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# Feeding Issues Associated with the Autism Spectrum Disorders

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Additional information is available at the end of the chapter

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## 1. Introduction

Feeding issues are prevalent in young children. Feeding will be defined here as the process of ingesting food and drink in social environments where such activities take place. Estimates of problems may range from 13 to 50% in typically developing children, but may be as high as 80% in children with developmental disabilities [1-7]. In 1 to 10% of these children problems may become chronic and may affect their health and development [1, 8]. Anatomical, metabolic, gastrointestinal, motor or sensory problems may be the cause of or may contribute to some of these feeding problems [8]. A global medical assessment is necessary when feeding problems persist, because some medical symptoms may not be recognized as associated with feeding at first sight, such as asthma. Even if the association remains unclear, a high prevalence of asthmatic children, particularly with nocturnal asthma, have gastro-esophageal reflux (GER) [9]. Both feeding and eating, the processing of food and drink in the mouth and swallowing, are also known as activities of daily living (ADL) and studies examining the specific problems of children with Autism Spectrum Disorders (ASD), found that 46 to 89% have feeding problems [10-18].

While these studies are important to determine the nature and extent of such problems, results have to be interpreted with caution. First, small and heterogeneous sample sizes do not permit generalization to the entire population of children with ASD. There is also no consensus regarding the terminology and definitions used to describe these problems, i.e. feeding problem, eating problem, food refusal, selective/picky eating, mealtime problems, etc... Furthermore, authors use different instruments to measure these problems. Caregiver questionnaires are the most commonly used tools for this purpose; however, their psychometric properties are not well established. Further, observational studies of these subjects' eating skills or self-reports from them are lacking. This makes it difficult to compare studies or to replicate their results.

Despite these methodological limitations, it is clear that feeding problems constitute a frequent and significant preoccupation for many parents of children with ASD [18]. In support of such concerns, some studies found that children with ASD are more susceptible to feeding problems than children with other developmental disabilities [19-23]. There is as yet no defined etiology for feeding problems in children with ASD neither is there for the pediatric population in general. Significant associations have been found between oral-motor, gastrointestinal and sensory problems in children with ASD [19, 24-26]. According to Skinner [27], individuals' responses to environmental stimuli shape their behaviors and this interaction constitutes the foundation for learning. When feeding is described as a struggle in the family environment, behavioral approaches such as escape extinction and positive reinforcement are used by professionals and gradually assumed by the caregiver. However, feeding problems may also arise from a limited ability to communicate or from poor social and cognitive skills. Eating skills and mealtime manners are learned by observation and imitation, yet these associations have not been correlated with ASD. More recent studies have found similarities between anorexia nervosa (AN) and ASD, on the basis of global processing deficits, inflexible style of thinking, communication difficulties and impairment of interpersonal functioning and social interactions [28-30]. Hence, treatment approaches used for AN might also be suitable for ASD.

Considering the impact feeding problems can have on children's health, the stress experienced by parents, as well as the impact on social participation of child and family, it will be crucial to continue documenting feeding problems in this group, to better understand them and thereby, offer better treatment. Similarly, it will be just as important to provide professionals with better guidelines to evaluate feeding problems, as well as to appreciate the consequences they have on family function.

## 2. Essentials of diagnosis

The severity of pediatric feeding problems can range from mild to severe. Despite this wide range, there are no clear indicators to determine which problems will be transient and those that will persist over the long term and may have an impact on children's health [1]. The DSM-IV-TR, a classification for psychiatric disorders, describes criteria for *feeding disorder of infancy and early childhood*; however, this particular diagnosis is rarely used in research or clinical practice. There are several reasons for this. A majority of the children who are referred for feeding problems, in general, do not meet all of the criteria outlined in the DSM-IV-TR (Table 1) [7, 31]. For example, children do not qualify even if they have severe feeding problems but normal weight (e.g. eating foods of poor nutritional value; eating only purees or being tube fed) [7]. It is also not clear which medical or mental conditions, including ASD, would exclude a child from a diagnosis of *feeding disorder of infancy and early childhood*. Other diagnostic classifications and screening criteria appear promising. These are: *Feeding Behavior Disorder* [32, 33], *Avoidant/Restrictive Food Intake Disorder* [34] and *Feeding Disorder* [35-37], the *Wolfson Diagnostic Criteria* [38] and the framework proposed by Davies et al.[39].

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Criterion A. Feeding disturbance as manifested by persistent failure to eat adequately with significant failure to gain weight or significant loss of weight over at least 1 month.

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Criterion B. The disturbance is not due to an associated gastrointestinal or other general medical condition (e.g. esophageal reflux).

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Criterion C. The disturbance is not better accounted for by another mental disorder (e.g., Rumination Disorder) or by lack of available food.

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Criterion D. The onset is before age 6 years.

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**Table 1.** Diagnostic Criteria for *Feeding Disorder of Infancy or Early Childhood* from the DSM-IV-TR [31]

## 2.1. DC: 0-3R and Proposed DSM-V

*Feeding Behavior Disorder* [32] applies «when the child does not regulate his feeding in accordance with physiological feelings of hunger or fullness» and comprises six categories to be described below. The future DSM-V [34] *Avoidant/Restrictive Food Intake Disorder* will include a description of three main subtypes that will map onto the first three categories of the DC:0-3R [32]. The reader is referred to the APA DSM-V website for further details on the inclusion criteria [34]. A clarification has been made to consider severe feeding problems, when they exceed what is normally expected with a concurrent medical condition or another mental disorder, which may include ASD [34]. The criterion has been further modified to also include children that do not lose or fail to gain weight.

### 2.1.1. Infantile anorexia

The central problem of infantile anorexia is a lack of appetite, as manifested by a lack of interest in eating and food refusal, and issues of control and autonomy that may exist between the parent and the child [33, 35]. Parent recall indicates that the child will be easily distracted by environmental stimuli, which interfere with nursing from the bottle or breast from the very first weeks of life. Later, children in this category never complain of hunger and are satisfied with only a few bites. Parents worry when their child does not eat enough and often try different strategies to encourage their child to eat. Early on distraction manoeuvres may work, but they do not last, and parents are forced to invent new strategies to entice their child to eat. They may coax the child and sometimes use force-feeding. Despite these efforts the child does not eat enough to maintain normal growth, which may later lead to malnutrition, but will come to attention when the child does not follow his expected growth curve.

### 2.1.2. Sensory food aversions

In contrast to *infantile anorexia*, children with sensory based feeding problems are not lacking in appetite and eat an adequate diet as long as it meets their preferences which are consistent and stable over time [33]. These food preferences may be based on food texture, taste, smell, temperature or appearance. Sensory aversions may range from mild to severe, with some children refusing only a few items and others a whole food category. The varying in-

tensities of these aversive reactions may lead to food refusals that may get generalized to foods with similar characteristics or to all new foods. Some children are so sensitive to the sensory characteristics of the rejected food that they will not eat any other food that comes in contact with the refused food, or refuse that certain foods be placed in their line of vision, or refuse to eat when others, seated next to them, eat a food that has been rejected or it may trigger an aversive reaction (Figure 1). What distinguishes *Sensory Food Aversions* from normal food preferences is the degree of severity of the food refusal and the presence of nutritional deficiencies or oral-motor delays arising from a lack of exposure to more demanding food textures [33]. Some studies have shown a significant relationship between food selectivity or mealtime problems and problems with sensory modulation [26, 40].



**Figure 1.** Children learn about food through exploration with their senses

### 2.1.3. *Feeding disorders associated with insults to the gastrointestinal tract*

This diagnosis, later renamed *posttraumatic feeding disorders* by Chatoor [33], has a sudden onset and results in severe food refusal. Young children with this diagnosis refuse to be fed, and often cry, hyper-extend their trunk and refuse to open their mouth when food is offered. Posttraumatic feeding problems are the result of a traumatic event or chronic, repeated traumatic events that affect the oropharynx or the esophagus. The event may have been aspiration of solid food into the trachea, related to force-feeding, due to medical procedures, such as placement of a nasogastric tube or enteral feeding. The refusal of food may manifest itself in different ways, depending on the type of feeding that is associated with the trauma. Depending further on the situation where the trauma occurred, such as the location or the positioning associated with feeding, the child may show signs of anxiety and marked distress at the approach of the bottle or the spoon, or when the food is placed in the mouth. Fear will override any sense of hunger and the effects on the child's health may vary, depending on the duration and extent of the food refusal, and the adequacy and adaptations made for nutritional compensation. If the food refusal extends over a prolonged period of time, delay in oral-motor skills, or overall development may be the result [33].



#### *2.1.4. Feeding disorder associated with concurrent medical conditions*

The DC: 0-3R [32] also lists feeding problems that are associated with medical conditions whereas the DSM-V [34] will only deal with mental health issues, not medical problems. Children with medical conditions and associated feeding problems are able to initiate eating; however, they may soon show signs of distress and/or fatigue and may not be able to finish their meal [33]. This inability may vary according to the severity of the medical condition. Heart and respiratory problems, as well as allergies and gastro-esophageal reflux are frequently associated with this type of feeding disability. Resolving the medical issues often improves the feeding related problems, although the latter may not always be eliminated completely. Several symptoms such as gagging, lack of appetite, food refusals, weight loss or growth faltering, may also be found in conjunction with other medical diagnoses. It is essential therefore, that children with feeding problems be carefully examined for associated medical problems.

#### *2.1.5. Feeding disorder of state regulation*

This feeding disorder is characterized by its onset in infancy, difficulty in establishing a quiet alert state necessary for feeding, weight loss, and absence of any medical condition that could explain these problems. This disturbance in state regulation, similar to disturbances in sleep or crying, will not be included in the next issue of the DSM-V [34]. Feeding is the first competent motor skill of infants [41] and is also an early indicator of self-regulation [33]. Therefore, specific aspects of feeding problems that also coincide with the behavior characteristics of ASD, might become 'red flags' for its diagnosis. Infants must be alert and able to maintain a calm state during feeding right from birth, i.e. the infant should not fall asleep at the onset of feeding, be too agitated or too distressed to feed [33]. Infants triple their body weight in the first year of life [41]. Therefore, a child who does not gain weight will not be able to maintain his established growth curve, or tends to cross over into a lower growth curve, which is interpreted as 'losing weight'. Mother and infant are 'mutual caregivers' [42]; the child who engages the mother visually, smiles or babbles and gains weight provides feedback to the mother that she is 'doing a good job', whereas a child who is colicky, cries, arches away from the mother and does not seem to eat enough causes the mother to worry and to try to compensate. She may feed the child more frequently than a child who eats well and she will also feed the child longer to compensate for the emerging weight loss [43]. The recent development of the P.O.P.S.I.C.L.E Center Infant and Child Feeding Questionnaire© (Parent Organized Partnerships Supporting Infants and Children Learning to Eat), an age-specific questionnaire available on the web, gives parents information regarding typical feeding development and helps them identify whether referral to a health professional (feeding specialist) is indicated [44]. Future studies will need to determine whether the constellation of early weight loss, lack of reciprocity, and distractibility during feeding may be an early indicator of ASD.

### 2.1.6. Feeding disorder of caregiver-infant reciprocity

Feeding disorders of caregiver-infant reciprocity have their onset in the infant's first year of life and may come to attention through a problem that needs medical attention. The infant's developmental progression shows growth retardation and a lack of age appropriate engagement with the primary caregiver. Careful examination of the child-family relationships often point toward child neglect that may have its origin in the caregiver's history. These difficult problems will need to be addressed in conjunction with the original feeding problems of the infant [33]. In the DSM-V, this problem will be classifiable under a V code (i.e. a relational problem) [34].

## 2.2. Feeding Disorders as classified by Dovey and collaborators

The classification by Dovey et al. [35, 36] is built on an older classification by Chatoor and Ganiban [45]. Of the five types of feeding disorder, which will be further described below, four are similar to the classifications mentioned above. *Learning-dependant food refusal* is added and will include many children seen briefly in clinical practice. In their decision-making model [36, 37], *Autism-Related Food Refusal* is mentioned as a distinct category, but not further elaborated. In an earlier paper Dovey et al. [35] briefly describe feeding problems associated with ASD and touch upon the importance of the cognitive and social aspects of these problems. However, at that time, the authors seemed to include *Autism-Related Food Refusal* in their *selective food refusal* category. For clarity we will present a brief definition of the *Autism-Related Food Refusal* as a sixth category in this chapter.

### 2.2.1. Medical complications-related food refusal

Similar to the *Feeding Disorder Associated with Concurrent Medical Conditions* [32], food refusal is associated with one or more medical conditions. Medical professionals (e.g. gastroenterologist, general practitioner, health visitor, etc.) are needed to address these issues. The child may lack developmentally appropriate experiences with food because of major medical interventions that may have required nasogastric tube feeding which is often followed by gastrostomy feeding until the medical issues are resolved. Periods of longer than 1 week of tube feeding put the child at risk for 'oral deprivation,' i.e. they deprive the child of the daily practice of oral behaviors which in turn seem to have a detrimental effect on the associated brain development [46, 47]. If it occurs in infancy children will experience great difficulty in making the transition to oral feeding. If children have had oral feeding experience before intubation there will be a transition time where they will have 'to learn to eat' again, but the transition will be shorter than in infants who have not had any feeding experience [46]. Dovey et al. [35] describe these children as not interested in eating but generally as happy to explore and play with food. Food refusal can also be present due to an association of food and/or eating with pain or discomfort. Many children who were tub-fed for extended periods will require additional support when making the transition to oral feeding [48].

### *2.2.2. Learning-dependent food refusal*

According to Dovey et al. [35], the feeding disorder defined in this category is «completely dependent on the child's experience with it (eating)». Children in this category may have temper tantrums when new foods are offered to them and the usual response of the parent is to take their plate away and replace it with something they know their child will eat. Eventually, parents adapt the family menu to better fit their child's preferences and avoid unfamiliar foods or ones they know will trigger aversive reactions. Children between 2 and 6 years of age often refuse to taste new foods, which generally improves as the children get older. Food refusal based on novelty is called food neophobia and is considered an evolved behavior from human ancestry that protects the organisms from poisoning, at a time when children begin to leave their parents' supervision and gain more autonomy [35]. Repeated exposure, a positive experience and social influence will help children to overcome food neophobia. Therefore, caregiver education will be the first strategy to use when a learning dependent feeding disorder is suspected and rapid change can be expected.

### *2.2.3. Selective food refusal*

Initially the picture of the «selective child» will be similar to learning dependent food refusal but for various reasons will evolve into a significant decrease in dietary variety. Here, exposure and social facilitation will have little to no effect on food acceptance and the child will not play with food. His diet will rely mostly on hedonic foods, e.g. foods that have a high salt, sugar and fat content. The child may eventually develop gastrointestinal problems as a result of a lack of fiber in his diet. Similar to Chatoor's Sensory Food Aversion category [33], these children have some sensory sensitivities, both tactile and/or oral defensiveness. Enlargement of dietary variety is a long process for children in this category and needs collaboration of parents, other caregivers and professionals. Dovey et al. [35] suggest that children in this category be referred for diagnostic work-up because of the high prevalence of sensory problems in the ASD population.

### *2.2.4. Appetite-awareness-autonomy-based food refusal*

This category is the same as Infantile Anorexia described earlier by Chatoor and her colleagues [33] and is included in the above classification. The reader is referred to it for further details.

### *2.2.5. Fear-based food refusal*

Fear-Based Food Refusal is also called Food Phobia. This category is identical to Posttraumatic Feeding Disorders of Infancy [33]. Some authors believe that, for many of these children, food phobia might be associated with a more general anxiety or affective disorder [49]. Food refusal in this category can be distinguished from other categories by the intensity of the emotional reaction when the child is asked to eat the target food.



### 2.2.6. *Autism-related food refusal*

Dovey et al. [35] describe children with ASD and feeding problems as having «seemingly illogical rules around what constitutes an acceptable meal». We are not aware of any studies that have examined these children's rationale for their eating behaviors and the cognitive decisions that have led to them. Although, we do not know whether Dovey and collaborators have studied these, they acknowledge that these children must make decisions whether to eat something or not. This constitutes an important gap in our understanding of these children's feeding behavior and has important consequences on how we treat them. We observe children's behaviors and decide to manipulate them without understanding the underlying rationale that has led to these behaviors. An interpretation based on the hyper-systematization theory of Baron-Cohen et al. [50] will be discussed in the intervention section of this chapter. Meanwhile, perhaps one approach would be to study adults with autism and/or higher functioning children with ASD where some communication and insight is present, in order to access this very challenging domain. Even here, we must be sensitive to the fact that many other domains of ADL might be affected, besides eating, and that children and their family must be treated holistically.

### 2.3. The 'Wolfson group' diagnostic criteria of infantile feeding disorders

The 'Wolfson Group', a collaboration of medical professionals from Israel, has studied infantile feeding problems for a number of years [38, 51, 52] and has shown considerable success in discriminating between infantile feeding disorders (non-organic) and medically based feeding problems (organic). Levine et al. [38] compared the diagnostic criteria of the Wolfson group to DC: 0-3R [32], and the DSM-IV [31] classifications in a group of children referred for food refusal. Results discriminated 100%, 77% and 47% respectively. The Wolfson criteria (Table 2) successfully identified a substantial proportion of treatable patients that the two other existing classifications could not identify [38].

1. Persistent food refusal $\geq 1$ month
2. Absence of obvious organic disease leading to food refusal or lack of response to medical treatment of an organic disease
3. Age of onset $< 2$ years, age at presentation $< 6$ years
4. Presence of at least one of the following: <ul style="list-style-type: none"> <li>a. Pathological feeding or</li> <li>b. Anticipatory gagging</li> </ul>

**Table 2.** The Wolfson Diagnostic Criteria

## 2.4. Davies and collaborators' framework for classification

Finally, another convincing argument for a reconceptualization of diagnostic criteria of feeding problems has been advanced by Davies and collaborators [39], suggesting that feeding problems are the result of a relational disorder of the child in his social context. The authors propose that feeding problems be diagnosed along 6 axes that define 1) a feeding disorder between parent and child, characterized by the child's persistent failure to eat foods in accordance with his developmental stage and the cultural or sub-cultural expectations. 2) a character/developmental disorder of parent and/or child, where the feeding relationship may be disrupted due to the caregivers' own psychopathology or life demands, and/or where the child may have a difficult temperament or medical and developmental issues that interfere with feeding, 3) This axis describes medical disorders of parent and/or child, that need to be addressed before feeding problems can be resolved 4) psychosocial stressors need to be identified "through use of the multi-axial diagnosis, to reflect the multi-determined nature of feeding disorders" 5) global functioning of parent and child will be examined separately for each, and 6) the global parent-infant relationship is classified through assessment of the quality of the parent-child relationship.

## 2.5. Parent reported feeding problems

A systematic literature review of feeding problems reported by parents, shows that many symptoms are similar to those associated with sensory feeding problems [4, 5, 10, 11, 14, 17, 20, 26, 53-55]. The peculiar ways in which sensory input is treated by persons with ASD are well documented in the literature [56-59]. The most frequently mentioned problems are texture, color, and smell selectivity, refusal of new foods, and food refusals in general. These problems were not associated with weight loss in a study comparing body mass index between typically developing children and those with ASD [60]. One study even reported a large proportion of children with ASD to be obese [61].

Parents' perception of their child's feeding problem often leads them to seek professional advice. In terms of nutritional deficiency, results vary widely [62-64]. Application of standards of reference with different criteria for severity levels may explain these discrepancies [65]. Furthermore, none of the studies reviewed so far have exclusively studied children with clinically significant feeding problems. Within a normally distributed population one would expect some children with, but the majority to be without nutritional deficiencies. Thus, it is not yet possible to determine whether or not children with ASD and severe feeding problems would also have nutritional deficiencies. Some case studies and larger studies report negative health effects due to selective eating or restrictive diets [66, 67]. Therefore, it is always advisable to refer a child to a qualified nutritional expert when the child presents with selective eating.

Some parents report problems with chewing and abnormal drooling even after the child's developmental age has been taken into account [13, 68]. Nadon et al. [13] compared children with ASD and their typically developing siblings of the same mean age and found that only the children with ASD had problems with eating related drooling, chewing, moving their tongue or swallowing. While parents interpreted these problems as a source of their child's

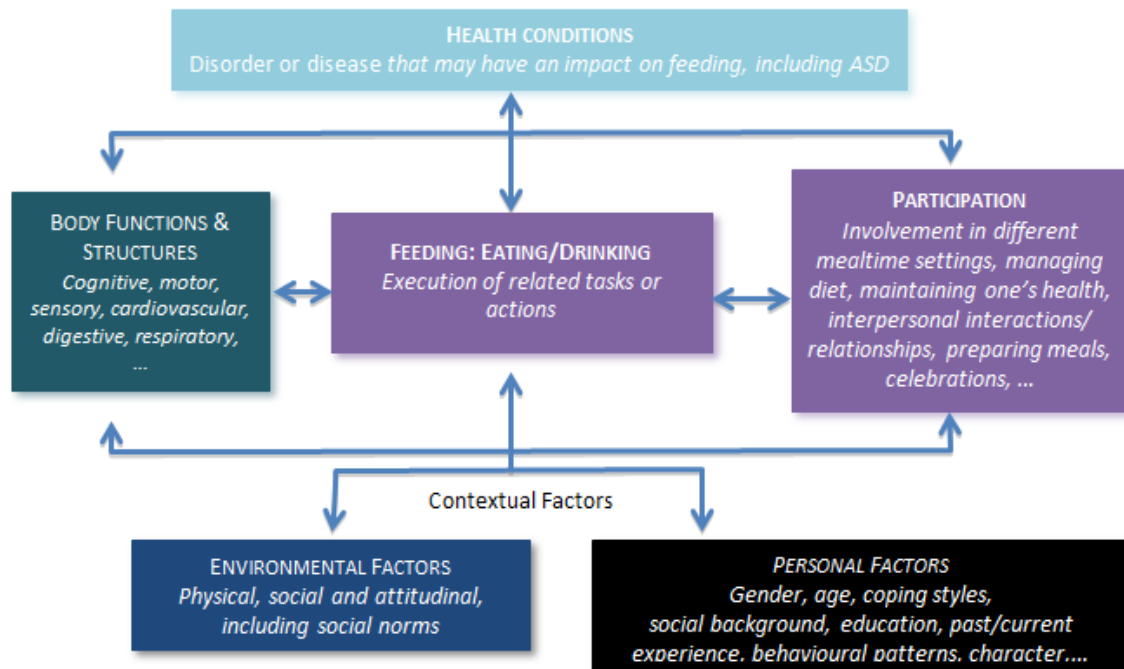
feeding problem, this study showed that these motor behaviors were associated with tactile sensitivity but independent of mental retardation, attention deficit disorder or hyperactivity that is often present in these children [13]. These oral-motor problems are often overlooked, because it is generally a small group when compared to the whole population of children with ASD. However, careful evaluation may be particularly helpful for this group of children, because specific treatments exist, and have been shown to be effective for other neurologically based feeding problems [41].

Anticipatory behavior is an early indicator of social engagement. Kanner [69] noted that infants who later were described as 'autistic' did not reach out to an adult who was engaged in picking them up. Brisson and colleagues [70] made use of this characteristic by studying anticipatory behavior associated with feeding. The authors performed a retrospective review of home movies of infants, 3 to 6 months of age, who were later diagnosed with autism, expecting that they would perform poorly on opening their mouth (the anticipatory behavior) in response to an approaching spoon. Results were compared to an age matched typically developing group. While typically developing children, as a group, achieved 79% correct responses, only 46% of the children with autism did so. There was a clear learning curve in both groups, with younger infants showing fewer mouth opening responses than the older ones, and a larger proportion of typically developing infants opening their mouth to an approaching spoon than did infants with autism. These results are consistent with parent descriptions that infants were easily distracted when feeding, right from birth, and this behavior may indeed become an early diagnostic indicator, in conjunction with other behaviors that characterize the ASDs.

### 3. Evaluation

Feeding at mealtimes occurs as the result of the interaction between a child's body functions and structures, his health condition and some contextual factors (i.e. environmental factors as well as personal factors). An illustration of these interactions, using the model of the International Classification of Functioning, Disability and Health (ICF) is illustrated in Figure 2. The complexity of these interactions may be the reason why many investigators developed their own assessment tool, because existing ones did not adequately cover the domains to meet the authors' needs [71]. To have a complete picture of a child's problems, it is necessary to combine various methods of evaluation and to collaborate with professionals who have different domains of expertise.

There are a number of methods and feeding assessments, with varying content as well as different psychometric properties (e.g. caregiver questionnaires, interviews, child observations). The following review will be selective and is not intended to be exhaustive. For a more complete review the reader is referred to Nadon et al. [71] and Seiverling, Williams and Sturmey [72]. Other evaluations may be performed using standardized assessments if the child's condition suggests additional problems.



**Figure 2.** Adapted from the International Classification of Functioning, Disability and Health (ICF)

### 3.1. Parent questionnaires

Parent questionnaires with interview formats are commonly used [71-74]. These have the advantage that they can cover an extended period of the child's life. As well, documenting the feeding history during the first year of life, and again around 18 months when most of the problems become apparent, sheds light on the evolution of the presenting problems. Parents can provide a more complete picture of the child's feeding behaviors because they usually provide their child's daily meals. The advantage for the evaluator is that he is not dependent on a single meal observation that may not be representative of the daily routine in the home. It is also very important to get to know parents' motivation for consultation, their perception of the problems and their priorities for resolving them. It is important likewise, to learn what strategies parents have tried to solve the feeding problems and how the child reacted to them [75]. A detailed description of the child's food preferences is in order to determine the adequacy of the nutritional content. As well, common sensory characteristics of his preferred and non-preferred foods need to be assessed (color, texture, consistency, taste, smell, appearance,...) to better understand the nature of the problem and assist in the formulation of a treatment plan [76]. A sensory profile of the child is essential and, to understand his way of communicating, his motor abilities, learning strategies, and his cognitive and sensory information processing. It is also important to assess whether the child has a minimal understanding of negotiation, and what his play skills and interests are. These abilities will determine how best to approach his treatment.

### 3.2. Mealtime behavior questionnaires

The *Children's Eating Behavior Inventory* (CEBI-R) [77] covers eating and behavioral problems at mealtimes in 2 groups: typically developing children (non-clinic) and a « clinic » group, aged 2 to 12 years. It uses a 5 point Likert scale to identify whether a problem occurs between « never » and « always », and a dichotomized scale for parents to note whether the behavior is perceived as a problem or not. Construct validity was demonstrated by significant differences between the two groups in total eating problems and the number of items perceived as problematic. Internal reliability or item consistency ranged from .58 to .76 using Cronbach's alpha, and test-retest reliability was .84 (parent score) and .87 (total eating problems).

The *Brief Autism Mealtime Behavior Inventory* (BAMBI) [73] measures the frequency of mealtime behavior problems in children with ASD between the ages of 3 and 11 years. The BAMBI contains 18 questions based on a 3 factor structure that identifies limited variety of foods (8 items), food refusals (5 items) and autistic behaviors (5 items). The BAMBI has good internal consistency .88, high inter-rater 0.78 and test-retest reliability 0.87, as well as strong construct and criterion-related validity [73].

The *Behavioral Pediatric Feeding Assessment Scale* (BPFAS) is a 35 item, standardized caregiver report inventory that was developed for children with feeding problems, 9 months to 8 years of age, but who are otherwise typically developing. The tool has a 5-point Likert scale and caregivers indicate how frequently children show a behavior, i.e. « never happens » to « always happens », parents' frequency of feelings or strategies is noted and a total frequency is computed. Higher scores indicate more problems. Internal consistency of the BPFAS is .88. Test-re-test reliability for the total score is .78 in both normal and clinical samples. The BPFAS was shown to have adequate reliability and validity [78].

The 31-item *Parent Mealtime Action Scale* (PMAS) [75] measures parents' actions regarding their child's mealtime behaviors in nine dimensions: snack limits, positive persuasion, daily fruit and vegetable availability, use of rewards, insistence on eating, snack modeling, special meals, fat reduction and many food choices. Parents also provide three-point ratings (1 = never, 2 = sometimes, 3 = always) how often they use each of these actions in a typical week. The clinician then provides specific recommendations to caregivers regarding actions they can implement to improve their child's feeding. The PMAS was developed with a sample of over 2000 typically developing children [75] but a recent study [79] examined its applicability with a clinical sample including 49 children with ASD. Mean internal reliability was .62 and convergent validity was demonstrated with expected associations between parent mealtime actions measured by the PMAS and some children's feeding problems. The five PMAS dimensions most associated with children's feeding problems were snack limits, insistence on eating, fat reduction, many food choices, and special meals [79].

The *Feeding Demands Questionnaire* is a parent report questionnaire that measures parents' belief how their child should eat [80]. Mothers of 3 to 7-year old children completed the 8-item Feeding Demands Questionnaire, the Child Feeding Questionnaire, measures of depression and fear of fat. The Feeding Demands Questionnaire revealed 3 factors: anger/



frustration, food amount demandingness, and food type demandingness, for which subscales were computed. The Feeding Demands Questionnaire showed acceptable internal consistency (.70 to .86). The authors concluded that different demand beliefs influence different feeding practices.

*About Your Child's Eating* (AYCE) [81] was developed to document positive mealtime environment, parent aversion to mealtime and child resistance to eating in a sample of typically developing and a group of chronically ill children, aged 8 to 16 years. The AYCE is scored on a Likert scale from « never » to « nearly every time » describing the frequency of the child's mealtime behaviors, the caregiver's interaction with the child and the caregiver's reaction to the meal. While the constructs evaluated would seem to be similar in a group of younger children, validity for the ASD diagnostic group remains to be determined. The AYCE internal consistency is .24 for child resistance, positive mealtime environment .55, and parent aversion -.37. There is also evidence for convergent validity with the *Family Environment* measure. Other psychometric properties still need to be developed.

The *Eating Profile* [13] covers eleven domains (145 items): 1) dietary history of the child, 2) child health, 3) family dietary history, 4) mealtime behaviors of the child, 5) food preferences, 6) autonomy with respect to eating, 7) behaviors outside of mealtimes, 8) impact on daily life, 9) strategies used to resolve difficulties encountered at mealtimes, 10) communication abilities of the child and 11) socio-economic factors of the family. The psychometric properties of this questionnaire have been studied to a limited degree [13, 82]. It was used to compare sibling mealtime behavior (ASD vs typically developing) in the same family. It showed that although typically developing children also had some mealtime problems (mean of 5.0), children in the same social and physical environment but with ASD, had significantly more such problems (mean of 13.0) than their siblings. Lack of variety of foods, i.e. less than 20 items, an inadequate number of meals, not eating at the table, or not staying seated during the meal, as well as showing some oral-motor deficits were the most significant differences between the two groups [13]. Even after developmentally related behaviors were excluded the difference between the number of mealtime problems in the two groups persisted. These results suggest that the impact of the diagnosis on mealtime behavior is greater than that of the environment.

### 3.3. Nutritional assessments

The *Youth/Adolescent Questionnaire* (YAQ) [83] is a self-report inventory for food frequency with 148 items to determine the nutritional intake of 9 to 18 year-olds and the average food serving frequency of six food groups. It provides an estimate of the average serving frequency per day for 6 food groups as well as the average intake over one year. In a validation study a correlation of .54 was achieved between the YAQ and 24-hour food recall interviews [83]. Test-retest reliability ranged from .26 to .58 for nutrients and from .39 to .57 for food groups. A modified version of the YAQ was used with children with ASD to quantify food refusal and food selectivity (i.e. 'High-Frequency Single Food Intake') on a daily basis [64]. Although food frequency questionnaires are known to commonly over-report dietary intake [84], they are useful to analyze children's preferences as it is required when using graduated exposure therapies.

*Food records* are routinely used by nutritionists to measure energy intake. A systematic review [84] suggests that the 24-hour multiple pass recall conducted over at least a 3-day period that includes weekdays and weekend days, using parents as reporters is the most accurate method for children aged 4 to 11 years and that weighted food records provided the best estimates of Estimated Intake for younger children aged 0.5 to 4 years. Cornish [54] used a three day food record to study a small group of children with ASD, aged 3 to 16 years where 8 had followed a gluten and/or casein free diet for various lengths (1 to 6 months) and 29 consumed a regular diet. Caregivers filled out a 3-day diary of all foods and drinks consumed. Nutrient intakes in 12 children were lower than recommended in 'Lower Reference Nutrient Intake' for zinc, calcium, iron, vitamin A, B<sub>12</sub> and riboflavin in the regular diet group and in 4 for zinc and calcium in the diet group although these differences were not statistically significant between the 2 groups. The median daily energy intake was 93% of *Estimated Average Requirements* (EAR) in both groups, and did not differ in the contribution of proteins, fats, or carbohydrates. Fruit and vegetable intake was higher and consumption of starches was lower in the diet group. The author notes that parents who followed the exclusion diet found that it isolated the family socially, food substitutes were difficult to find and costly, meals required longer preparation time, and it was very difficult for the child to make the change to the new diet.

### 3.4. Direct observations

Observation of the child's mealtime routine in his familiar environment provides insight into the family's daily life and the accommodations made for coping with problems [74]. The family may be so enmeshed in this routine that it does not always realize how it has adapted to the child's problem and to what extent the child's behavior or the environmental setting may contribute to the maintenance of problems. By making several visits to the home and by changing different variables (person, environment, social demands, sensory stimuli, liked vs non-liked foods...) the observer gets a clearer picture of the situation. If possible the evaluator should have a discussion with the child regarding his global understanding of eating and his recognition of any problems. If a home visit is not possible, the parent/caregiver should come to the clinic and bring some of the child's liked and non-liked foods. Familiar plates or utensils can also be brought. Evaluation will then focus on oral-motor skills, reaction to foods, intensity of food aversions, and acceptability of food modifications. A systematic presentation of foods was used by Ahearn et al. [10] for children with ASD. However, a major criticism with this type of evaluation is that it does not measure the severity or the problem experienced in the home, because the context is far from what the child is used to. It is more likely measuring the child's reaction to novelty or the influence of different contexts.

*The Multidisciplinary Feeding Profile* (MFP) was developed by Kenny and collaborators [85] with a group of 18 children, 6 to 18 years of age, who had neurological disabilities and were 'dependent feeders.' The evaluation is divided into six sections covering: 1) Physical/Neurological factors such as posture, tone and reflex activity, 2) Oral-Facial

Structure, consisting of 'an evaluation of the face and mouth at rest to identify variations from normal, using surface anatomy exclusively', 3) Oral-Facial Sensory Inputs: a subjective evaluation of sensory and reflex motor activity produced by stimulation of selected cranial nerves, 4) Oral-Facial Motor Function: a series of voluntary oral facial postures such as puckering the lips or deviating the jaw to the right or left, 5) Ventilation/Phonation: 'a subjective evaluation of breathing and sound production' and 6) Functional Feeding Assessment: an 'evaluation of oral-motor skills during specific feeding tasks' examining spoon feeding, biting, chewing, cup- and straw drinking and swallowing. Overall rater agreement, among 3 raters, was 0.83, and overall rater consistency was 0.90. Other psychometric properties such as validity, item consistency and test-retest reliability still need to be determined. As well, examination of the suitability for the population with ASD will be needed.

*The Schedule of Oral-Motor Assessment (SOMA)* by Reilly et al. [86] measures the oral-motor and feeding skills of children 8 to 24 months of age. A sample of 127 children constituted the original sample, 90% were typically developing and 10% were children with cerebral palsy. Differently textured foods and liquids are offered to the child in a pre-determined order: liquid, puree, semi-solids, solids, biscuits and dried fruit and scored in 6 sections. Scores are based on the quality of oral-motor, mandible, lip and tongue movements. Inter-rater reliability was 0.75 and internal consistency 0.85 [87]. The predictive validity was > 95% and sensitivity >.85 [88]. The age range of the SOMA makes it particularly attractive for use with young children because of the benefits of early intervention [41]. While a diagnosis of ASD may only be confirmed by two years or later, feeding problems are often recognized by parents from the first year. Treatment of feeding problems is not dependent on the diagnosis of ASD. Therefore, early intervention may prevent aggravation of feeding problems with time when not treated promptly.

#### **4. Treatment**

Treatment must take the complete evaluation into account, including the interaction of the person with his familiar environment. Feeding cannot be treated as an isolated problem and the strategies employed should not be limited to mealtimes only. To illustrate: the stress a child experiences during mealtime may decrease his appetite or decrease his tolerance for tactile or olfactory stimuli. Also, if functional analysis reveals environmental contributions to the feeding problems, like inappropriate parental strategies to cope with behavioral issues during mealtime, treatment needs to include these routines as well.

Whether the treatment approach will be interdisciplinary or trans-disciplinary [19, 89] collaboration between different professionals is desirable, given the complex nature of feeding problems and the many factors to be considered [21, 39, 90, 91]. The degree of involvement may vary, depending on the expertise of the individuals involved, the etiology of the problem to be addressed or the relationship the professionals have with the parents [89, 90].

#### 4.1. Parent education

When professionals help parents recognize the source of the feeding problem, the course of its evolution, and what contributes to its maintenance, the parent can become the professional's strongest ally, because parents know their child best. Engagement is better when parent and professional come to an agreement regarding treatment goals and parent involvement is essential in a family-centered approach to treatment [92]. If the child is still young, one would anticipate that the child will become more food selective around the age of two or three years, as seen in typical development, and that this stage will be more challenging for a child with ASD. When parents first learn of the child's diagnosis, it may be wise to show them a number of coping strategies (Table 3), in order to prepare them for the developmental food refusals, or to prevent some problems from getting worse. Particular attention must be paid to prevent intrusive feeding and to assure the child is regularly exposed to variation in the menu and presentation of foods [38, 93]. Parents' actions and their relationship with their child influence the course of mealtimes. Eating is not only about food. At the table members of the family enjoy each other's company, the meal, exchange feelings and family/cultural values. When mealtimes are not pleasurable and some members do not feel respected with regard to their needs and choices, the relationship may become affected. When the strategies chosen by the parent affect the relationship and contribute to the maintenance of a feeding problem, alternatives may be suggested and modeling used, to demonstrate different actions and attitudes in response to the child's behaviors. Regardless which treatment approach is chosen, parents must learn it and the transfer to different social environments must be carefully planned. It is hoped that regular follow-up with the family can be established, so that parent support is ensured and that changes can be made when needed.

- 
- Never force feed children
  - Never require that children empty their plate
  - Schedule regular meal times, to establish a cycle of hunger and satiety
  - Include activities before and after meals, to establish an anticipated routine.
  - Use adapted communication and/or visual cues to establish clear expectations
  - Limit the amount of liquids (especially juice and milk), because very small amounts can decrease appetite.
  - Each child needs a designated seat at the table.
  - Avoid commercial containers to facilitate the use of other brands
  - Praise 'good' behavior.
  - Change constituents of menus regularly.
  - Introduce changes that are big enough to be recognized, but small enough that they will be tolerated.
  - Adapt portion size to the age of the child and to his average appetite.
  - Plan for generalizations
- 

**Table 3.** Principles of feeding



## 4.2. Nutritional supplementation

Feeding problems may be long-term problems. This is one reason why nutritional supplements may be useful to ensure that the child's health is not compromised [94]. This will require a nutritionist's evaluation, to determine whether supplementation or modification of the existing diet is indicated. These changes have to be made carefully and follow-up is needed to ensure that they don't suppress the child's appetite or interfere with digestion. Another option is to introduce supplements in small quantities after each meal, or before bedtime. Modification of preferred recipes or the introduction of nutritional supplements to a child who refuses any change to his established mealtime routine may present a major challenge and considerable risk. It is best to try such changes under professional supervision because, if done wrong, children may eliminate another food from their already limited repertoire. To increase the chance of success, it will be best not to change the sensory properties of preferred foods and to present modifications as similar as possible to the taste and texture of preferred foods [76]. Fading and desensitizing techniques are usually best for introducing food supplements [94]. These will be described below.

## 4.3. Behavioral treatment approaches

Behavioral treatments must be based on a functional analysis in order to determine which behaviors contribute to the maintenance of feeding problems and what function these behaviors serve (avoidance, attention seeking, pleasure seeking, obtaining a reward). Qualified professionals must supervise interventions so that no undesirable behaviors are reinforced [95].

A number of studies have shown the effectiveness of behavioral interventions for increasing acceptance of new foods [15, 16, 96]. However, there are only a few studies demonstrating that acceptance of new foods generalizes to other foods or other environments and that preferences of the child have been taken into account [97, 98]. Different types of behavioral interventions are often used in varying combinations [8, 97]. Positive reinforcement, for example, consists of rewarding the child when he shows the desired response. Sequential presentation is a form of positive reinforcement. In this type of intervention acceptance of a non-preferred food is immediately followed by a preferred food. In simultaneous presentation the new, non-preferred food is presented together with the preferred food. Although not mentioned in the literature, clinical practice requires great care with this approach. If parents report that their child can detect the slightest change to a familiar recipe, or reacts negatively to different commercial brands when they look exactly alike, the child may be hypersensitive to flavors. When new foods are hidden in what is familiar to the child, they are often detected by the child. The danger of this approach is, that if the child has limited communication abilities, he may not understand what happened to his food and thus, may refuse to ever eat it again for fear that this problem will repeat itself. It is best not to use this method without the knowledge of the child. First, the caregiver will want to decrease the risk that the child would eliminate one of his preferred foods from an already limited repertoire. Second, the child should be aware that a new food is being introduced, if we want to gradually diminish anxiety toward this food and new foods in general.



In *food fading* a similar approach is used. The intensity of the taste or texture is decreased by mixing the new food with something that the child likes. For instance, one can mix a teaspoon of home-made applesauce in a cup of commercial applesauce. If the child tolerates it, one can add a second teaspoonful at the next meal, and so on. If the child reacts mostly to visual changes he may be a good candidate for this particular approach.

*Antecedent manipulation* aims likewise at modifying the characteristics of a novel food or its presentation (e.g. texture, bite size, utensil, etc.), to make it more acceptable to the child and to fit the oral-motor skills of the child [8].

Escape extinction is used when the functional analysis shows that problem behaviors during a meal result in avoidance of encountering or having to eat a certain food. Physical guidance and non-withdrawal of the spoon are the general methods used for this situation [15]. The spoon is presented to the child and kept near his mouth until the food is accepted. Physical guidance consists of exerting slight pressure on the chin, to elicit opening of the mouth. Bad behavior is ignored. This approach is very difficult to accept for parents because it can be very taxing emotionally for both parent and child. Professional supervision is strongly recommended, to prevent post-traumatic feeding problems or adverse effects on the parent-child relationship. We do not recommend using this approach on a long-term basis but rather for specific identified behavioral problems.

#### **4.4. Treatment based on the theory of sensory integration**

Sensory modulation describes a component of the theory of sensory integration [99]. It is defined as the ability of adjusting responses to the degree, nature, or intensity of the sensory environment [100]. Sensory modulation disorders (SMD) describe responses that are inconsistent, inflexible and fail to meet the demands and expectations of the environment or a task [100, 101]. One or more sensory systems may be involved, such as touch, vision, hearing, proprioception, vestibular, smell and taste. According to Miller et al. [101], there are three subtypes of SMD; over-responsivity, under-responsivity, and seeking/craving. Children who are over-responsive react to sensory input more rapidly, and with greater intensity and duration than the majority of their peers [101]. Over-responsivity can lead to avoidance or aggressive behavior, to escape discomfort caused by sensory input. Tactile defensiveness is part of this subtype and is probably the most documented SMD [40, 99, 100, 102-104]. Under-responsivity describes slower, less intense responses to sensory stimuli [101]. Children in this subtype are difficult to engage, they seem lethargic and lack the inner drive to explore their environment or initiate social contact. Sensory seeking/craving is defined as an 'intense, insatiable desire for sensory input' [100]. Available inputs are not enough for children in this subcategory. They need input of greater intensity. They may take risks and engage in socially unacceptable behaviors, and may have unusual olfactory or gustatory preferences.

People, in general, react differently to intrinsic (e.g. hunger, pain) or extrinsic (e.g. texture, taste of food) sensations. Reaction thresholds and sensory preferences are part of each individual's unique characteristics. However, these are not easy to measure objectively. Some investigators do measure them, but their tools are not readily available to the clinician [105].

Through analysis of a person's emotional as well as physiologic and autonomic reactions, professionals make a decision whether these constitute a SMD or not. The impact of this sensory excitatory state on activities of daily living, or on general development, must be significant in order to constitute a problem. The association of SMD with feeding problems has been documented by some investigators [26, 40, 106-108].

Analysis of the sensory components associated with meals is essential. For a child to function optimally at meal times, he has to be in a calm and alert state. The clinician assesses the child's overall level of arousal prior to mealtime and may intervene to ensure an optimal state for eating. Exploration and tactile desensitization activities may be recommended, such as exploration of new foods through touch, smell, and taste [109, 110]. Some investigators have found a correlation between anxiety and over-responsivity; heightened sensitivity to sensory information mediates the impact of anxiety on selective eating [106]. If the child's anxiety level is too high, it is appropriate to start tactile exploration of familiar foods or items outside the eating domain. Manipulating foods with subtle differences in texture, smell, temperature and taste can help the child feel more comfortable in their presence and is often a preliminary step before accepting them to eat. When these exercises are done playfully they are often less stressful for the child and facilitate participation. Finally, all components of a meal, e.g. utensils used or food textures, must be included in the analysis and can be modified to better suit the child's sensory profile. Despite the extensive use of these techniques in the clinical environment, research using appropriate controls is still lacking to corroborate results from anecdotal reports [8].

#### **4.5. Graduated exposure food therapy**

Graduated exposure food therapy is similar to systematic desensitization, a type of behavioral therapy used for specific phobias and other anxiety disorders. Treatment consists of systematic and gradual exposure to the fear producing stimulus (food), the learning and application of coping strategies, observation of the development of tolerance and maintenance of the engagement of the child; finally, acceptance without adverse reaction, so that the targeted food eventually becomes an integral part of the child's diet. Another goal of desensitization is to gradually eliminate the fear/anxiety that is associated with eating and to replace it with more positive sentiments such as pleasure. Graduated exposure may commence with two types of hierarchy: 1) introducing foods that share some sensory properties with the child's preferred food (e.g. visual, taste, texture) as suggested by Fraker et al. [76] in Food Chaining© or 2) increasing the food's proximity, e.g. tolerating the presence of the food on the table - on the plate - observing it - touching it - smelling it - tasting it - chewing it and, finally, swallowing it [110, 111]. It may be necessary to use both types of hierarchy when introducing a target food. Change can take a long time and it is important that the child does not refuse foods that he previously accepted which can happen when familiar food is modified without his knowledge.

- a. Kraft Dinner © (the child's preferred food)
- b. Other pasta, but with the Kraft cheese mixture
- c. Pasta with home-made cheese mixture
- d. Pasta with pink sauce
- e. Pasta with tomato sauce
- f. Pasta with meat sauce

**Table 4.** Example of Desensitization Based on Sensory Properties as in Food Chaining© [76]

In Food Chaining© [76], the child's food preferences are analyzed in detail to establish a point of departure from which professionals can enlarge the child's food repertoire (Table 4). No studies were found to support the effectiveness of this approach for children with ASD [112]. Nevertheless, it is currently in use in North American clinical environments and several documents addressed to parents and professionals mention it [76, 110, 113]. Hierarchical exposure, based on proximity, associated with individualized positive reinforcement showed promising results for some children with ASD [98]. Validation is needed with a more representative sample of the ASD population [98]. Graduated exposure may be used in combination with other approaches, mentioned earlier, to determine which foods may be easier to introduce first, to structure the progression of treatment, and to ensure that treatment does not progress too rapidly. Some use these strategies in combination with other trans-disciplinary interventions in group therapies as a means of exploring foods through games [111, 114]. This may be an interesting approach for children who have good symbolic play and imitation skills. Other authors have used graduated exposure with more cognitive-behavioral methods, such as in a competition table or a diary to describe the child's progress, or with positive reinforcement or strategies to decrease stress [115]. All children in this last study were 7 years old or older. Some had autistic features, but none had a definitive diagnosis of autism. A self/auto-evaluation scale for the child who has fair insight, as well as an observation scale, are suggested by the authors of Food Chaining© to rate reactions when exposed to a new food [76].

#### 4.6. Cognitive approach

Sensory hypersensitivities are very prevalent in ASD [56, 116, 117]. Baron-Cohen et al. [50] suggest that excellent attention to detail observed in ASD results from this sensory hypersensitivity and that it leads to hyper-systemizing, an exceptional capacity to recognize repeating patterns in stimuli; i.e. recognition of the rules that define a system. This theory explains «savantism» as well as non-social features of autism, like narrow interests, or resistance to change. When applied to feeding, some food selectivity or «illogical rules», like wanting food prepared exactly the same way every day, may be the expression of a strong systemizing capacity; i.e. sameness helps the child build concepts. According to Baron-Cohen et al. [50] a concept is a system and helps to define what items to include as members of the system. Therefore, a child's concept of 'French fries' may rely on visual systemizing (i.e. visual properties of the food are used to categorize: homogeneous light brown, thin and long, in a specific container), or alternatively on social/environmental sys-

temizing (i.e. categorizing according to who is present or when it is eaten: 'French fries' are eaten after swimming class, at McDonalds, with dad). Because the child with ASD is also hypersensitive, a minor change in cooking duration, a different tablemat, is immediately detected and the presence of this new feature (often more than one, considering all the variations possible during mealtime) may no longer allow the child to include the 'new' food in his concept of 'French fries'. This interpretation of autism-related feeding problems could explain amelioration of feeding problems as children with ASD get older, as well as 'miraculously resolved' feeding problems observed sometimes in clinic or reported by parents. When the child understands and has a better global conceptualization of food and mealtime situations, his feeding issues may resolve very rapidly. Other approaches such as sensory integration and graduated exposure may be complementary, because the first addresses sensory hypersensitivity, which leads to hyper-systemization, and the second supports how changes can be introduced. According to Baron-Cohen et al. [50], changing one variant at a time is better to support the child in building general concepts. Another avenue may be inspired by cognitive remediation therapy used for children and adolescents with anorexia nervosa but it would have to be adapted to ASD, and maybe also focus more on food concepts and feeding situations [118].

Developing a teaching method to learn global concepts of food and eating specific to ASD may be needed. Baron-Cohen et al. [119] found an «autism-friendly» way to teach emotions to children with ASD which may potentially be adapted to the feeding domain. Eating and the socialization associated with it, touches a spectrum of emotions. Children with ASD seem to only recognize 'like vs dislike' and not the broader spectrum of 'tolerate, appreciate, enjoy, love, or crave.' Understanding these may also help them to explore and eat a larger number of foods.

#### **4.7. Adaptation of commonly used tools/approaches to ASD**

To achieve acceptable table manners, *Social Stories*<sup>™</sup> [120] may be used to describe a mealtime situation, a skill or a food concept, that includes expected table manners, and aims at helping the individual with ASD better understand social expectations at mealtimes. A *Social Story*<sup>™</sup> may be illustrated such that it explains to the child how meals are set up, why one has to eat, or even to explain what table manners are and what is expected at home or outside the home (i.e. formal and informal rules). This type of intervention was shown to be effective in a young boy with Asperger syndrome, for decreasing unacceptable table manners, such as spilling food and increasing desirable behaviors such as mouth wiping [121]. The TEACCH approach seeks to promote understanding and independence by adapting the environment to better fit the learning style of children with ASD [122]. Visual supports used in TEACCH to enhance predictability and understanding of a task would also be appropriate for eating. For example, one would place only a tiny amount of a new food on the child's plate, if the goal is only to taste the food. To help the child understand the sequence of the meal, one could place a visual sequence next to the plate, to illustrate what he is expected to do, how/when the meal will end and what will happen after the meal (e.g. sit at the table - eat foods on your plate - drink beverage from your glass - wipe your hands - return to play).



Use of alternative and augmentative communication such as the *Picture Exchange Communication System* (PECS) [123] may enhance communication and understanding of social settings between the child and members of the family at mealtimes.

## 5. Discussion

Much progress has been made in our ability to discriminate between constellations of apparently similar feeding behaviors, and thereby establish differential diagnoses for children with ASD and feeding problems [33-35, 38, 39]. However, each new insight gained seems to beg new questions that call for an answer. The evaluation and treatment for these feeding problems has experienced a similar evolution. We will discuss these in the same order as the chapter has been presented so far, starting with diagnoses, followed by evaluation and treatment.

### 5.1. Differential diagnoses

One of the basic needs for the classification of a problem is the use of a nomenclature that is understood and used consistently by the professionals who work in the same domain. There is still no universal consensus what defines a 'feeding problem, eating problem, food refusal, selective/picky eating, mealtime problems' etc., in terms of their characteristics, duration, and severity. It may be the source of confusion and disagreement in the interpretation of results from research. Therefore, such a classification would do much to advance the field, by minimizing the need for defining terms by individual investigators in the course of their work. Consensus building of this type is usually called upon by nationally recognized professional organizations which in the case of feeding problems will need to ensure that as broad a spectrum of professionals is represented in the discussions and formulation of such a classification of this complex topic.

Several classification systems are currently in use. These may contribute to some of the inconsistencies of results, but each makes a unique contribution, and so, a comparison may be helpful to conclude the discussion on differential diagnoses. The DC: 0-3R [32], the proposed DSM-V [34] and Dovey et al.' [35] classifications have several advantages over the current DSM-IV-TR classification. These are the addition of the constructs of appetite, self-regulation, and the sensory and post-traumatic feeding problems. Despite these advances, there will always be children who will not exactly fit these new definitions. It must also be noted that the authors of these classifications do not exclude the possibility that a child may present with more than one diagnosis at a time. Nonetheless, there are still gaps. For example, much attention has been paid to nutritional deficiencies and weight loss, whereas normal weight gain or over-weight due to hyper-caloric diets associated with high hedonic value from sugars, fats and salt are not yet covered. These diets are quickly becoming an important societal problem. Certain symptoms and diagnostic criteria sometimes overlap and standardized tools are not yet available, especially for sensory food aversions [124]. The recognition of sensory based feeding problems is new and studies will be needed to validate



criteria for sensory based food aversions. It is also not yet clear whether some of these feeding problems are specific to the population with ASD, if they are an associated condition or a learned behavior complicated by their diagnosis.

## 5.2. Evaluation

In the section on evaluation we noted that the age ranges of evaluations vary from infancy to late adolescence. New assessments may be needed if the age range for a particular domain is not yet available. While a diagnosis of ASD is often not confirmed until a child is 3 to 4 years old, feeding problems are prevalent and often come to attention in infancy [70]. Treatment of a feeding problem does not depend on a diagnosis of ASD. Therefore, it can be dealt with as early as it comes to attention. Such an approach may prevent the serious long-term consequences in terms of weight gain and brain development [46]. Whether early feeding behaviors may become predictors for a diagnosis of ASD will need further study. However, inclusion of feeding evaluation at the time of the diagnostic work-up is highly recommended for the many reasons that have been stated throughout this chapter.

We proposed the *International Classification of Functioning* (ICF; WHO) as the model for evaluation, in order to ensure that the interactions between the child's body functions and structures, his health condition, and some contextual factors (i.e. environmental as well as personal factors) will be included in the global evaluation. As of this writing no standardized evaluation exists that covers all domains of this model. Some evaluations may cover some domains, e.g. activity/participation and environment, or personal factors and activity/participation and so, feeding assessments based on all domains have to be accomplished by using several evaluations that in combination cover these domains. Another problem is that some of these evaluations have been developed for typically developing children or children with other diagnoses, and will need to be validated for children with ASD. As stated in the discussion of differential diagnoses, collaboration by an interdisciplinary team to develop a tool comprising all three domains would move the field forward substantially.

Many of the evaluation tools reviewed above are questionnaires and may have satisfactory psychometric properties [73, 77, 78], while others have only limited psychometric properties [13, 85] and need further development. Questionnaires offer the advantage of describing the child's usual abilities. These behaviors are described by a person who is familiar with the child, usually a parent or teacher, and reflects the observer's perception of the child's performance. Direct observations of the child's performance in his familiar environment are still lacking. This constitutes a significant gap in the treating professional's knowledge, because the treatment plan will be based on results obtained from a questionnaire or from contexts unfamiliar to the child.

Evaluation of children's nutritional state is based on caloric and nutrient sufficiency of the diet. These are commonly evaluated by food frequency questionnaires, and by 1, or 3-day food records [84]. Food intake is very individual, depending on the child's age and activity level, as well as the cultural environment of the family unit. To judge intake adequacy, results are compared to established national standards such as *Estimated Average Requirements*, or *National Recommended Intake Standards* (NRIS). Evaluation of nutrient adequacy

(vitamins and micronutrients) should be part of a nutritional evaluation. A particular challenge is the peculiar eating habits of children with ASD; they may be of normal weight, hence pose no major 'medical problem', but their diet may consist predominantly of sugars, fats and salt. Such diets may also eventually lead to obesity. To assist parents in their daily mealtime struggles a number of evaluations also focus on parent perceptions of their successes and difficulties [80, 81]. We are not aware of any standardized dietary evaluation for children with ASD.

Although some standardized sensory evaluations exist [125-127], they cover sensory reactions in many domains of ADL and so, only a few items deal directly with feeding and eating. Hence, the greatest need in this area is an assessment that will fully cover the sensory domains associated with feeding and eating. Preliminary data are available from a study by Tessier [124], but now need to be subjected to a full psychometric evaluation. Common sensory characteristics should include color, texture, consistency, taste, smell, shape, size of a bite, and appearance which may have an influence on the variety of foods eaten. A study of how language and social skills affect feeding ability and the cognitive aspects that are involved for or against eating a certain food may be appropriate to include, since meals are social events. We are also still lacking self-report studies from individuals with ASD who may help us understand the challenges they associate with eating. An update of evaluation guidelines or even new guidelines for clinicians and researchers may well arise from the research suggested in this section and would immediately benefit the population we are trying to serve.

### 5.3. Treatment

A combination of treatment strategies, based on a holistic evaluation is, in our opinion, the most promising approach to intervention. Regardless which treatment approaches are chosen, intervention based on the contextual factors suggested by the ICF will facilitate the transfer to different environments, maintenance of the gains over time and hopefully further improvement. Early parent education may be critical to prevent the establishment of feeding problems but will need further study.

We have seen that careful manipulation of foods, the mealtime environment or the nutrient content of the diet may lead to some success in the acceptance of a new food, but one of the challenges remaining is that success with one food or domain does not necessarily generalize to other foods or domains. Such progress will probably only happen once children's cognitive decisions/intuitive reactions for acceptance/rejection of foods will be more clearly understood. We have suggested that one approach may be to study the more highly functioning children with ASD or Asperger's syndrome where some communication skills and insight are present. It may also be helpful to begin work by letting the child determine his food preference to facilitate co-operation.

Typically developing children also go through food jags, i.e. phases where they will only eat a limited variety of foods over an extended period of time. One of the authors (E.G.) recalls a parent telling her that his three-year-old son ate only pasta for three months and once he had his fill he 'returned' to eating the well balanced family diet. What this 'fill' was, the pa-

rent could not tell, but it upset the family considerably. Therefore, the definition of what is 'normal' or 'abnormal' at different stages of development has not yet been adequately defined. Despite the extensive use of behavioral and sensory integration techniques in the clinical environment, research using appropriate controls is still lacking to corroborate results from anecdotal reports [8]. Most of the behavioral approaches are 'patient' centered and so, may not take the whole family unit into account. This point has been particularly emphasized by Davies et al. [39]. With an activity that is so 'family/culture' centered as mealtimes are, a further challenge will be to integrate the family into our treatment approaches.

## 6. Conclusion

This literature review has illustrated how common feeding problems are in children with ASD. However, it is not yet definitively established whether these problems are different from the general pediatric population. There is no consensus yet on the terminology to be used to describe these problems, on evaluation methods, and use of different diagnostic classification systems. This makes comparisons of different studies very difficult at present. Some feeding problems are similar to the sensory problems described in the DC: 0-3R. This would justify the use of the sensory integration approach, as well as hierarchic desensitization in the treatment of children with ASD and feeding problems. Updating guidelines for diagnoses and clinical practice will contribute to knowledge translation from research to general practice. Preventive approaches, and teaching parents how to handle feeding problems also seems promising. Further research is needed to support these beginnings.

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