.14. However, there was no correlation between FHI and lip

movements for both the age groups and moderate correlation between tongue movement and FHI only for lower age group.

### Table 4.14

Correlation between total FHI score and oro-motor score and its sections for children with ID

Lower age group	Higher age group
(Correlation coefficient)	(Correlation coefficient)
-0.78**	-0.74**
-0.47*	-0.32
-0.23	-0.33
-0.59*	-0.53*
	(Correlation coefficient) -0.78** -0.47* -0.23

\* p< 0.01,\*\* p < 0.001

These finding suggested that oro-motor deficits can only be one of the reasons for feeding difficulties in these children. Feeding could be getting affected by other factors such as behavioral problems, cognitive deficits, sensory issues etc.

### c) Comparison between the ID group and the ASD group on the FHI scores

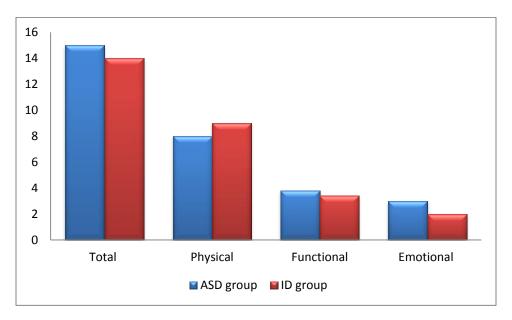
The total FHI scores and FHI section (Physical, Functional & Emotional) scores obtained from ASD group was compared with that of the ID group. The mean and standard deviation obtained have been depicted in table 4.15. On comparison, it was seen that the mean scores were almost comparable for both the groups. Mann-Whitney test revealed that there was no significant difference between both the groups. The /z/ values have also been depicted in table 4.15. The mean of the total FHI scores and the scores obtained across the three sections of the two groups has been depicted graphically in figure 4.9.

## Table 4.15

Mean, standard deviation (SD) and /z/ values of ASD and ID groups for the total FHI score and the section scores

FHI score	ASD group	ID group	/z/ value	
Total	15.59±9.95	14.76±9.956	0.59	
Physical	8.41±6.42	9.31±6.571	0.83	
Functional	3.89±3.82	3.41±2.972	1.21	
Emotional	3.30±3.77	$2.05 \pm 1.888$	1.80	

Values are given as Mean±SD



*Figure 4.9*.Mean of the total FHI score and the total section scores for both ID and ASD groups.

The frequency of occurrence of the responses for each item for the ASD and ID group has been depicted in table 4.16. To investigate whether significant differences, if any, existed in the different aspects of feeding between both the groups for each item chi-square test was used. The results revealed that only item no. 31, 37 and 38 was significantly different between both the groups (p< 0.05). These items mainly focused on the need for usage of specific utensils (utensils with a specific attribute) while feeding, discomfort among children to have food with peer group and in social gathering. Greater number of children with ID needed specific utensils compared to the ASD group, while, greater number of children in the ASD group were uncomfortable to have food in social situations and with their peers in comparison to ID group. However, there was no significant difference between both the groups for the rest of the items.

Frequency of responses for each item in the ASD and ID groups and the results of chi square

Item no.	ID group (59)				ASD group (60)		
	Never	Sometimes	Always	Never	Sometimes	Always	$-\chi^2$
1.	53	1	5	54	3	4	1.087
2.	55	2	2	54	3	4	0.843
3.	43	5	11	41	9	11	1.157
4.	32	12	15	30	14	17	0.310
5.	25	7	27	23	9	29	0.372
6.	49	5	5	55	4	2	1.710
7.	24	7	28	21	8	32	0.500
8.	53	6	0	58	1	2	5.765
9.	43	11	5	52	3	6	5.483
10.	37	3	19	39	0	22	3.240
11.	47	5	7	57	1	2	5.930
12.	49	4	6	55	5	1	3.996
13.	27	3	29	31	7	23	2.536
14.	23	11	25	25	3	33	5.726
15.	39	1	19	47	3	11	3.845
16.	44	4	11	54	3	4	4.398
17.	54	0	5	55	3	3	3.477
18.	59	0	0	59	2	0	1.967
19.	52	6	1	52	8	1	0.252
20.	52	6	1	56	5	0	1.206
21.	52	6	1	57	9	2	1.196
22.	49	2	8	50	5	6	1.549
23.	52	2	5	58	1	1	4.295
24.	28	18	13	36	15	10	1.631
25.	27	10	22	15	15	31	5.925
26.	58	0	1	59	1	1	0.975
27.	57	1	1	56	2	3	1.309
28.	55	0	4	58	2	1	3.847
29.	35	14	10	30	15	16	1.771
30.	48	4	7	51	5	5	0.502
31.	51	8	0	59	1	1	6.995*
32.	59	0	0	60	0	1	0.975
33.	59	0	0	59	0	1	0.975
34.	37	15	7	35	19	7	0.493
35.	40	12	7	41	14	6	0.210
36.	39	7	13	47	3	10	3.703
37.	52	1	6	34	6	20	15.848**
38.	48	2	9	36	7	18	7.461*

<sup>38.</sup> <sup>48</sup> <sup>48</sup> <sup>48</sup>

### Section II: Test-retest reliability

The test-retest reliability was determined for 33% of the samples from both the groups using Cronbach's alpha. The alpha values for the total FHI scores and its subscales in the ID group was found to be high (Total FHI= 0.95, Physical= 0.95, Functional= 0.89, Emotional= 0.94) which indicated significantly high test-retest reliability. The alpha values in the ASD group too was found to be high (Total FHI= 0.95, Physical= 0.95, Functional= 0.90, Emotional= 0.93) which again indicated a high test retest reliability.

In sum, the results of the present study indicated that the total FHI scores and scores for each section was significantly higher for the ASD and ID group in comparison to the typical group. Both the groups had greatest difficulty in usage of finger and spoon for eating, drinking through straw, usage of tongue to clear the food from gums and cheeks, rinsing and spiting; inappropriate weight gain, spillage of food while eating, neophobia, aversion to specific food items, longer mealtime duration, temper tantrums during feeding, and discomfort to eat in social gathering or peer group.

In both ASD and the ID group, there was a no significant difference between the lower and the higher age groups for the FHI scores. This suggested that both lower and higher age groups exhibited similar type and extent of feeding problems and there was no improvement in feeding skills with development or with intervention in children with ASD and ID. However in the typical group there was a significant difference between both the age groups.

Further, the overall scores for FHI were higher for children with greater degree of intellectual deficit rather than the children without or with milder degree of intellectual deficit. This pattern of results was seen in both the groups. It was seen that higher scores were obtained for the group with moderate degree of intellectual deficit compared to those with milder intellectual deficit. It was also seen that the parents/caregivers were not aware of the feeding problems present in their children. Almost 79.7% of the parents/caregivers in the ASD group and 63.9% of the parents/caregivers in the ID group had reported that their children had normal feeding abilities, as opposed to 68.8 % of children in the ASD group and 83% of children in the ID group having the problem.

The total oro-motor scores and the domain scores were lower in the ASD group (for both the age groups) in comparison to the norms published as a part of the checklist. Also, there was a strong correlation between the total FHI score and the oro-motor score for both age groups in children with ASD. In the ID group, the total oro-motor scores, the scores for tongue and lip movement for both the age groups were lower in comparison to the norms. The jaw movement were relatively unaffected and there was a moderate correlation between FHI scores and oromotor scores for both lower and higher age groups.

## **CHAPTER V**

## **Summary and Conclusions**

Feeding problems are fairly common in children with autism spectrum disorder (ASD) and intellectual disability (ID). Several studies have been carried out to identify the nature and extent of feeding problems. It is possible that the problems in feeding have a negative impact on the life of the child, which may in turn hinder the progress of the child during intervention. The feeding problems could affect the day to day living, social and emotional life and he/she could perceive the feeding problems as a big handicap. Hence, a need was felt to assess the feeding problems in children with ASD and ID in three domains, viz., physical, functional and emotional.

In this regard, a feeding handicap Index was developed by Srushti (2014). The FHI was prepared by collating information from the literature and from the complaints concerning feeding received from the parents of children with communication disorders. This was standardized by administering it on 60 typically developing children and later validated on 60 children with cerebral palsy. However, since feeding problems are also common in children with ASD and ID, a need was felt to validate the FHI on this population too.

The FHI has a total of 38 items with 21 in the physical domain, 10 in the functional domain and 5 in the emotional domain. Feeding handicap index was administered on the parents of sixty one children with children with Delayed/Inadequate speech and language with ASD and fifty nine children with a diagnosis of Delayed/Inadequate speech and language with ID in the

age range of 2-10 years. Their oro-motor abilities were assessed by administering the Checklist for Assessment of Oro-motor skills in Toddlers (Archana & Karanth, 2008).

The responses obtained from the parents/caregivers during the administration of the FHI were documented based on the rating scale. The parents/caregivers were also asked to rate the overall severity of the feeding problem based on the 7 point rating scale. In addition, the children were given different items to eat and drink (e.g., biscuit, water etc.) to permit a first-hand observation of the feeding skills. The scores obtained from each participant were totaled to obtain the total FHI score and the total oro-motor scores. These scores were totaled for all the participants, tabulated and subjected to statistical analyses using SPSS software version 20. The data obtained from typically developing children as a part of the study by Srushti (2014) was used.

The results of the present study indicated that the total FHI scores and scores for each section was significantly higher for the ASD and ID group in comparison to the typically developing group. Both the groups had greatest difficulty in usage of finger and spoon for eating, drinking through straw, usage of tongue to clear the food from gums and cheeks, rinsing and spitting; inappropriate weight gain, spillage of food while eating, neophobia, aversion to specific food items, longer mealtime duration, temper tantrum while feeding, and discomfort to eat in social gathering or peer group. In addition it was found that most of the children with ID (around 45-50%) had difficulty in scooping food using spoon and eating using spoon independently, inability to clear the food particles stuck in teeth and gums using tongue and difficulty in rinsing and spitting. Most of the children with ASD (50-55%) had greatest difficulty in eating using spoon independently, inability to clear the food particles stuck in teeth and gums using tongue, neophobia and aversion to specific food items based on taste/temperature/texture/smell.

In both ASD and ID group, there was no significant difference between lower and higher age groups for the FHI scores. This suggested that both lower and higher age groups exhibited similar type and extent of feeding problems and there was no improvement in feeding skills with development or with intervention in children with ASD and ID. However in the typical group there was a significant difference between both the age groups.

Further, the overall scores for FHI were higher for children with greater degree of intellectual deficit rather than the children without or with milder degree of intellectual deficit. This pattern of results was seen in both the groups. It was seen that higher scores were obtained for the group with moderate degree of intellectual deficit compared to those with milder intellectual deficit.

Further, it was seen that the parents/caregivers were not aware of the feeding problems present in their children. Almost 79.7% of the parents/caregivers in the ASD group and 63.9% of the parents/caregivers in the ID group had reported that their children had normal feeding abilities, as opposed to 68.8% of children in the ASD group and 83% of children in the ID group having the problem when examined using the feeding handicap index.

The total oro-motor scores and the domain scores were lower in the ASD group (for both the age groups) in comparison to the norms published as a part of the checklist. Also, there was a strong correlation between the total FHI score and the oro-motor score for both age groups in children with ASD. In the ID group, the total oro-motor scores, the scores for tongue and lip movement for both the age groups were lower in comparison to the norms. The jaw movement was relatively unaffected and there was a moderate correlation between FHI scores and oromotor scores for both lower and higher age groups. Thus, it can be concluded that children with ASD and ID had feeding deficits since they were significantly different from typical group. This indicated a good clinical validity for the tool developed. The cronbach's alpha values obtained were also high indicating a good reliability. Therefore, it can be concluded that the feeding handicap index is a valid and reliable tool for measuring handicapping effect of feeding problems in children with ASD and ID.

### **Implications of the study**

The Feeding handicap index that has been developed provides us with information on the physical, functional and emotional aspects related to feeding present in a child. It helps in quantifying the feeding difficulties in these children by providing a quantitative score called the feeding handicap index. This study also provided the feeding handicap index scores in the children with ASD and ID. These indices can be used as reference data for comparison purposes. The quantitative scores obtained from the parents will strengthen the clinical findings made by speech-language pathologists and other relevant professionals regarding the feeding problems of the child. This will also help the speech-language pathologists in prioritizing the goals taken up during feeding therapy. The rating scale can also be used to monitor the progress achieved during feeding therapy by comparing the pre-therapy with the post-therapy scores.

### **Future directions**

The tool can be modified for the children below 2 years of age and normative scores can be obtained. FHI can be validated for the children with other developmental disabilities who feeding issues such as cleft lip and palate.

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# Appendix

## Demographic data

Name:
Age/ Gender:
Date of birth:
Provisional Diagnosis:
Language:
Findings on ComDEALL checklist:
Type of therapy taken: Physiotherapy/ Occupational therapy/ Speech and Language therapy
Duration of therapy:
Supervisor:
Educational background:
Socio-economic status: (NIMH Socio-economic status Scale)
Highest occupation
Highest education
Annual family income
Property
Per Capita Income

Any other associated problems:

# Medication:

Address & Phone No.

Feeding Handicap I	ndex
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Item No.	Domain *	Statements	Never has this problem	Sometimes has this problem	Always has this problem	Remarks Please specify
1.	Р	My child has/had difficulty in sucking from the feeding bottle/ breast milk.	0	1	2	
2.	Р	My child has difficulty in biting hard food (e.g., biscuit, wafer, cucumber etc.) and/or soft food (e.g. cake, bread, dairy milk, banana etc.)	0	1	2	
3.	Р	My child has difficulty in chewing the hard food (e.g., chapatti, puri etc.) and/ or soft food (e.g., idli, banana, rice, sweets etc.)	0	1	2	
4.	Р	My child is not able to eat independently with his fingers	0	1	2	
5.	Р	My child is not able to scoop the food from the bowl/plate with a spoon	0	1	2	
6.	Р	My child is not able to clear the food from the spoon when held near the lips	0	1	2	
7.	Р	My child is not able to eat with a spoon independently	0	1	2	
8.	Р	My child is not able to drink liquid from a glass/cup when held	0	1	2	
9.	Р	My child is not able to drink	0	1	2	

		independently				
10	Р	My child has a problem in drinking through a straw	0	1	2	
11	Р	My child drools while feeding	0	1	2	
12	Р	My child has difficulty in holding the solid/ liquid food in mouth (food/liquid leaks from the mouth) in upright position	0	1	2	
13	Р	My child is not able to use the tongue to clear the food particles stuck in between the teeth or between the gums and the cheeks	0	1	2	
14	Р	My child cannot rinse the mouth and spit the water after eating	0	1	2	
15	Р	My child's weight gain is inappropriate (under/over- weight) and/or has nutritional deficiency due to feeding issues.	0	1	2	
16	Р	My child keeps the food in the mouth without swallowing for a long time	0	1	2	
17	Р	My child has difficulty in swallowing solid/ semi-solid or mashed/ liquid food	0	1	2	
18	Р	The food/liquid comes through the nose during swallowing	0	1	2	
19	Р	My child gags when solid/liquid food is given	0	1	2	
20	Р	My child vomits when solid/liquid food is given	0	1	2	
21	Р	My child chokes while feeding	0	1	2	

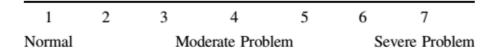
22	F	My child eats less because of the feeding problem	0	1	2	
23	F	I avoid giving solid food to my child because of feeding difficulty.	0	1	2	
24	F	My child spills a considerable portion of the solid food/liquid during feeding (E.g. spilling the food near the mouth or spilling the food while taking it from the plate). <i>Specify</i> <i>the quantity of food spilled in</i> <i>percentage.</i>	0	1	2	
25	F	My child strongly refuses newly introduced food or certain food based on the taste/temperature/ texture/ smell.	0	1	2	
26	F	My child need to be placed in a specific position during feeding (e.g. may be using special chair, bean bag etc.)	0	1	2	
27	F	My child requires smaller meals more often due to the feeding problem	0	1	2	
28	F	I push the food to back of the mouth of my child so that he/she can swallow it easily	0	1	2	
29	F	My child takes longer to be fed	0	1	2	
30	F	I pour water/milk to ensure that the food is swallowed	0	1	2	
31	F	My child needs special/ specific (his own spoon, plate, etc.) utensils and/or different way of feeding (e.g., feeding tube,	0	1	2	

		special feeding bottles etc.)				
32	F	I pinch my child's nose to make him swallow the food	0	1	2	
33	F	I shake the child/close the lips/jaw for easy swallow	0	1	2	
34	E	My child refuses to open his/her mouth while feeding	0	1	2	
35	E	My child exhibit frustration or temper tantrums before/during feeding	0	1	2	
36	E	He doesn't like being dependent on the others for feeding	0	1	2	
37	E	My child feels upset that he can't eat food like the other children/ doesn't like to eat with other children.	0	1	2	
38	Ε	My child feels embarrassed/ is not comfortable to eat food in social gathering	0	1	2	

\*P-Physical, F-Functional, E-Emotional

#### Other significant findings:

### **Rating scale for parent/caregivers:**



Please circle the number that matches the severity of your child's feeding difficulty (1- no difficulty at all; 4- somewhat problem is present; 7- the worse problem my child could have)