

Georgia State University

ScholarWorks @ Georgia State University

Public Health Capstone Projects

School of Public Health

Spring 5-10-2024

Assessment of a Multidisciplinary Feeding Program's Caregiver Education Material through the Application of Health Literacy Principles

Mary Thomas
Georgia State University

Follow this and additional works at: https://scholarworks.gsu.edu/iph_capstone

Recommended Citation

Thomas, Mary, "Assessment of a Multidisciplinary Feeding Program's Caregiver Education Material through the Application of Health Literacy Principles." , Georgia State University, 2024.
doi: <https://doi.org/10.57709/36948455>

This Capstone Project is brought to you for free and open access by the School of Public Health at ScholarWorks @ Georgia State University. It has been accepted for inclusion in Public Health Capstone Projects by an authorized administrator of ScholarWorks @ Georgia State University. For more information, please contact scholarworks@gsu.edu.

**ASSESSMENT OF A MULTIDISCIPLINARY FEEDING PROGRAM'S CAREGIVER
EDUCATION MATERIAL THROUGH THE APPLICATION OF HEALTH LITERACY
PRINCIPLES**

By

Mary Thomas

A Capstone Submitted to the Graduate Faculty of
Georgia State University in Partial Fulfillment of the
Requirements for the Degree of

Master of Public Health

In

Health Promotion and Behavior

Atlanta, Georgia 30302

Spring 2024

Author's Statement Page

In presenting this capstone as a partial fulfillment of the requirements for an advanced degree from Georgia State University, I agree that the Library of the University shall make it available for inspection and circulation in accordance with its regulations governing materials of this type. I agree that permission to quote from, to copy from, or to publish this thesis may be granted by the author or, in his/her absence, by the professor under whose direction it was written, or in his/her absence, by the Associate Dean, College of Health and Human Sciences. Such quoting, copying, or publishing must be solely for scholarly purposes and will not involve potential financial gain. It is understood that any copying from or publication of this dissertation which involves potential financial gain will not be allowed without written permission of the author.

Mary Thomas

APPROVAL PAGE

**ASSESSMENT OF A MULTIDISCIPLINARY FEEDING PROGRAM'S CAREGIVER
EDUCATION MATERIAL THROUGH THE APPLICATION OF HEALTH LITERACY
PRINCIPLES**

By

Mary Thomas

MPH, Health Promotion and Behavior

GEORGIA STATE UNIVERSITY

Approved:

Committee Chair

Committee Member

Committee Member

Date

Acknowledgements

I would like to extend my sincere gratitude and appreciation to Dr. Kimberley Freire, Dr. Iris Feinberg, and Dr. Sandhya Rajagopal for guiding and advising me throughout the process of developing my capstone. I am thankful that I had the opportunity to learn so much from each of them and for helping me grow within my own professional development.

To my family and friends, thank you for encouraging and cheering me on every step of the way. Thank you for shaping me to be the person that I am today.

To my colleagues in the Multidisciplinary Feeding Program, thank you for contributing to my personal and professional growth and for providing me with so many opportunities. Thank you for challenging me to step outside of my comfort zone and thank you for always believing in me.

To the autism, ARFID, and PFD community, I am with you every step of the way, and it is my aspiration to use the knowledge and expertise I have received to help create a safer, healthier, and more inclusive world for you all. You are my inspiration.

Table of Contents

Abstract.....	6
Chapter I- Background.....	7
1.1. Autism Spectrum Disorder (ASD).....	7
1.2 Avoidant/Restrictive Food Intake Disorder (ARFID).....	7-10
1.3 Pediatric Feeding Disorders (PFD).....	10-11
1.4 Health Literacy	11-13
1.5 Caregivers.....	13-14
Purpose of Capstone.....	14-15
Chapter II. Literature Review.....	15
2.1 Health Literacy.....	15-16
2.2 Limited Caregiver Health Literacy.....	16-17
2.3 Health Literacy Assessment Tools.....	17-19
2.4 Organizational Health Literacy.....	19-20
2.5 Parent-Mediated Interventions.....	20-21
2.6 Cultural and Linguistic Factors for Health Literacy.....	21
2.7 Caregiver Education Materials.....	21-23
Chapter III. Methods.....	23
3.1 Materials.....	23-25
3.2 Assessment Procedures using Clear Communication Index.....	25-27
3.3 Assessment Procedures for Patient Education Materials Assessment Tool....	27-29
Chapter IV. Results.....	29
4.1. Interpretation of Clear Communication Index Scores.....	29-31
4.2 Interpretation of Patient Education Materials Assessment Tool Scores.....	31-32
Chapter V. Discussion/Recommendations.....	32-36
Conclusion.....	35-36
References.....	37-43
Appendices.....	44-55

Abstract

The current capstone project examines the health literacy level of a Multidisciplinary Feeding Program's Day Treatment Information Sheet. This material is disseminated to caregivers of autistic children after completion of the child's feeding evaluation, which is conducted to determine eligibility for admission into the program. The current caregiver material was assessed using the CDC's Clear Communication Index and Patient Education Measurement Assessment Tool, which are health literacy tools used to measure the understandability, communication level, and actionability of caregiver materials in written communication methods. After the Day Treatment Information Sheet was assessed and a score from each tool was produced, the scores were interpreted to determine how health literate the material was. The results based on the score suggest that the material has areas of needed improvement to be more health literate for families in the feeding program. There are various components of the material that can be modified to enhance communication between caregivers and providers.

Keywords: Autism Spectrum Disorder, Avoidant/Restrictive Food Intake Disorder, Pediatric Feeding Disorders, Health Literacy, Caregivers, Clear Communication Index, Patient Education Material Assessment Tool

Chapter I. Background

1.1 Autism Spectrum Disorder (ASD)

The CDC (2022) defines autism as a disorder that affects the developmental progression of an individual as it relates to their “social, communication, and behavioral challenges” and abilities. Indicators of autism may appear differently among individuals such as repetitive behaviors, challenges in social functioning, and narrow interests (Lord et al., 2020). Signs of autism may appear early in a child’s life, as young as one year. Healthcare professionals who specialize in autism diagnostics and assessments, however, typically diagnose children around the age of two, which is when young children begin to reach major milestones in their developmental trajectory (CDC, 2022). As a result of advancements in technology and enhanced assessment tools, autism diagnoses are on the rise in the United States and around the world. In the United States, the prevalence of autism is currently 1 in 36 among children and is often diagnosed more in boys than girls (CDC, 2022). Although there is not a cure or one specific cause for autism, biological and environmental factors may increase one’s risk of being diagnosed with ASD. Biological factors such as genetic conditions, other family members in one’s blood line with ASD, complications at birth, and parents having children at an older age can increase one’s risk of developing ASD (CDC, 2022). Similarly, as it relates to severe food refusal/selectivity, restrictions in one’s diet and sensory challenges around foods have been indicators of ASD (Bourne et al., 2021).

1.2 Avoidant/Restrictive Food Intake Disorder (ARFID)

The Multidisciplinary Feeding Program at Children’s Healthcare of Atlanta implements an evidence-based treatment approach to treating severe food refusal for conditions such as Avoidant/Restrictive Food Intake Disorder (ARFID) and Pediatric Feeding Disorders (Volkert et

al., 2021). The Intensive Multidisciplinary feeding model of the current intervention is evidence-based because experts in the field and the study supports its effectiveness in treating severe food refusal/selectivity among children (Volkert et al., 2021). The current feeding interventions follows a behavior analytic approach through direct services provided and supervised by a licensed psychologist and/or board-certified behavior analyst. According to Brigham et al. (2018), an individual with ARFID may have little to no variety of foods consumed, have sensitivities based on different sensory characteristics of food, or even worry about choking or vomiting from the intake of food. Additionally, due to the psychosocial effects that ensue with ARFID, this disorder is listed in the Diagnostic and Statistical Manual of Mental Disorders- 5th Edition (DSM-5) and consists of various diagnostic criteria that psychologists and doctors use to assess the condition. AFRID is distinct from general “picky eating.” An individual may present as a “picky eater,” if they eat a limited variety of foods from the food groups without severe health consequences. In contrast, ARFID manifests in a severe food refusal/selectivity that may lead to medical and nutritional issues such as weight loss and reliance on supplements (Zickgraf et al., 2016). Similar to Zickgraf et al. (2016), Brigham et al. (2018) explained that due to the impacts of ARFID, an individual may experience weight loss, malnutrition, formula/supplement dependence, or feeding tube dependence. Although there currently is not a clear understanding of the etiology of ARFID, it is possible there may be external and genetic/biological factors that may influence an individual's ARFID diagnosis.

From a biological perspective, health conditions such as gastrointestinal issues, eosinophilic esophagitis, and swallow difficulties can all contribute to the development of ARFID (Brigham et al., 2018). However, there is also debate about whether there is a genetic component to an individual’s likelihood of being diagnosed with ARFID. In a twin study of

children between the ages of 6 and 12 that examined the phenotype for ARFID; using the ARFID diagnostic criteria, the researchers determined that 79% of participants carried the genetic trait for ARFID (Dinkler et al., 2023). This finding provides strong evidence of a heritable component of ARFID.

Additionally, the overarching condition of ARFID can be further broken down into sub-criteria. During assessment procedures, an individual will receive a sub-diagnosis of ARFID that represent related health consequences including A1 (“weight loss or failure to gain weight/grow”), A2 (“nutritional deficiency”), A3 (dependence on supplements/enteral nutrition), and A4 (interference with psychosocial functioning”); (Dinkler et al., 2023). These sub-criterion diagnoses can sometimes occur simultaneously and will help interventionists determine the most appropriate treatment plan for the individual. In the aforementioned twin study, Dinkler et al. (2023) found that of the child participants in their study, 67.2% fell under the A1 criterion, 50.6% were diagnosed with A4, 0.6% with A2, and 8.5% with A3 criterion. These findings demonstrate the varying degrees of ARFID that an individual can be diagnosed with.

Along with the biological and psychological characterizations of ARFID, some researchers have examined whether there is a correlation between autism and ARFID. Individuals with autism often present with repetitive behaviors, limited social skills, and sensitivities to sensory aspects, which may ultimately impact their food intake (Bourne et al., 2022). For instance, a child who has a preference to a specific taste or texture of food may exclusively consume that food only because it has been routinely consumed without any harm or discomfort, and it is a food they are familiar with. The incidence of autism brings into question whether the rate of ARFID is also increasing, making much more crucial for increased access to feeding interventions. Because more people are being diagnosed with ARFID, it becomes crucial

for feeding interventions such as the one implemented by the Multidisciplinary Feeding Program, to be readily understood by patients and their families.

1.3 Pediatric Feeding Disorders (PFD)

In conjunction with ARFID, pediatric feeding disorder (PFD) is another food-intake related medical issue that is increasingly recognized within various disciplines. The increased understanding of PFD has been facilitated by its inclusion in the International Classification of Diseases on October 1st, 2021 (Feeding Matters, 2022). PFD is defined as oral feeding challenges that may impact a child's medical, nutritional, skills, and/or psychosocial wellbeing (Goday et al., 2018). Professionals who specialize in the areas of behavior, medicine, nutrition, and skill building will closely examine a child's health and abilities to determine if and how their feeding difficulties are impacting their wellbeing. A retrospective cohort study conducted by Kovacic et al. (2020), examined the prevalence of PFD among children insured by public and private insurers and determined that the prevalence rate among children ranged from 1 in 23 to 1 in 37. This further demonstrates the commonality of PFD and the multiple ways it can interfere with a child's day-to-day life such as through their school, emotional, and social functioning (Simione et al., 2023). While ARFID and PFD are food-related disorders, it is important to note that these are different from eating disorders because distorted body image is not a factor in determining an ARFID or PFD diagnosis (Goday et al., 2019). Although ARFID and PFD have similarities and differences, the diagnostic criterion for PFD varies.

Similar to the diagnostic criteria for ARFID, PFD also has indicators that help determine if a child falls under this branch of feeding difficulties. Through a consensus definition, Goday et al. (2018) states that in order for a child to be diagnosed with PFD, they must exhibit at least one abnormal pattern of medical, nutritional, feeding skill, or psychosocial needs that impact their

feeding experiences and must be present for approximately two weeks. When a child's oral intake of food does not match up to their age and development, such as complete dependence on formula supplements (Pediasure, Boost) at the age of 6, this could also be an indicator of PFD in a child. Additionally, Goday et al. (2018) determined that a child can also present with acute (less than three months) and chronic (three months or longer) PFD, depending on the severity of their food refusal and feeding difficulties. Ultimately, families with children with ARFID and/or PFD face various barriers and stressors surrounding mealtime and food. These challenges make it much more important for families to receive enough support and resources to improve the quality of their child's and families' lives.

1.4 Health Literacy

Health literacy is made up of individual/personal and organizational attributes. According to the CDC (2023), individual or personal health literacy is defined as how well a person is able to locate and comprehend health information in order to act on it. In contrast, organizational health literacy determines how well an organization is able to assist individuals in locating and comprehending health information to act on it in an equitable manner (CDC, 2023). Based on these definitions, there is a relationship between individual and organizational health literacy in that both the individual and an organization have important roles in ensuring that health information is presented in the appropriate way and is being used and understood. Health literacy is critical for patients/caregivers to be able to understand and act on health information presented to them. Many health education materials are produced at reading and understandability levels that are higher than average level (Mayer and Villaire, 2009). According to Baker (2006), one's ability to understand health information materials helps determine how well an individual retains information and implements instructions to make health-informed

decisions. A person's individual capacities can also influence their level of health literacy through reading fluency and prior knowledge (Baker, 2006). Reading fluency examines how an individual comprehends written information and their intake of new information, while prior knowledge assesses the information an individual already knew about a topic prior to written and oral communication methods with a professional (Baker, 2006). This may also include any familiar words the individual can recognize from their prior knowledge (Baker, 2006).

When discussing the importance of health literacy, various modes of communication should be considered. Oral or verbal communication is one method used to engage in conversation and exchange information from one person to another. According to Figure 2 of the study conducted by Harrington and Valerio (2014), verbal exchange health literacy involves the ability to listen and speak to understand and implement informed health decision behaviors. Harrington and Valerio (2014) emphasized the importance of maintaining appropriate patient-provider communication by making certain that individuals have an active role in the decision-making process for their health. For instance, if a patient is prescribed medication to treat a condition with specific instructions, to ensure their health and safety, the individual can have a verbal exchange with the provider by listening to their directions, and then the provider may ask the patient if they have any questions. This back-and-forth exchange can also help relay to the provider whether the information being presented is being understood by the patient and also determine if the provider is understanding the patient's thought process.

Written communication is another aspect of health literacy and a way in which health information is disseminated to the public. Mayer and Villaire (2009) discussed the importance of producing patient written materials that are at or between the 3rd grade and 5th grade reading level. A report by Nielsen-Bohlman et al. (2004) determined that written materials for patients

are often produced at a high school reading level. The Program for the International Assessment of Adult Competencies (PIAAC) examines “literacy”, “numeracy”, and “digital problem solving” to determine how and if different skills and backgrounds impact literacy levels (U.S. Department of Education, 2016). The PIAAC assessed the U.S. and international literacy score based on a scale from 0 to 500, which measures proficiency based on literacy and proficiency, and found that the average literacy score in the U.S. was 272 (U.S. Department of Education, 2016). This equates to an approximate 7th or 8th grade reading level for the average American (Zauderer, 2023). Information that is critical to a patient’s understanding of their health, but is not appropriately written based on their needs, can lead to detrimental impacts on the individual’s health and wellbeing. When developing written materials, it is suggested that plain, everyday language is used throughout the material (Mayer and Villaire, 2009). Medical terminology consists of language and jargon that is at higher reading and understandability levels, which adds to the complexities of patient education materials. These materials are intended to provide patients, families, and caregivers with knowledge about a particular issue including instructions, which justifies the importance of ensuring materials are written following health literacy guidelines.

1.5 Caregivers

Johns Hopkins Medicine (2022) defines a caregiver as an individual who helps a sick or disabled person or someone who needs additional assistance with various forms of care; they may be family members, friends, or unrelated caretakers. There are formal and informal caregivers who may or may not receive payments for the care they are providing (Johns Hopkins Medicine, 2022). Additionally, caregivers hold a critical role in the decision-making process for an individual’s treatment plans. According to Given et al. (2008), it is crucial for caregivers to be

able to understand procedures and instructions given by healthcare providers to care for a patient safely and effectively. Further, Costarelli et al. (2022) found a correlation between parental feeding practices, health literacy, and nutrition literacy, which indicated a positive relationship between health and nutrition literacy and the different methods of feeding parents used. In order for a caregiver to make informed decisions and implement a healthy lifestyle for a child's nutritional intake, it is crucial for them to understand, interpret, and practice the instructions provided by a health professional. Incorporating health literacy guidelines of plain language and clear communication into patient education and treatment plans -helps caregivers understand instructions and give the right level of care.

Purpose of Capstone

This capstone project examined the need for health literacy principles and guidelines to be incorporated into the development and enhancement of caregiver education materials in a healthcare setting. Specifically, the project assessed the health literacy level of the Children's Healthcare of Atlanta's Multidisciplinary Feeding Program's Day Treatment caregiver information sheet that families receive at the facility after completion of the child's feeding assessment and evaluation with a multidisciplinary team of professionals. Through the assessment, the feeding evaluation team will determine if the child is eligible to be admitted into the program for Day Treatment feeding interventions, which follows a more intensive interdisciplinary intervention model. The education sheet provides caregivers with a significant amount of information that is crucial for their understanding of the structure of the program. Through the use of health literacy tools such as the CDC's Clear Communication Index and the Patient Education Materials Assessment Tool, these methods will aid in improving the health literate and clear communication quality and effectiveness of written communication materials

that are disseminated to caregivers. Ultimately, this capstone project will seek to answer the following questions regarding the current topic:

- After assessment of the feeding caregiver education material, do the scores obtained from the CCI and PEMAT indicate low or high health literacy?
- What changes could improve materials based on the CCI and PEMAT?

These questions address a gap in the literature in that health literacy tools such as the CCI and PEMAT have not widely used practices in developing and improving education materials that are for families of children with feeding disorders. The aim of the current project is to assess the extent to which written communication documents from a feeding clinic adhere to health literacy principles/guidelines and to recommend changes. Recommendations are intended to increase caregiver families' ability to understand the complex nature of patient health care.

Chapter II. Literature Review

2.1 Health Literacy

The CDC (2023) defines individual health literacy as finding, understanding and utilizing health information to make informed decisions regarding the health of an individual. For individuals with limited health literacy, it may be challenging for them to interpret health information provided by a healthcare practitioner, which could be detrimental to the health of an individual if a treatment plan is not appropriately followed. Additionally, there are four levels of literacy including “below basic,” “basic,” “intermediate,” “and proficient. Kutner et al. (2006) describes below basic as understanding written documents, basic as reading and comprehending materials that are minimal in verbiage, intermediate as identifying understanding more complicated materials, and proficient as being able to engage in literacy related tasks that present in more complicated ways. According to Kutner et al. (2006), 14% of adults fell under the

“Below Basic” health literacy level. Health literacy is a universal precaution in that any individual can have low health literacy at any moment depending on the context and situation. This universal precaution of health literacy helps ensure that making health information less complex in nature may set patients up for success in understanding the material they are presented with (DeWalt et al., 2016). Ultimately, a greater awareness and understanding of health literacy is critical for healthcare organizations and practitioners to provide caregivers and patients with the most effective methods of communicating education/instructional materials.

2.2 Limited Caregiver Health Literacy

There is an understanding that limited caregiver health literacy may lead to negative impacts on a child’s health and wellbeing. According to the Newest Vital Sign’s assessment that examines health literacy, a score of 0 to 4 obtained signifies ‘low health literacy’ (Morrison et al., 2014). In a cross-sectional study involving caregivers and child hospital visits, 55% of the caregivers had limited health literacy and these individuals were also more likely to bring their child to the emergency department for health conditions that were not life threatening (Morrison et al., 2014). A caregiver’s limited health literacy and understanding of their child’s health condition can be detrimental to the child’s health and safety. One study examined the correlation between limited caregiver health literacy and asthma in children. The findings demonstrated that caregivers who had limited health literacy knew less general information about asthma and how to approach treatment compared to caregivers with advanced health literacy skills (Shone et al., 2009). If a condition such as asthma goes mistreated, this could lead to life threatening consequences for any individual, which further demonstrates the need for increased written materials using health literacy guidelines such as clear communication, elimination of jargon, and lower reading level that meet the needs of caregivers for them to increase their

understanding of various health outcomes.

2.3 Health Literacy Assessment Tools

Increased knowledge and awareness of health literacy issues has prompted individuals and organizations to develop assessment tools to measure the level of health literacy of patient education materials. One of these assessments was developed by the CDC entitled The Clear Communication Index. The Index was created to improve health literacy and foster the appropriate method of communication with the public through written health materials (CDC CCI User Guide, 2019). The criteria that the Index assesses are a material's main message and call to action, language/use of plain language, information design, state of the science, behavioral recommendations, numbers, and risk (CDC CCI User Guide, 2019). According to the CDC's CCI User Guide (2019), the main message is a few sentences, at the very beginning of the material, and includes crucial information about the main idea. The material should be written in active voice and plain language and should include lists/bullet points and headings. The behavioral recommendations section should provide the audience with suggestions on how to take care of their health and wellbeing. When numbers are used, the values should be simple and not require the audience to calculate any math. Lastly, risk assesses the risks and benefits involved in engaging in a recommended behavior (CDC CCI User Guide, 2019).

Reviewers using the Index can examine and score written health materials to determine whether they are written using health literate guidelines (CDC, 2023). A study by Porter et al. (2019) assessed education materials with the Index for a behavior intervention and concluded that health literacy tools such as this one are a crucial part of encouraging positive behavior change in patients and individuals. The CCI is important because it helps determine how understandable the material is for patients/caregivers. This tool also can aid in providing health

professionals and organizations with feedback on how to improve their written materials.

Another measurement tool is the Patient Education Materials Assessment Tool (PEMAT). The PEMAT examines how understandable patient education documents are and whether patients would be able to take action based on the instructions the education materials provide (Shoemaker et al., 2014). The PEMAT User Guide, developed by Shoemaker et al. (2014) -assesses word choice and style by determining whether plain language was used in the material, including numbers that are simple to understand, use of visual aids (images, boxes, arrows, bullets etc.), and appropriate organization of information with headings and small chunks of information. The rating scale is 0 for 'disagree,' 1 for 'agree,' and N/A if the material does not include a specific item (Shoemaker et al., 2014). Unaka et al. (2019) utilized PEMAT to assess how understandable the discharge documents (diagnosis, names of medications, upcoming appointments, information on reason for visit) were for caregivers at Cincinnati Children's Hospital Medical Center. Using PEMAT, the researchers calculated a median score of 73% for understandability, which indicates that some portions of the discharge paperwork may be difficult to understand (Shoemaker et al., 2014). Although a score of 70% for PEMAT is considered low for understandability, 73% is close to this threshold, which demonstrates lower health literacy of the discharge documents.

In addition to the CCI and PEMAT assessment tools, the teach-back method is an implementation technique within health literacy that can be implemented to provide effective verbal communication to patients. According to Talevski et al. (2020), the teach-back method occurs when a healthcare professional communicates health information and/or instructions to a patient and the patient is asked to confirm what the provider said. Likewise, this helps the healthcare professional determine whether the information was interpreted correctly and provide

the patient with corrective feedback, if needed. When a patient visits the doctor's office or gets admitted at the hospital, they are often provided with a myriad of information filled with a significant amount of medical jargon in patient instructions. Incorrectly misinterpreting health-related information can be detrimental and potentially life threatening to one's health, which further demonstrates how valuable teach-back implementation may be within a health care setting. Furthermore, the literature by Talevski et al. (2020) stated that teach-back is a cost-efficient intervention that has demonstrated effectiveness for practical use among patients and healthcare providers.

Teach-back method is a communication technique that can be utilized in pediatrics and with parents/caregivers. For children who are under the legal age of consent, parents or caregivers are typically who communicate with healthcare providers. Health literacy principles are crucial for effective parent-provider communication. Badaczewski et al. (2017) measured health literacy among parents using an assessment tool and found that teach-back provided greater levels of "patient-centered communication." The findings by Badaczewski et al. (2017) make evident that teach-back could be a useful method through verbal communication to ensure that families understand general information regarding the model of the feeding program.

2.4 Organizational Health Literacy

According to the CDC (2023), organizational health literacy is how organizations provide patients with the tools and resources to comprehend information regarding their health and for them to be able to make informed health decisions. Because Children's Healthcare of Atlanta's- Multidisciplinary Feeding Program serves children, caregivers often make health decisions for the program's patients. In order for caregivers to demonstrate their literacy skills pertaining to health education materials, written materials should be provided that enable them to

‘access,’ ‘understand,’ and ‘maintain communication’ with the various professionals and individuals involved in the patient’s health care (Yuen et al., 2018). When a caregiver is designated to provide health-related care to an individual and has the authority to make decisions regarding the individual’s treatment and care, their limited understandability can put the patient’s health and safety at risk. A study conducted by Wittenberg et al. (2017) evaluated the health literacy level of cancer education written materials for caregivers and found that only a handful of resources were written at appropriate reading levels, which was considered to be the sixth-grade level. In addition, the researchers used readability tests and PEMAT tool to evaluate the materials (Wittenberg et al., 2017). This demonstrates that healthcare organizations must do more and hold an active role in communicating clear and effective healthcare information to the patients and families they serve.

2.5 Parent-Mediated Interventions

Parents/caregivers hold a vital role in their child’s treatment trajectory for ARFID and/or PFD, especially for autism. According to Bearss et al. (2015), parent training can be conducted in various forms such as psychoeducation and care coordination in the form of support for the family, as well as provide greater knowledge to parents. Parent-mediated interventions such as the feeding program equips parents with the skills and training to work through and manage refusal behaviors a child may exhibit (Bearss et al., 2015). Through parent-mediated interventions, parents are crucial for implementing change, the intervention is intended to help the child (Bearss et al., 2015). Similarly, these components of parent-mediated interventions are incorporated into the Multidisciplinary Feeding Program’s approach in training and educating the caregivers on a child’s feeding protocols. After parents have completed their feeding training, they are asked to conduct protocol sessions at home, replicating how it is implemented in the

clinic setting (Bearss et al., 2015). During this time, caregivers also receive packets of written information on how to prepare the clinic foods at home. It is important to consider health literacy in these education documents to ensure that the caregiver understands what and how to implement the feeding protocols at home. This ultimately benefits the child in that they would receive consistent care both at home and in the clinic.

2.6 Cultural and Linguistic Factors for Health Literacy

Additionally, there are multiple culturally and linguistically related barriers that contribute to limited health literacy and caregivers' ability to understand health education materials. According to Andrulis and Brach (2007), diverse populations of people who also have limited English proficiency are often at risk of receiving inadequate health care due to limited understandability and communication skills. A 2003 report from the National Assessment of Adult Literacy by Kutner et al. (2006) determined that bilingual/multilingual individuals had lower rates of health literacy compared to those whose primary language was English. Schaffler et al. (2018) conducted a study by seeking feedback from a diverse population of caregivers and patients to determine the most effective ways to improve written health education materials. A few of the recommendations that caregivers suggested were to receive the documents in their cultural language, access information in the simplest way, and adjust the physical appearance of the materials by separating the information into sections (Schaffler et al., 2018).

2.7 Caregiver Education Materials

Caregivers play a crucial role in their child's treatment progression when implementing interventions to treat feeding disorders such as the one conducted by the Multidisciplinary Feeding Program. Johnson et al. (2019) conducted a randomized control trial where researchers implemented a parent training manual that provided caregivers with education on managing and

working through their child's feeding behaviors. The caregivers reported that they felt more prepared and knowledgeable about managing their child's feeding difficulties after the parent training than before (Johnson et al., 2019). The manual included information for the therapist to discuss with the parent, videos that demonstrated the appropriate methods of managing problem and/or refusal behaviors surrounding feeding sessions, and written handouts and information documents written at a sixth grade reading level as supplemental educational materials for the caregivers (Johnson et al., 2019).

Another intervention, the Autism MEAL Plan (Managing Eating Aversions and Limited variety) model developed by Sharp et al. (2014), consists of caregiver education materials for parents to learn how to hold an active role in managing their child's mealtime behaviors. During the education sessions, the caregivers received various written communication documents and worksheets that outlined information on "Structuring meals and monitoring behaviors," "Ways to increase appropriate behavior," "Effective communication" and several more topics (Sharp et al., 2014). According to Sharp et al. (2014), developing a tool to treat feeding problems among autistic individuals at a community level was a central reason behind the creation of the Autism MEAL Plan intervention. After completion of the curriculum, caregiver participants completed a satisfaction questionnaire at the end of the intervention where they expressed pleasure with the MEAL Plan strategy, and they also provided areas of needed improvement such as having the child be physically present during the training sessions (Sharp et al., 2014). When improving education materials, it is important to consider feedback from caregivers/the audience because this will help determine the best way to meet the needs of the individuals who are seeking to understand the information presented in the material.

Chapter III. Methods

For the purpose of this capstone, there were no participants and human subjects were not involved in the project. Therefore, IRB approval was not needed. Permission was received from the Multidisciplinary Feeding Program to access and assess the caregiver information documents. Permission was also granted to provide recommendations on how to improve the documents and to illustrate a developed section of the material.

3.1 Materials

The score sheet for the Clear Communication Index consists of four parts including “Part A: Core,” “Part B: Behavioral Recommendations,” “Part C: Numbers,” and “Part D: Risk.” Each of the four parts asks a series of questions about the material and each section produces its own score (see Appendix for the full list of score sheet questions). In Part A, the questions focused on topics such as the ‘Main Message and Call to Action,’ ‘Language,’ ‘Information Design,’ and ‘State of the Science’ of the caregiver document. Part B referred to the presence or absence of behavioral recommendations, as well as specific instructions on how to act on the behavior. Part C assessed whether numbers were included in the material. Lastly, Part D examined if risk and benefits were included in the document. The questions on the Clear Communication Index Score Sheet were ‘yes’ or ‘no’ questions and the answer ‘yes’ was associated with a score of 1 and the answer ‘no’ reflected a score of 0. Each of these components of the Clear Communication Index are essential to determine the health literacy level of the current caregiver education material to be assessed.

Furthermore, the Patient Education Material Assessment Tool is divided into the “Understandability” and “Actionability” sections. The two sections consist of a series of sub-questions that pertain to various topics. Within “Understandability,” the items concentrated on the material’s ‘Content,’ ‘Word Choice & Style,’ ‘Use of Numbers,’ ‘Organization,’ ‘Layout &

Design,’ and ‘Use of Visual Aids.’ In addition, the items under “Actionability” examined clear actions that the audience could take, simple steps, tangible tools, explanation on how to perform calculations, if necessary, explanation of charts/graphs, and the inclusion of visual aids throughout the material. The response options for PEMAT were ‘disagree’, which was associated with a rating score of 0, ‘agree’ reflected a score of 1, or an option of ‘N/A’ if the question was not applicable to the material.

The current caregiver education material developed by the Multidisciplinary Feeding Program is a written document that is provided to caregivers after completion of the child’s feeding evaluation for ARFID/PFD. The feeding evaluation team will deliver this four-page document to the family and provide an oral explanation of the information that is included in the material. This document is entitled “Multidisciplinary Feeding Program: Day Treatment Information Sheet,” and includes multiple section headings about the Day Treatment program and what to expect upon admission into the program. The first section is titled "Program Overview” and provides a short introduction into the program including information about the structure of the meals, who conducts meals, disciplines involved, caregiver involvement, and texture of food that will be used for treatment. The next section focuses on “Caregiver Involvement” and the role of caregivers during a child’s admission in Day Treatment. ‘Schedule’ is the third part and includes a visual on two different meal schedules that a child may be on. Likewise, this portion of the document also contains information on what time families should arrive for the first meal of the day, as well as various breaks that are a part of the child’s schedule. Additionally, “Patient Success and Outcomes” is the section that presents data that demonstrates the effectiveness and outcomes achieved from past patients following completion of the current feeding intervention.

The remaining sections of the caregiver information material provide the families with information on navigating through the logistical components of the Day Treatment program. The section on “Transportation and Lodging” gives an overview of the role that the feeding program’s social worker holds in working through any barriers that may hinder the family’s ability to complete their child’s admission. The social worker’s name and contact information is also listed in the document. This section is followed by information on “School and Employment,” which includes crucial details on documentation needed for school purposes, education services for patients offered by counties, and the Family and Medical Leave Act (FMLA) for parents. Moreover, the portion on “Coverage for Treatment” briefly discusses insurance coverage and the point of contact in case of a change in insurance plans. In addition, the “What Happens Next” portion gives the families insight on utilizing MyChart to communicate information to the feeding evaluation team and being placed on the waitlist for admission into the program. Lastly, “After Day Treatment” is the final section of the document, which informs the caregivers about follow-up services with the program’s outpatient clinic after the child completes the Day Treatment program. The contact information for the feeding department is also included at the end of this document.

3.2 Assessment Procedure using the Clear Communication Index

To assess the Multidisciplinary Feeding Program’s feeding evaluation caregiver information document, the document and CCI score sheet were both viewed in a side-by-side layout on the computer. The data were collected by answering each question from the score sheet as it relates to the caregiver information document. The index has a total of 20 questions (Table 1). A ‘yes’ or ‘no’ answer was selected for each question. After a response was recorded for each question, the end of each part produced a score, which was generated by adding up the ones and

zeros from each question. “Part A: Core” produced a score out of 11 possible points. “Part B: Behavior Recommendations” was out of 3 points. For this particular section, if the document did not consist of any behavior recommendations, directions say to skip to “Part C: Numbers.” Likewise, this section was also out of 3 points however, if the document did not include at least one number, the scorer is advised to move to the next part. “Part D: Risk” is the final part of the CCI, which in addition to ‘yes’ or ‘no’ responses also provide the option for “Not Applicable.” This section can produce a score out of 3. If risk does not pertain to the material, the scorer should skip this part and move on to “Calculate the Score.” After each section is completed, the final step is to calculate the final score of the material.

The CCI score sheet provided step-by-step instructions on how to calculate the final score of a material for health literacy. The first step was to place the number of points the material received in total in the numerator. Next, the denominator included the possible number of points the document could have earned. Finally, the last step was to divide the numerator and denominator, then multiply this number by 100. The score sheet provided a guide on the value range that would consider a document to be understandable, which resulted in a score of 90 or above. However, a score of 89 or lower indicated that a material had areas of needed improvement. According to the CCI score sheet, the user guide for this health literacy tool was utilized to determine how the Multidisciplinary Feeding Program’s caregiver education material can be enhanced to account for health literacy.

Table 1.

Part A: Core	Score options
1. Does the material contain one main message statement?	Yes= 1 No= 0
2. Is the main message at the top, beginning, or front of the material?	Yes= 1 No= 0
3. Is the main message emphasized with visual cues?	Yes= 1 No= 0
	Yes= 1 No= 0

4. Does the material contain at least one visual that conveys or supports the main message?			
5. Does the material include one or more calls to action for the primary audience?	Yes= 1	No= 0	
6. Does the main message and the call to action use the active voice?	Yes= 1	No= 0	
7. Does the material always use words the primary audience uses?	Yes= 1	No= 0	
8. Does the material use bulleted or numbered lists?	Yes= 1	No= 0	
9. Is the material organized in chunks with headings?	Yes= 1	No= 0	
10. Is the most important information the primary audience needs summarized in the first paragraph or section?	Yes= 1	No= 0	
11. Does the material explain what authoritative sources, such as subject matter experts and agency spokesperson, know and don't know about the topic?	Yes= 1	No= 0	
Part B: Behavioral Recommendations	Score options		
12. Does the material include one or more behavioral recommendations for the primary audience? <i>If no, STOP here and don't score Part B</i>	Yes= 1		
13. Does the material explain why the behavioral recommendation(s) is important to the primary audience?	Yes= 1	No= 0	
14. Does the behavioral recommendation(s) include specific directions about how to perform the behavior?	Yes= 1	No= 0	
Part C: Numbers	Score options		
15. Does the material always present numbers the primary audience uses?	Yes= 1	No= 0	
16. Does the material always explain what the numbers mean?	Yes= 1	No= 0	
17. Does the audience have to conduct mathematical calculations?	Yes= 1	No= 0	
Part D: Risk	Score options		
18. Does the material explain the nature of the risk?	Yes= 1	No= 0	
19. Does the material address both the risks and benefits of the recommended behaviors?	Yes= 1	No= 0	NA
20. If the material uses numeric probability to describe risk, is the probability also explained with words or a visual?	Yes= 1	No= 0	NA

3.3 Assessment Procedure for the Patient Education Material Assessment Tool (PEMAT)

The PEMAT measurement follows a similar procedure in determining the health literacy level of written patient education documents. The first set of statements on the PEMAT score sheet focuses on understandability, while the second portion assessed the actionability of the

material and consists of nineteen statements. For responses to the statements, the user can choose 'Disagree' with a score of zero, 'Agree' which is associated with one, or 'N/A' if the if the statement does not apply to the material. After answering each question, separate scores were produced for the understandability and actionability of the Multidisciplinary Feeding Program's caregiver information document. The section on understandability includes statements that focused on topics such as 'Content,' 'Word Choice & Style,' 'Use of Number,' 'Organization,' 'Layout & Design,' and 'Use of Visual Aids.' Once responses are selected for each statement, the total number of points are added up, and this value is the numerator. Next, the total possible number of points will be added together, which is the denominator. After dividing the numerator and denominator, this number will be multiplied by 100, to produce a percentage for the understandability score.

The actionability section consists of seven questions with similar answer choices found within understandability. After the user rates each of the response options based on the statements provided, to calculate the actionability score, the user adds up the total points achieved through the ratings and divides this value by the total possible points. This value is then multiplied by 100, which will produce the actionability score of the caregiver material. The PEMAT provides the value range of scores that are considered understandable and/or actionable, which will help determine whether the material is an effective resource for patients/caregivers to make informed decisions regarding an individual's health needs.

After assessing the Multidisciplinary Feeding Program's caregiver information sheet using the CCI and PEMAT tools, each assessment feature produced a score that helped determine the health literacy level of the material. While the CDC's Clear Communication Index score sheet automatically populated the final score of the material, the PEMAT score for the

information sheet was calculated by the user. After the scores were produced using each assessment tool, the questions were further examined to determine the ways in which the caregiver material could be improved, whether it be through the inclusion of more visuals or plain language.

Chapter IV. Results

4.1 Interpretation of CCI Scores

The sub-scores from each part and the final score from the score sheet of the CCI were examined to determine the key components of the Day Treatment Information Sheet that would need to be enhanced. (See Appendix A and Table 2 for the CCI Score Sheet) ‘Part A: Core’ produced a score of 9 out of 11 total points. The questions that received a ‘no’ or ‘zero’ response were, “Does the material always use words the primary audience uses?” and “Does the material explain what authoritative sources, such as the subject matter experts and agency spokespersons, know and don’t know about the topic?” Therefore, these questions received a score of zero because the material occasionally uses the passive voice such as ‘will be fed’, and the document did not include information on any potential unknowns regarding the topic. In one example, the material included a jargon term such as “medical necessity,” which should not be used in caregiver education materials because these words are not a part of everyday vocabulary.

Additionally, Part B of the CCI score sheet focused on the ‘Behavioral Recommendation’ presented through the material, producing a score of 2 out of 3 total points. The current material incorporated a behavioral recommendation for the audience and general information on conducting the recommendation. However, the material did not include an explanation on the importance of the behavioral recommendation. Furthermore, Part C assessed the use of numbers in the material, which resulted in a score of 3 out of 3. To further breakdown the answer choices,

a few numbers were presented in the material and were simple values the audience knows how to use. In addition, the audience did not have to conduct any mathematical calculations to understand the material. Similarly, the numbers mentioned in the material always had a brief explanation about the meaning of the value(s). The score from this part was the only section of the CCI assessment that received 100%, which demonstrates that the numbers included were appropriately presented for the understandability of the primary audience.

The final section of the CCI score sheet evaluated any information regarding risk in the material. Because the Day Treatment information sheet did not include material about the topic of risk, this section of the score sheet was skipped, as directed by the CDC's instructions. Therefore, the next step was to calculate the final score of the material. The total number of points the material actually earned was 14 and the total points the caregiver information sheet could have earned was 17. To calculate the final score, 14 and 17 are divided, then multiplied by 100. This produces a final score of 82.4 for communication of the Multidisciplinary Feeding Program's Day Treatment Information Sheet. According to the CDC's interpretation of the CCI's score sheet, a score of 82.4 falls under the '89 or below' range, which indicates that the material needs some revisions in order to improve the quality and communication style to the primary audience. To make these revisions, the CDC recommends using the CCI User Guide to assist with the necessary improvements to the material.

Table 2.

Clear Communication Index Section	Score	
Part A: Core	9 out of 11	
Part B: Behavioral Recommendations	2 out of 3	
Part C: Numbers	3 out of 3	
Part D: Risk	0 out of 3	
Total	14 (points actually earned)	82.4

	/ 17 (points could have earned)	
--	---------------------------------	--

4.2 Interpretations of the PEMAT Scores

Similar to how the CCI scores were calculated, the PEMAT scores were populated for the material's understandability and actionability. Each of these two features produced its own scores. (See Appendix B for the PEMAT Score Sheet). The understandability section of PEMAT received a score of 14 total points out of 19 possible points. The items of the PEMAT topics that received a zero or 'disagree' response option were related to the use of common language, active voice, and visual aids for more simple understanding within the material. These response options were selected for the current material because there were a few complex word choices, passive voice statements, and limited visuals. The final calculated score for the understandability of the Day Treatment Information Sheet was 73.7%, which indicates a need for areas of improvement within the material. This can be determined by further analyzing the items of understandability that received a 'zero' response.

Furthermore, the actionability scores were assessed separately from understandability. Out of the 7 question items displayed, one of them was not applicable, which was the statement that questioned whether the information sheet included procedures on how to calculate mathematical equations. Because the Day Treatment Information Sheet does not include calculations the audience has to perform, this component would not be applicable. Additionally, the statements that focused on whether the material provides more information on how to use the visuals, charts, and tables received a score of zero, as this additional information was not present in the material, even though there were tables and visuals. The actionability section received a score of 4 total points out of 6 possible points, producing a final actionability score of 66.67%.

This suggests that the actionability aspect of the caregiver material needs improvement and the PEMAT user guide can be utilized as a tool to aid in making any necessary revisions to the document.

Table 3.

PEMAT Section	Scores
Understandability (Content, Word Choice & Style, Use of Numbers, Organization, Layout & Design, Use of Visual Aids)	14 (total points) / 19 (total possible points) x 100= 73.7%
Actionability	4 (total points) / 6 (total possible points) x 100= 66.67%

Chapter V. Discussion and Recommendations

The results from the CCI and PEMAT helped determine the health literacy level of the material. The scores from each of these assessments also indicated potential areas for improvement of the material based on the user guides of the CCI and PEMAT. Any CCI score that falls below 90 should be considered for revisions (Baur and Prue, 2014). Based on the scores achieved through the CCI, the material received a clear communication score of 82.4%, which demonstrates a need for revisions within the document for health literacy. Similarly, the PEMAT scores were 73.7% for understandability and 66.67% for actionability, meaning that there are enhancements that could be made to ensure patients/caregivers understand and know how to take action on the information provided in the Day Treatment information sheet. The differences in the percentages of scores could be due to the number of items the health literacy tools consisted of, as well as the different elements each assessed such as the main message and an appropriate

chronological ordering of information listed in the material.

Furthermore, the score obtained from the CCI suggests potential areas of improvement within the Multidisciplinary Feeding Program's information sheet. To ensure that the complexities of the material are minimized, the information sheet should consistently use verbiage that the public and audience use every day. For instance, the terms 'medical necessity' are not words that are used on a regular basis. Alternative terms that could instead be used may be "medical need for treatment" or "need for treatment for medical reasons." In addition, the current material clearly states what is known about program and outcomes related to the intervention. However, information on the unknowns regarding feeding intervention is not included, which is a part of the 'state of the science' section of the CCI score sheet. This additional information may be important to include in the information sheet to ensure that caregivers develop realistic expectations and goals for their child's feeding treatment in the Day Treatment program. Moreover, the information sheet lists several recommendations in a logical sequence for caregivers to engage in prior to starting the feeding intervention. However, the material does not specifically explain why the recommendations are important to consider or act on. A more in-depth explanation of this may help provide a rationale for the recommendations, further encouraging the caregivers to take the appropriate steps to prepare for admission into the program.

According to the results from the PEMAT score, one area of improvement for the current program's material involves the use of visual aids. Although the Day Treatment Information Sheet is broken down into chunks, includes subheadings, and information is listed in bullet form, the material visually consists of a significant number of words on all four pages, with limited use of images, charts, and tables. The document currently contains 1,017 words. One

recommendation to improve the health literacy level of the material would be to incorporate more visual appeal to the material to encourage the caregivers to want to read the information included. Adding small images to different sections of the material that are relevant to the information within that specific section may help in providing caregivers with a general idea on what that segment of the material is going to discuss. The information sheet did not include any tangible tools such as planners or checklists to assist with the actionability of the steps that need to be taken in the education material to consider PEMAT. Incorporating at least one of these items into caregiver materials may help the reader visualize the steps they must take to implement the action items appropriately.

The results from both the CCI and PEMAT provided guidance during revision of various sections of the Multidisciplinary Feeding Program's Day Treatment Information Sheet. First, based on the topic of each subheading, relevant visual images were added to provide the caregiver with additional support in understanding the general idea of the section they are about to read. For instance, the "program overview" segment provides the audience with the main message of the feeding program, which involves helping children develop a positive relationship with non-preferred foods they do not typically eat. The visual images added to this section include carrots, a heart, and an apple, which signifies the positive relationship with nutritious foods. These images may aid in simplifying the audience's understanding of "program overview" and allow for caregivers to make the connection of the main message to the visuals. Similarly, the "Transportation and Housing" section includes images of a house and car. Key terms and subheadings have been bolded in the revised document to further emphasize the main topic of the section.

The CCI and PEMAT assessments both highlighted the importance of avoiding the use of

jargon in materials that are disseminated to caregivers. The scores from both measurement tools indicated that the current material incorporated some medical jargon without plain language definitions. For example, the words “medical necessity of treatment” are not terms that are used in everyday language. To reflect health literacy guidelines, these words can be modified to “medical need for feeding treatment” because these are more common terms that are used when speaking with caregivers. In addition, the original information sheet included some use of numbers throughout. To further emphasize clarity of the numerical values, for the subheading regarding “Patient Success and Outcomes,” we displayed the 90% outcome measure in a simplified pie chart. This is an important value as it relates to the effectiveness of the feeding program because it highlights that approximately 90% of patients achieve their treatment goals by the end of their admission. Likewise, the “caregiver satisfaction” section stated that nine out of ten families would recommend the current program to their social circle, which is another critical value that further demonstrates the successes of the program’s intervention method. The original material depicted this outcome in word form; the revised version included this feature in bolded number form in order for this to stand out to the reader. These improvements add further visual aids and appeal to the caregiver material to help them in understanding the myriad of crucial information that is incorporated into the information sheet.

Conclusion

In conclusion, the primary purpose of this capstone was to assess how health literate the Multidisciplinary Feeding Program’s Day Treatment Information Sheet is. The Information Sheet is written patient education material that is disseminated to caregivers at the time of their child’s feeding evaluation to determine eligibility criteria for admission into the program. The capstone sought to answer two questions: After assessment of the feeding caregiver education

document, do the scores obtained from the CCI and PEMAT indicate low or high health literacy of the material? and what changes could improve materials based on CCI and PEMAT?

To answer the primary question, the scores produced from the two assessment tools suggest that the material needs to be improved to account for health literacy principles. However, the material also had some strengths such as very limited use of jargon and the use of bullets and headings. Second, the scores from the CCI and PEMAT indicate areas of needed improvement within the caregiver materials such as the incorporation of more visual aids, plain language, use of the active voice, and adjusting the wordiness of the document without removing critical information. Because the program serves a diverse patient population, it may also be beneficial to have the caregiver material available in multiple languages. Including health literacy guidelines into the written caregiver education materials would help ensure that the needs of all individuals who enter the program are met and further help to improve the quality of patient care.

References

- Andrulis, D. P., & Brach, C. (2007). Integrating literacy, culture, and language to improve health care quality for diverse populations. *American Journal of Health Behavior, 31 Suppl 1*(Suppl 1), S122–S133. <https://doi.org/10.5555/ajhb.2007.31.supp.S122>
- Badaczewski, A., Bauman, L. J., Blank, A. E., Dreyer, B., Abrams, M. A., Stein, R. E. K., Roter, D. L., Hossain, J., Byck, H., & Sharif, I. (2017). Relationship between Teach-back and patient-centered communication in primary care pediatric encounters. *Patient Education and Counseling, 100*(7), 1345–1352. <https://doi.org/10.1016/j.pec.2017.02.022>
- Baker D. W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine, 21*(8), 878–883. <https://doi.org/10.1111/j.1525-1497.2006.00540.x>
- Baur, C., & Prue, C. (2014). The CDC Clear Communication Index is a new evidence-based tool to prepare and review health information. *Health Promotion Practice, 15*(5), 629–637. <https://doi.org/10.1177/1524839914538969>
- Bearss, K., Burrell, T. L., Stewart, L., & Scahill, L. (2015). Parent Training in Autism Spectrum Disorder: What's in a Name?. *Clinical Child and Family Psychology Review, 18*(2), 170–182. <https://doi.org/10.1007/s10567-015-0179-5>
- Bourne, L., Mandy, W., & Bryant-Waugh, R. (2022). Avoidant/restrictive food intake disorder and severe food selectivity in children and young people with autism: A scoping review. *Developmental Medicine and Child Neurology, 64*(6), 691–700. <https://doi.org/10.1111/dmcn.15139>
- Brigham, K. S., Manzo, L. D., Eddy, K. T., & Thomas, J. J. (2018). Evaluation and treatment of Avoidant/Restrictive Food Intake Disorder (ARFID) in adolescents. *Current Pediatrics Reports, 6*(2), 107–113. <http://doi.org/10.1007/s40124-018-0162-y>

Centers for Disease Control and Prevention. (2023, April). *Data & Statistics on Autism Spectrum Disorder*. Centers for Disease Control and Prevention.

<https://www.cdc.gov/ncbddd/autism/data.html>

Centers for Disease Control and Prevention. (2023). *What is health literacy?*. Centers for Disease Control and Prevention. <https://www.cdc.gov/healthliteracy/learn/index.html>

The CDC Clear Communication index | the CDC clear communication index ... CDC- Centers for Disease Control and Prevention. (2023). <https://www.cdc.gov/ccindex/index.html>

Centers for Disease Control and Prevention. (2022). *What is autism spectrum disorder?*. Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/autism/facts.html>

Costarelli, V., Michou, M., Panagiotakos, D. B., & Lionis, C. (2021). Parental Health Literacy and Nutrition Literacy Affect Child Feeding Practices: A cross-sectional study. *Nutrition and Health*, 28(1), 59–68. <https://doi.org/10.1177/02601060211001489>

DeWalt, D. A., Broucksou, K. A., Hawk, V., Brach, C., Hink, A., Rudd, R., & Callahan, L. (2011). Developing and testing the health literacy universal precautions toolkit. *Nursing Outlook*, 59(2), 85–94. <https://doi.org/10.1016/j.outlook.2010.12.002>

Dinkler, L., Wronski, M. L., Lichtenstein, P., Lundström, S., Larsson, H., Micali, N., Taylor, M. J., & Bulik, C. M. (2023). Etiology of the Broad Avoidant Restrictive Food Intake Disorder Phenotype in Swedish Twins Aged 6 to 12 Years. *JAMA psychiatry*, 80(3), 260–269. <https://doi.org/10.1001/jamapsychiatry.2022.4612>

Given, B., Sherwood, P. R., & Given, C. W. (2008). What knowledge and skills do caregivers need?. *The American Journal of Nursing*, 108(9 Suppl), 28–34.

<https://doi.org/10.1097/01.NAJ.0000336408.52872.d2>

- Goday, P. S., Huh, S. Y., Silverman, A., Lukens, C. T., Dodrill, P., Cohen, S. S., Delaney, A. L., Feuling, M. B., Noel, R. J., Gisel, E., Kenzer, A., Kessler, D. B., Kraus de Camargo, O., Browne, J., & Phalen, J. A. (2019). Pediatric Feeding Disorder: Consensus Definition and Conceptual Framework. *Journal of Pediatric Gastroenterology and Nutrition*, 68(1), 124–129. <https://doi.org/10.1097/MPG.0000000000002188>
- Harrington, K. F., & Valerio, M. A. (2014). A conceptual model of verbal exchange health literacy. *Patient Education and Counseling*, 94(3), 403–410. <https://doi.org/10.1016/j.pec.2013.10.024>
- Johnson, C. R., Brown, K., Hyman, S. L., Brooks, M. M., Aponte, C., Levato, L., Schmidt, B., Evans, V., Huo, Z., Bendixen, R., Eng, H., Sax, T., & Smith, T. (2019). Parent Training for Feeding Problems in Children With Autism Spectrum Disorder: Initial Randomized Trial. *Journal of Pediatric Psychology*, 44(2), 164–175. <https://doi.org/10.1093/jpepsy/jsy063>
- Being a caregiver*. Johns Hopkins Medicine. (2022). <https://www.hopkinsmedicine.org/health/caregiving/being-a-caregiver>
- Kovacic, K., Rein, L. E., Szabo, A., Kommareddy, S., Bhagavatula, P., & Goday, P. S. (2021). Pediatric Feeding Disorder: A Nationwide Prevalence Study. *The Journal of Pediatrics*, 228, 126–131.e3. <https://doi.org/10.1016/j.jpeds.2020.07.047>
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). (rep.). *The Health Literacy of America's Adults Results From the 2003 National Assessment of Adult Literacy*. U.S. Department of Education.
- Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J. H., Jones, R. M., Pickles, A., State, M. W., Taylor, J. L., & Veenstra-VanderWeele, J. (2020).

Autism spectrum disorder. *Nature reviews. Disease primers*, 6(1), 5. <https://doi.org/10.1038/s41572-019-0138-4>

Mayer, Gloria, EdD,R.N., F.A.A.N., & Villaire, M., M.S.L.M. (2009). Enhancing written communications to address health literacy. *Online Journal of Issues in Nursing*, 14(3), 10. Retrieved from <https://www.proquest.com/scholarly-journals/enhancing-written-communications-address-health/docview/501876526/se-2>

Morrison, A. K., Schapira, M. M., Gorelick, M. H., Hoffmann, R. G., & Brousseau, D. C. (2014). Low caregiver health literacy is associated with higher pediatric emergency department use and nonurgent visits. *Academic Pediatrics*, 14(3), 309–314. <https://doi.org/10.1016/j.acap.2014.01.004>

Nielsen-Bohlman, L. (2004). Health literacy a prescription to end confusion. *National Academies Press*. https://www.researchgate.net/profile/Lynn-Nielsen-Bohlman/publication/303697782_Health_Literacy_A_Prescription_to_End_Confusion/links/574e41d208ae8bc5d15bfda9/Health-Literacy-A-Prescription-to-End-Confusion.pdf

PFD ICD-10 FAQ. Feeding Matters. (2022). <https://www.feedingmatters.org/pfd-icd-10-faq/>

Porter, K. J., Alexander, R., Perzynski, K. M., Kruzliakova, N., & Zoellner, J. M. (2019). Using the Clear Communication Index to Improve Materials for a Behavioral Intervention. *Health Communication*, 34(7), 782–788. <https://doi.org/10.1080/10410236.2018.1436383>

Schaffler, J. L., Tremblay, S., Laizner, A. M., & Lambert, S. (2019). Developing education materials for caregivers of culturally and linguistically diverse patients: Insights from a qualitative analysis of caregivers' needs, access and understanding of information. *Health Expectations*, 22(3), 444–456. <https://doi.org/10.1111/hex.12867>

- Sharp, W. G., Burrell, T. L., & Jaquess, D. L. (2014). The Autism MEAL Plan: a parent-training curriculum to manage eating aversions and low intake among children with autism. *Autism: The International Journal of Research and Practice*, 18(6), 712–722. <https://doi.org/10.1177/1362361313489190>
- Sharp, W. G., Burrell, T. L., Berry, R. C., Stubbs, K. H., McCracken, C. E., Gillespie, S. E., & Scahill, L. (2019). The Autism Managing Eating Aversions and Limited Variety Plan vs Parent Education: A Randomized Clinical Trial. *The Journal of Pediatrics*, 211, 185–192.e1. <https://doi.org/10.1016/j.jpeds.2019.03.046>
- Shoemaker, S. J., Wolf, M. S., & Brach, C. (n.d.). *The Patient Education Materials Assessment Tool (PEMAT) and User's Guide*. AHRQ. <https://www.ahrq.gov/health-literacy/patient-education/pemat5.html>
- Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, 96(3), 395–403. <https://doi.org/10.1016/j.pec.2014.05.027>
- Shone, L. P., Conn, K. M., Sanders, L., & Halterman, J. S. (2009). The role of parent health literacy among urban children with persistent asthma. *Patient Education and Counseling*, 75(3), 368–375. <https://doi.org/10.1016/j.pec.2009.01.004>
- Simione, M., Harshman, S., Cooper-Vince, C. E., Daigle, K., Sorbo, J., Kuhlthau, K., & Fiechtner, L. (2023). Examining Health Conditions, Impairments, and Quality of Life for Pediatric Feeding Disorders. *Dysphagia*, 38(1), 220–226. <https://doi.org/10.1007/s00455-022-10455-z>

Talevski, J., Wong Shee, A., Rasmussen, B., Kemp, G., & Beauchamp, A. (2020). Teach-back:

A systematic review of implementation and impacts. *PloS one*, *15*(4), e0231350.

<https://doi.org/10.1371/journal.pone.0231350>

Unaka, N. I., Statile, A., Haney, J., Beck, A. F., Brady, P. W., & Jerardi, K. E. (2017).

Assessment of readability, understandability, and completeness of pediatric hospital medicine discharge instructions. *Journal of Hospital Medicine*, *12*(2), 98–101.

<https://doi.org/10.12788/jhm.2688>

U.S. Department of Education. (2016). (rep.). *Skills of U.S. Unemployed, Young, and Older*

Adults in Sharper Focus: Results From the Program for the International Assessment of Adult Competencies (PIAAC) 2012/2014 First Look.

User guide | CDC clear communication index. Centers for Disease Control and Prevention.

(2019). <https://www.cdc.gov/ccindex/pdf/clear-communication-user-guide.pdf>

Volkert, V. M., Burrell, L., Berry, R. C., Waddle, C., White, L., Bottini, S., Murphy, M., & Sharp, W. G. (2021). Intensive multidisciplinary feeding intervention for patients with

avoidant/restrictive food intake disorder associated with severe food selectivity: An Electronic Health Record Review. *International Journal of Eating Disorders*, *54*(11), 1978–1988. <https://doi.org/10.1002/eat.23602>

Wittenberg, E., Goldsmith, J., Ferrell, B., & Ragan, S. L. (2017). Promoting improved family caregiver health literacy: evaluation of caregiver communication resources. *Psycho-*

oncology, *26*(7), 935–942. <https://doi.org/10.1002/pon.4117>

Yuen, E. Y. N., Dodson, S., Batterham, R. W., Knight, T., Chirgwin, J., & Livingston, P. M.

(2015). Development of a conceptual model of cancer caregiver health literacy. *European Journal of Cancer Care*, *25*(2), 294–306. <https://doi.org/10.1111/ecc.12284>

Zauderer, S. (2023). *55 US Literacy Statistics: Literacy rate, average reading level*. Life-Changing ABA Therapy - Cross River Therapy.

<https://www.crossrivertherapy.com/research/literacy-statistics#:~:text=The%20average%20American%20reads%20at,according%20to%20The%20Literacy%20Project>.

Zickgraf, H.F., Franklin, M.E. & Rozin, P. (2016). Adult picky eaters with symptoms of avoidant/restrictive food intake disorder: comparable distress and comorbidity but different eating behaviors compared to those with disordered eating symptoms. *Journal of Eating Disorders* 4, 26. <https://doi.org/10.1186/s40337-016-0110-6>

Appendix A

CCI Scores

[Previous Page](#)

CDC Clear Communication Index Score Sheet

Using the Score Sheet

The Index has a total of 20 items in 4 parts. These 20 items are presented as questions.

- Questions 1-11 in Part A **apply to all materials**.
- Questions 12-20 in Parts B, C, and D may not apply to all materials.
- Choose one answer for each item you score.
- Only score a point when all instances of an item in the material meet the criteria.

More detailed descriptions and examples of each item can be found in the User Guide.

Part A: Core	
The items in this section (1-11) apply to all materials.	
Questions	Score (Check one per question)
Main Message and Call to Action	
<p>1. Does the material contain one main message statement?</p> <p><i>A main message is the one thing you want to communicate to a person or group that they must remember. A topic, such as heart disease or seasonal flu, isn't a main message statement. If the material contains several messages and no main message, answer no. (User Guide page 5)</i></p> <p>NOTE: If you answered No to Question 1, score 0 for Questions 2-4 and continue to Question 5.</p>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<p>2. Is the main message at the top, beginning, or front of the material?</p> <p><i>The main message must be in the first paragraph or section. A section is a block of text between headings. For a Web material, the first section must be fully visible without scrolling. (User Guide page 6)</i></p>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<p>3. Is the main message emphasized with visual cues?</p> <p><i>If the main message is emphasized with font, color, shapes, lines, arrows or headings, such as "What you need to know," answer yes. (User Guide page 7)</i></p>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<p>4. Does the material contain at least one visual that conveys or supports the main message?</p> <p><i>For example, count photographs, line drawings, graphs and infographics as visuals. If the visual doesn't have a caption or labels, answer no. If the visual has human figures who aren't performing the recommended behaviors, answer no. (User Guide page 8)</i></p>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<p>5. Does the material include one or more calls to action for the primary audience?</p> <p><i>If the material includes a specific behavioral recommendation, a prompt to get more information, a request to share information with someone else, or a broad call for change, answer yes. If the call to action is for someone other than the primary audience, answer no. (User Guide page 10)</i></p>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<input type="button" value="Save Form"/>	<input type="button" value="Next Page"/>

[Previous Page](#)

CDC Clear Communication Index Score Sheet

Language	
6. Do both the main message and the call to action use the active voice? <i>If only the main message or only the call to action uses the active voice, answer no. If you answered no to #1 or #5, answer no. (User Guide page 11)</i>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
7. Does the material always use words the primary audience uses? <i>If all specialized or unfamiliar terms are explained or described (not just defined) the first time they are used, answer yes. Acronyms and abbreviations must be spelled out and explained if unfamiliar to the audience. (User Guide page 12)</i>	<input type="checkbox"/> Yes = 1 <input checked="" type="checkbox"/> No = 0
Information Design	
8. Does the material use bulleted or numbered lists? <i>If the material contains a list with more than 7 items, and the list is not broken up into sub-lists, answer no. If the list is for additional information or references only or at the end of the material, answer no. (User Guide page 14)</i>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
9. Is the material organized in chunks with headings? <i>This item applies to prose text and lists. If the chunks contain more than one idea each, answer no. If the headings don't match the information chunks, answer no. (User Guide page 15)</i>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
10. Is the most important information the primary audience needs summarized in the first paragraph or section? <i>The most important information must include the main message. A section is a block of text between headings. For a Web material, the first section must be fully visible without scrolling. (User Guide page 17)</i>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
State of the Science	
11. Does the material explain what authoritative sources, such as subject matter experts and agency spokespersons, know and don't know about the topic? <i>If the material addresses both, answer yes. If the material addresses only one (what is known or not known), answer no. (User Guide page 18)</i>	<input type="checkbox"/> Yes = 1 <input checked="" type="checkbox"/> No = 0
Part A score	Total 9 / 11

 Comments
 [Save Form](#)
[Next Page](#)

CDC Clear Communication Index Score Sheet

Part B: Behavioral Recommendations Answer this question to determine if items 12-14 apply to the material. Does the material include one or more behavioral recommendations for the primary audience? <ul style="list-style-type: none"> If yes – score items 12-14. If no – skip to Part C. Go to Part C 	
Questions	Score (Check one per question)
12. Does the material include one or more behavioral recommendations for the primary audience? <i>If no, STOP here and don't score Part B. (User Guide page 19)</i>	<input checked="" type="checkbox"/> Yes = 1
13. Does the material explain why the behavioral recommendation(s) is important to the primary audience? <i>If you offer only numbers to explain the importance of the behavioral recommendation with no other relevant information for the audience, answer no. (User Guide page 20)</i>	<input type="checkbox"/> Yes = 1 <input checked="" type="checkbox"/> No = 0
14. Does the behavioral recommendation(s) include specific directions about how to perform the behavior? <i>This may include step-by-step directions or a simple description (for example: Look for cereal with 100% daily value of folic acid). If the material includes information about when and how to contact a medical provider or health official, answer yes. If the material mentions when and how often to perform a behavior, answer yes. (User Guide page 21)</i>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
Part B score	Total <u>2</u> / 3

Comments

CDC Clear Communication Index Score Sheet

Part C: Numbers

Answer this question to determine if items 15-17 apply to the material.

Does the material include one or more numbers related to the topic?

- If **yes** – score items 15-17.
- If **no** – skip to Part D. [Go to Part D](#)

Questions	Score (Check one per question)
<p>15. Does the material <u>always</u> present numbers the primary audience uses?</p> <p><i>Many audiences find numbers distracting or confusing. Make sure the numbers in the material are both familiar and necessary to support or explain the main message statement. If not, delete them. Whole numbers are used by most audiences. The types of numbers used will vary for each audience. (User Guide page 22)</i></p>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<p>16. Does the material <u>always</u> explain what the numbers mean?</p> <p><i>For example, "The amount of meat recommended as part of a healthy meal is 3 to 4 ounces – it will look about the same size as a deck of cards." (User Guide page 23)</i></p>	<input checked="" type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<p>17. Does the audience have to conduct mathematical calculations?</p> <p><i>Adding, subtracting, multiplying, and dividing involve calculations. Calculating a common denominator for the purposes of comparison is a mathematical calculation. Use the same denominator, even for absolute risk (example: 1 out of 3), throughout the material so that audiences don't have to calculate. (User Guide page 24).</i></p>	<input type="checkbox"/> Yes = 0 <input checked="" type="checkbox"/> No = 1

NOTE: for this item, Yes is scored 0 and No is scored 1.

Part C score

Total 3 / 3

Comments

Previous Page

CDC Clear Communication Index Score Sheet

Part D: Risk

Answer this question to determine if items 18-20 apply to the material.

Does the material present information, including numbers, about risk?

- If **yes** – score items 18-20.
- Items 19 and 20 have a “not applicable” (NA) option.
- If **no** – skip to Calculate the Score. [Go to Calculate](#)

Questions	Score (Check One per Question)
<p>18. Does the material explain the nature of the risk?</p> <p><i>If the material states the threat or harm and how and why people may be affected, answer yes. If the material has only the threat or harm but no explanation, answer no. For example, if the material states there are 1,000 new cases of a contagious disease in Springfield, does it also state that people in Springfield may be more likely to get the disease, why they may be more likely, and how serious the threat of the disease is? (User Guide page 26)</i></p>	<input type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0
<p>19. Does the material address both the risks and benefits of the recommended behaviors?</p> <p><i>This includes actual risks and benefits and those perceived by your audience. If the material addresses <u>only</u> risks or <u>only</u> benefits, answer no. If no behavioral recommendation is presented, answer not applicable (NA). (User Guide page 27)</i></p>	<input type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0 <input type="checkbox"/> NA
<p>20. If the material uses numeric probability to describe risk, is the probability also explained with words or a visual?</p> <p><i>Examples of probability information in a risk message are numbers (such as 1 in 5 or 20%). If the material presents numeric risk and also uses text to explain the probability, answer yes. If the material presents numeric risk and also uses a visual to explain the probability, answer yes. If the material only presents numeric risk, answer no. If the material does not include this type of probability information, answer not applicable (NA). (User Guide page 28)</i></p>	<input type="checkbox"/> Yes = 1 <input type="checkbox"/> No = 0 <input type="checkbox"/> NA

Part D score

Total 0 / 3

Comments

Save Form

Next Page

[Previous Page](#)

CDC Clear Communication Index Score Sheet

Calculate the Score for the Material

- **Step 1:** The total points that the material earned (this is the numerator).
» A: 9 B: 2 C: 3 D: 0 = 14
- **Step 2:** The total possible points that the material could have earned (this is the denominator).
» A: 11 B: 3 C: 3 D: 0 = 17
- **Step 3:** The numerator divided by the denominator multiplied by 100 to get the total score.

$$\frac{14}{17} \times 100 = 82.4$$

How to Interpret the Score

The purpose of the Index is to improve the clarity of communication products.

If the total score is 90 or above:

Excellent! You have addressed most items that make materials easier to understand and use.

If the total score is 89 or below:

Note which items scored 0 points. Use the descriptions and examples in the User Guide to revise and improve the material. Then apply the Index again to check your work. You can use the Index as many times as you need to revise the material to get a score of 90 or above.

Additional Comments

[Email Form](#)
[Print](#)
[Save Form](#)

Appendix B

PEMAT Scores

Understandability

Item #	Item	Response Options	Rating
Topic: Content			
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	1
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	1
Topic: Word Choice & Style			
3	The material uses common, everyday language.	Disagree=0, Agree=1	0
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	1
5	The material uses the active voice.	Disagree=0,	0

		Agree=1	
Topic: Use of Numbers			
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	1
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	1
Topic: Organization			
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short material=N/A	1
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material=N/A	1
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	1

11	The material provides a summary.	Disagree=0, Agree=1, Very short material=N/A	1
Topic: Layout & Design			
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1, Video=N/A	1
Topic: Use of Visual Aids			
15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	0
16	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	1
17	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	1

18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	1
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	1

Total Points: _____ 14 _____

Total Possible Points: _____ 19 _____

Understandability Score (%): _____ 73.7% _____

(Total Points / Total Possible Points x 100)

Actionability

Item #	Item	Response Options	Rating
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	1
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	1

22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	1
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	0
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=NA	N/A
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	1
26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	0

Total Points: _____ 4 _____

Total Possible Points: _____ 6 _____

Actionability Score (%): _____ 66.67% _____

(Total Points / Total Possible Points x 100)


Appendix C

Revised Section of Caregiver Information Sheet for Day Treatment


School and Employment

School services are not provided in the feeding program. The team can work with your family to provide documents to your child's school about the medical need for treatment.

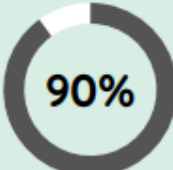
Parents often use FMLA (Family and Medical Leave Act) benefits to take time off work to attend treatment. Contact your employer to find out if you can use FMLA during treatment.



Your child may be eligible to receive hospital homebound services through your county. Contact your child's school to learn about requesting hospital homebound services.



Patient Success and Outcomes





90%

Treatment Goals: Your family and treatment team work together to create goals for treatment within the first 2-4 weeks. On average, 90% or more of goals set by parents and the treatment team are reached at the end of therapy.

• **Caregiver Satisfaction:** We ask all families who complete the program to provide feedback on surveys. On average, 90% or more caregivers report that treatment improved their child's feeding problem.

9 OUT OF 10

Would recommend our treatment to a friend or colleague with a child with a similar feeding problem.

New Foods: On average, patients start treatment eating 3 foods and leave eating 16 (4 from each food group) or more new foods.