



feeding **matters**

ABOUT US



Jen Lambert

Senior Director of Community Engagement



WHO WE ARE

Feeding Matters is the first organization in the world uniting healthcare professionals, families, and the broader community to improve the system of care for children with pediatric feeding disorder through advocacy, education, support, and research.

OUR VISION

A world in which children with pediatric feeding disorder will thrive





ABOUT US

- 501c3 Nonprofit Organization
- National with international reach
- Established in 2006
- First organization in the world uniting the concerns of families with the field's leading advocates, experts, and allied healthcare professionals
- Pediatric feeding disorder (PFD) and Avoidant/Restrictive Food Intake Disorder (ARFID)

***We are Advocates, Educators,
Researchers, and Policy Influencers***



SHANNON GOLDWATER



Our organization started with, by, and for a FAMILY who needed help.



OUR GOALS



EDUCATE PROFESSIONALS



SUPPORT FAMILIES



AWARENESS & ADVOCACY



OUR VALUES



INCLUSIVE



COLLABORATIVE



INNOVATIVE

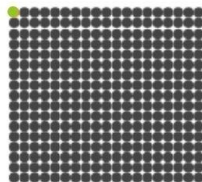


STAGGERING PREVALENCE

...

*Yet, often this is
a “silent” issue*

1 in 37 young children have
pediatric feeding disorder.



1 in 323 children have
cerebral palsy ¹



1 in 44 children have
autism ¹



1 in 37 young children have
pediatric feeding disorder



feeding matters



“I am constantly worried. I am consumed by his eating and dread every meal. I often feel I am neglecting my other children and husband; my family’s entire life revolved around Sam’s feeding schedule. The worst part is how helpless we all feel when Sam coughs, gags or vomits at almost every meal.”

WHAT DOES THIS MEAN FOR FAMILIES?



FAMILY SUPPORT



"We are so thankful for Feeding Matters and the Power of Two. Before I connected with Robyn, I really felt alone. I was feeling extreme guilt I was failing my son. I thought I did something during my pregnancy to cause Shiv to have his feeding issues and now as a mom I couldn't even feed my son. Others may say the same things she does but coming from a mom that has gone through similar issues with her son, to me I appreciate her comments and suggestions because I know she truly gets it."
- Pinali



feeding **matters**

BUILDING CONSENSUS



System Change + Impact



THE HISTORY OF PFD

A CALL FOR A UNIVERSALLY ACCEPTED DEFINITION



Pediatric Feeding Disorder—Consensus Definition and Conceptual Framework

*Praveen S. Goday, ^{††}Susanna Y. Huh, *Alan Silverman, [§]Colleen T. Lukens, ^{||}Pamela Dodrill, [¶]Sherri S. Cohen, *Amy L. Delaney, [#]Mary B. Feuling, **Richard J. Noel, ^{††}Erika Gisel, ^{‡‡}Amy Kenzer, ^{§§}Daniel B. Kessler, ^{|||}Olaf Kraus de Camargo, ^{¶¶}Joy Browne, and ^{###}James A. Phalen

ABSTRACT

Pediatric feeding disorders (PFDs) lack a universally accepted definition. Feeding disorders require comprehensive assessment and treatment of 4 closely related, complementary domains (medical, psychosocial, and feeding skill-based systems and associated nutritional complications). Previous diagnostic paradigms have, however, typically defined feeding disorders using the lens of a single professional discipline and fail to characterize associated functional limitations that are critical to plan appropriate interventions and improve quality of life. Using the framework of the World Health Organization *International Classification of Functioning, Disability, and Health*, a unifying diagnostic term is proposed: “Pediatric Feeding Disorder” (PFD), defined as impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction. By incorporating associated functional limitations, the proposed diagnostic criteria for PFD should enable practitioners and researchers to better characterize the needs of heterogeneous patient populations, facilitate inclusion of all relevant disciplines in treatment planning, and promote the use of common, precise, terminology necessary to advance clinical practice, research, and health-care policy.

Key Words: dysphagia, failure to thrive, feeding disorder

(JPGN 2019;68: 124–129)

Feeding is a complex process that requires interaction of the central and peripheral nervous systems, oropharyngeal mechanism, cardiopulmonary system, and gastrointestinal (GI) tract with support from craniofacial structures and the musculoskeletal

What Is Known

- Pediatric feeding disorders lack a universally accepted definition.
- Previous diagnostic paradigms have defined feeding disorder from the perspective of a single medical discipline.

What Is New

- A unifying diagnostic term, “Pediatric Feeding Disorder”, using the framework of the World Health Organization *International Classification of Functioning, Disability, and Health* is proposed.
- This term unifies the medical, nutritional, feeding skill, and/or psychosocial concerns associated with feeding disorders.
- The proposed diagnostic criteria should promote the use of common, precise, terminology necessary to advance clinical practice, research, and health care policy.

system. This coordinated interaction requires acquisition and mastery of skills appropriate for a child’s physiology and developmental stage. In children, feeding occurs in the context of the caregiver-child dyad. A disruption in any of these systems places a child at risk



“Feeding Matters is helping bring the experts together and shaping the future generations of parents and children with feeding struggles. Feeding Matters has their sights on a vision that surmounts current healthcare and legislative barriers.” – Dr. Julie Barkmeier-Kraemer



THIS IS BIG...REALLY BIG

THERE IS NOW A DIAGNOSTIC CODE FOR PFD

CLICK TO THE NEXT IMAGE TO
UNDERSTAND WHY THIS MATTERS



feeding matters



FORUM OPEN ACCESS

A US-Based Consensus on Diagnostic Overlap and Distinction for Pediatric Feeding Disorder and Avoidant/Restrictive Food Intake Disorder

Hayley H. Estrem¹ | Jaclyn L. Pederson² | Pamela Dodrill³ | Cuyler Romeo⁴ | Kelsey Thompson⁵ | Jennifer J. Thomas⁶ | Nancy Zucker⁷ | Richard Noel⁸ | Hana Zickgraf⁹ | Jessie Menzel¹⁰ | Colleen T. Lukens¹¹ | Praveen S. Goday¹² | Sarah MacLaughlin¹³ | William G. Sharp¹⁴

¹School of Nursing, University of North Carolina at Wilmington, Wilmington, North Carolina, USA | ²Feeding Matters, Phoenix, Arizona, USA | ³Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts, USA | ⁴Banner-University Medical Center South, Tucson, Arizona, USA | ⁵The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA | ⁶Massachusetts General Hospital, Boston, Massachusetts, USA | ⁷Duke University Health Center, Durham, North Carolina, USA | ⁸Duke Children's Hospital and Health Center, Durham, North Carolina, USA | ⁹Rogers Behavioral Health Oconomowoc Main Campus, Atlanta, Georgia, USA | ¹⁰Equip, California, USA | ¹¹The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA | ¹²Nationwide Children's Hospital, Columbus, Ohio, USA | ¹³Zero to Three, Washington, Columbia, USA | ¹⁴Emory Medical School, Children's Healthcare of Atlanta, Atlanta, Georgia, USA

Correspondence: Hayley H. Estrem (estremh@uncw.edu)

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Keywords: ARFID | diagnosis | DSM-5 | feeding and eating disorder | ICF | PFD | research diagnostic criteria

ABSTRACT

Objective: As diagnoses covering dysfunctional feeding and eating in pediatrics, avoidant/restrictive food intake disorder (ARFID) and pediatric feeding disorder (PFD) contain inherent areas of overlap in their diagnostic criteria. Areas of overlap include criteria regarding nutritional consequences associated with feeding/eating dysfunction and shared emphasis on possible psychosocial impairment associated with restricted food intake. Complicating the differential diagnosis process is a lack of guidance regarding when the two conditions occur independently, co-qualify, and/or transition into the other. Feeding Matters' Research Initiatives Task Force planned and hosted a PFD-ARFID consensus meeting, with the aim of reaching a consensus regarding diagnostic clarity on PFD and ARFID.

Method: Criteria for participation focused on US residents who either: (a) served as an author on the ARFID workgroup or PFD consensus papers, or (b) provided community representation via board or committee roles. The consensus process followed three stages: prework, the meeting, and post-work/writing. Twelve participants were present for the meeting, with 14 involved in pre- and post-work/writing.

PFD  ARFID



EDUCATION

OVER 1,200+ REGISTRANTS

50 STATES

30+ COUNTRIES

INTERNATIONAL
PFD CONFERENCE

2024 FEEDING + EATING PSYCHOLOGY SUMMIT AND CONSENSUS MEETING

BOARD REPORT



PSYCH SUMMIT

This pivotal event brought experts in PFD and ARFID together to advance our understanding of psychological interventions available for these disorders. This critical discussion has forged a path towards consistent communication, evidence-based practices, and future research in the field of feeding and eating disorders.

"These conversations are so important to my learning about how to listen to and support families and their children while bringing the educational pieces that I have learned through the years."

- Attendee

ATTENDEES

220

GOAL

520

ACTUAL

+136%

VARIANCE

REGISTRATION REVENUE

\$15,000

GOAL

\$25,526

ACTUAL

+70%

VARIANCE

SPONSORSHIPS

\$1,500

GOAL

\$1,500

ACTUAL

EXACT

VARIANCE

"Thankful that Feeding Matters is allowing the space for these conversations. I think it is becoming more clear that this is very complex and hopeful that as these conversations continue the fields can work more in unison and less in silos." - Attendee

CONSENSUS MEETING

The Psych Summit served as a conversation conduit to dive deeper into how our psychology experts make clinical decisions in the treatment of PFD and/or ARFID. For the first time, the community's voice was at the forefront of conversation as field leaders discussed:

- the ongoing challenges navigating the overlap between PFD and

ARFID



RESEARCH

IGNITING RESEARCH

Devising a pathway
for professionals to
serve as qualified
providers for PFD.





Family-Centered
**PFD RESEARCH
CONSORTIUM**



ADVOCACY & AWARENESS

IT'S PFD AWARENESS MONTH.
SPREAD THE WORD.

Each May, we celebrate Pediatric Feeding Disorder (PFD) Awareness Month, both in the United States and around the world. This celebration takes a village, and we need you to help spread the word! How you can help:

Download our 2024 graphics above (or create your own!) and share with the hashtags #CallitPFD #ARFIDaware.

Did you know every like, comment, and share helps us reach more families? Engaging on our social media feed is an easy way to help us reach more people who need support.



[Click the images to download.](#)



Facebook Impact	Instagram Impact
79K account reach	29.9K account reach
123.9K impressions	3.9K account engagement
4.4K interactions	60 new followers
95 new followers	



IT'S NOT
PICKY EATING

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When eating is hard, scary, or hurts...

IT'S NOT PICKY EATING

*Addressing pediatric feeding disorder (PFD) and
avoidant/restrictive food intake disorder (ARFID) with care*

[Resources & Support](#)

[Get Involved](#)

This book is dedicated to the brave individuals who face feeding disorders and differences in their own unique way, and to the families who support them. Your strength, love, and patience shine through with every step of the journey. For the thousands of meals you have shared—each one filled with hope, worry, and perseverance—we see you, and we honor your resilience.



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ABOUT THIS BOOK

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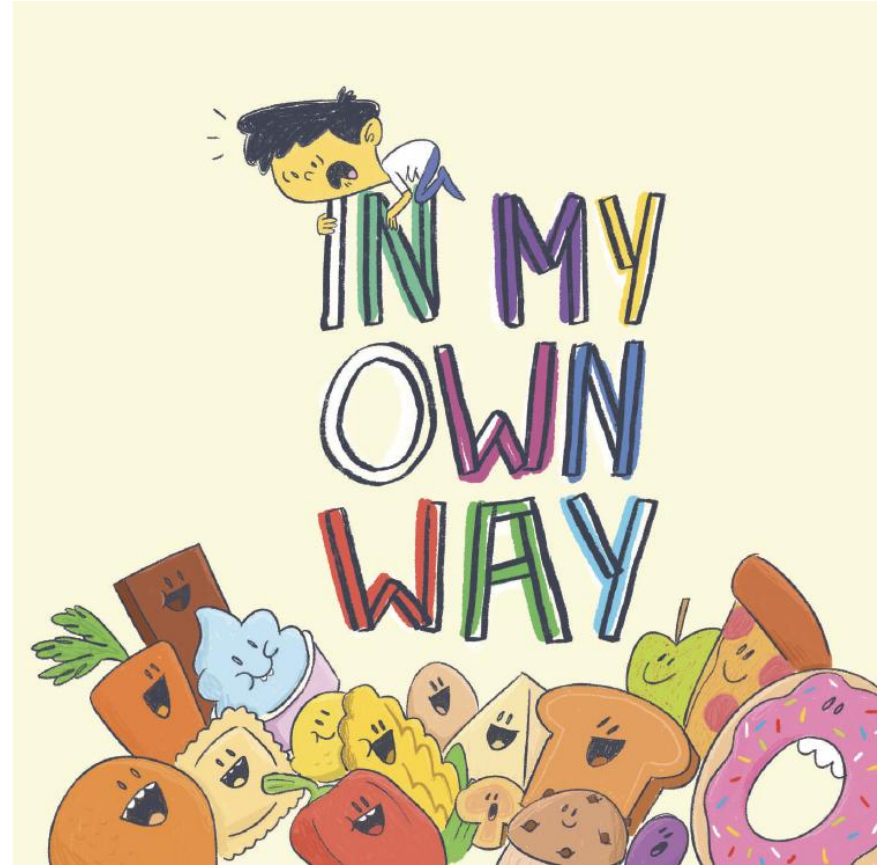
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THE MANY FACES OF PFD





feeding matters