

Feeding Matters knows how difficult it is to find the right team of doctors and healthcare professionals who understand Pediatric Feeding Disorder (PFD.) That's why we've created a list of questions for families to ask when faced with getting help for their child. If you haven't been given a referral or need help finding providers, please check out our [provider directory](#).

QUESTIONS FOR FEEDING TEAMS

- 1. How long have you been seeing children with PFD?**
 - Look for practitioners who have at least a few years of experience.

- 2. Does your team have specific education and training regarding PFD?**
 - Look for someone who has sought out additional training to understand best practices.

- 3. How long does it take to get an appointment?**
 - Many organizations have waiting lists. Be sure you understand what the possible wait time is for the evaluation and then how long it will take until treatment can be offered.

- 4. What type of medical information will you need prior to admitting my child to the program?**
 - Look for a team that will do a thorough review of your child's medical history.

- 5. What type of insurance do you take? Do you have a program to help families get coverage?**
 - Find out if they take your insurance and if prior-authorization is needed. Also if they have a coordinator who works with families to get the necessary paperwork filed.

NOTES:

6. Are there a number of specialists who represent various disciplines involved in the evaluation? Are the same specialists involved in the treatment of my child? If not, how do they differ and why?

- You want to make sure the team has a number of disciplines represented in both the evaluation and the treatment. Many experts agree that the most efficient means of evaluating and treating pediatric feeding disorder is a team approach. This means obtaining care from multiple specialists, often in the same clinic, who all work together, share the same goals and use similar theoretical approaches.

7. Describe your program's overall approach to treating PFD.

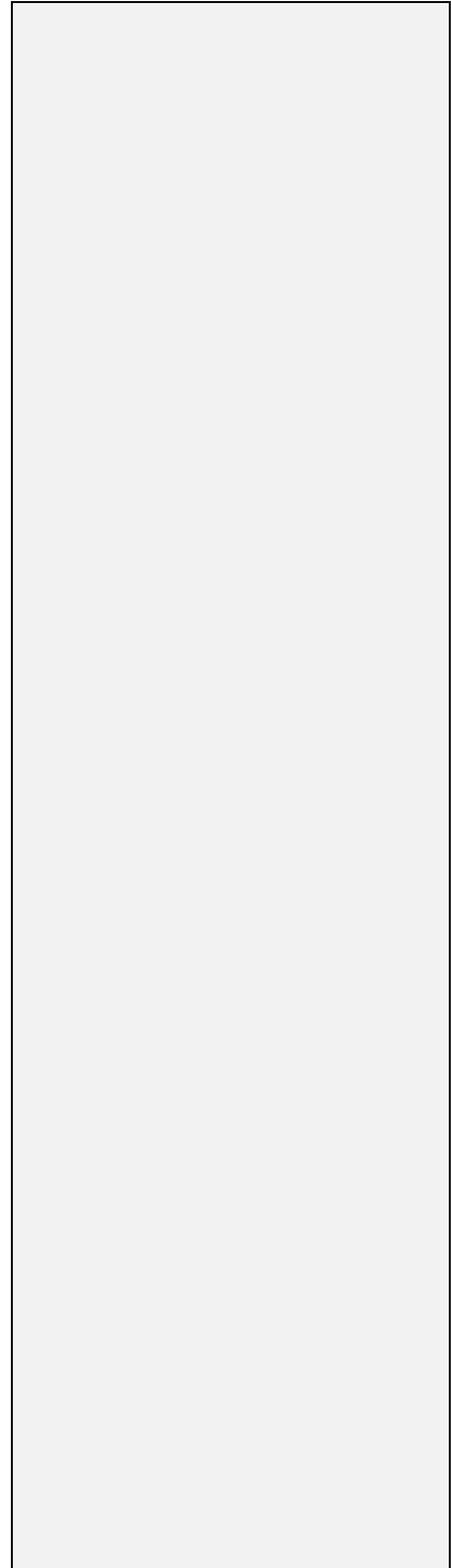
- Look for a team that understands that your child gives cues when something isn't going well. The team should value your voice and seek to understand why your child is struggling.

8. How do you communicate the results of diagnostic testing, treatment goals, and other information with me and other providers who are on my child's team?

- Look for a team who partners with other disciplines and keeps open lines of communication amongst each other as well as with you. One who provides you copies of reports and takes the time to go over reports with you and makes sure you completely understand the results.

9. How do you establish feeding goals?

- Look for a team that works with you to determine what goals are important to your family; realistic goals that will build on your child's skills and abilities, nutritional needs, and medical needs. The goals should take into



consideration the parent and child relationship. (example: It is hard to assess if your child will be completely weaned from a feeding tube until the program understands their current skill and ability.)

10. If tube weaning is a primary goal for treatment, how does your facility manage it?

- Look to make sure they balance nutritional stability with weight management.

11. What is the response in a therapy session if my child becomes upset, refuses to eat, coughs, gags, or vomits?

- Look for a team who is willing to explore what might be causing these behaviors to happen and doesn't just push past the cues, force feed, or assume it is only behavioral.

12. How frequently do you re-examine my child's progress and how do you modify treatment goals as a result?

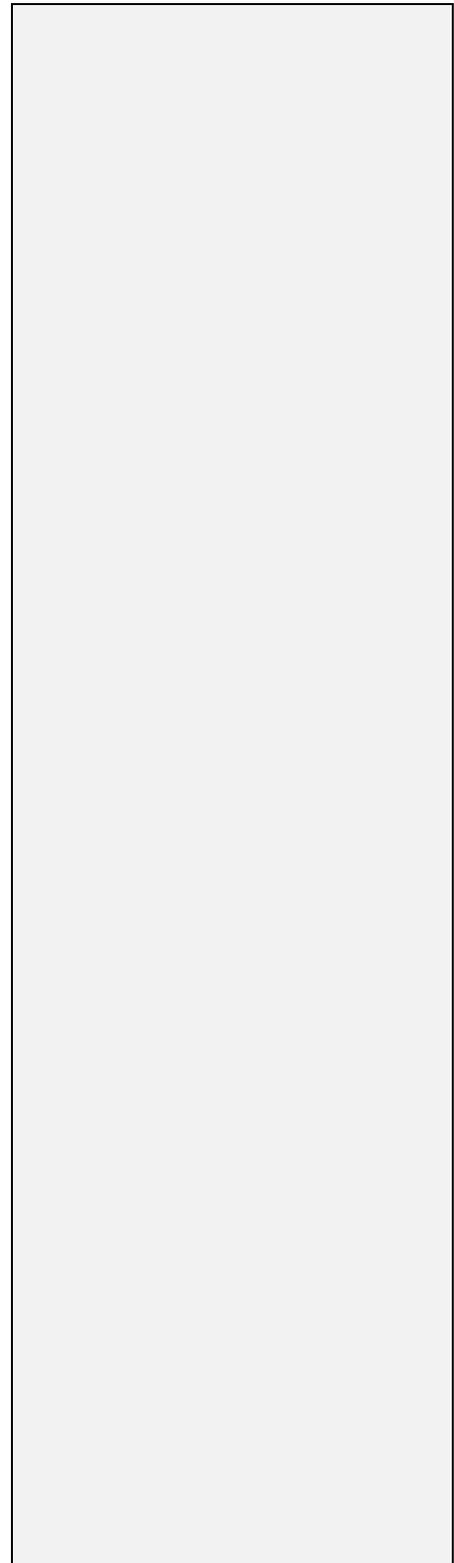
- Look to make sure they are assessing progress and will modify the goals if something isn't working to ensure progress is made.

13. What is the best way for me to communicate with you?

- The more ways you can communicate with your provider the better. Having a patient portal is a great way to get quick responses.

ADDITIONAL QUESTIONS FOR INTENSIVE INPATIENT AND OUTPATIENT PROGRAMS

We define feeding programs as programs where a child is accepted to and discharged from the program, treatment



occurs for a set period of time such as two, four, six, or eight weeks, and is more intensive than traditional outpatient therapy. There are two common options for feeding programs - intensive outpatient or intensive inpatient.

Intensive outpatient treatment typically occurs one or more times a day, several days a week, usually five days a week.

Intensive inpatient treatment typically requires an overnight stay; feeding sessions occur multiple times a day, usually seven days a week.

1. How long has the program been in existence?

- Look for some history so you can feel confident the program is reputable.

2. Can I contact parents who have completed the program I'm interested in?

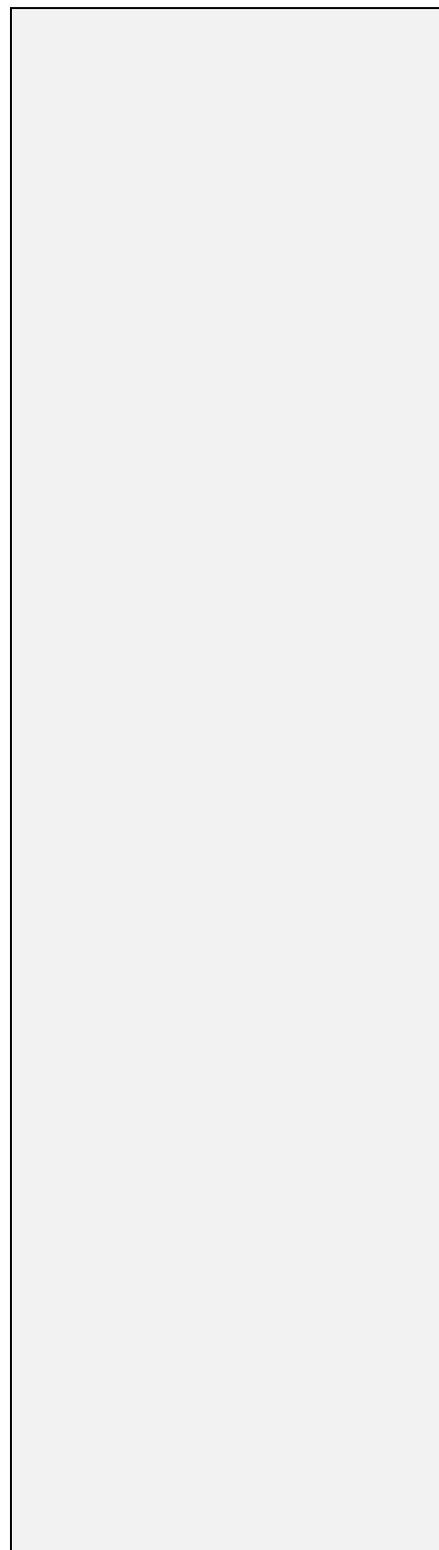
- If not, do they have parent satisfaction polls they can share with you and do they have long term data they can share about their success rate?

3. How long is the duration of the program?

- Some programs may be up to eight weeks or more. Look to make sure a program will fit your family's needs and resources.

4. Will my child be evaluated by your team before being accepted into the program?

- The best programs want to independently evaluate your child so they can design the most effective treatment plan prior to beginning



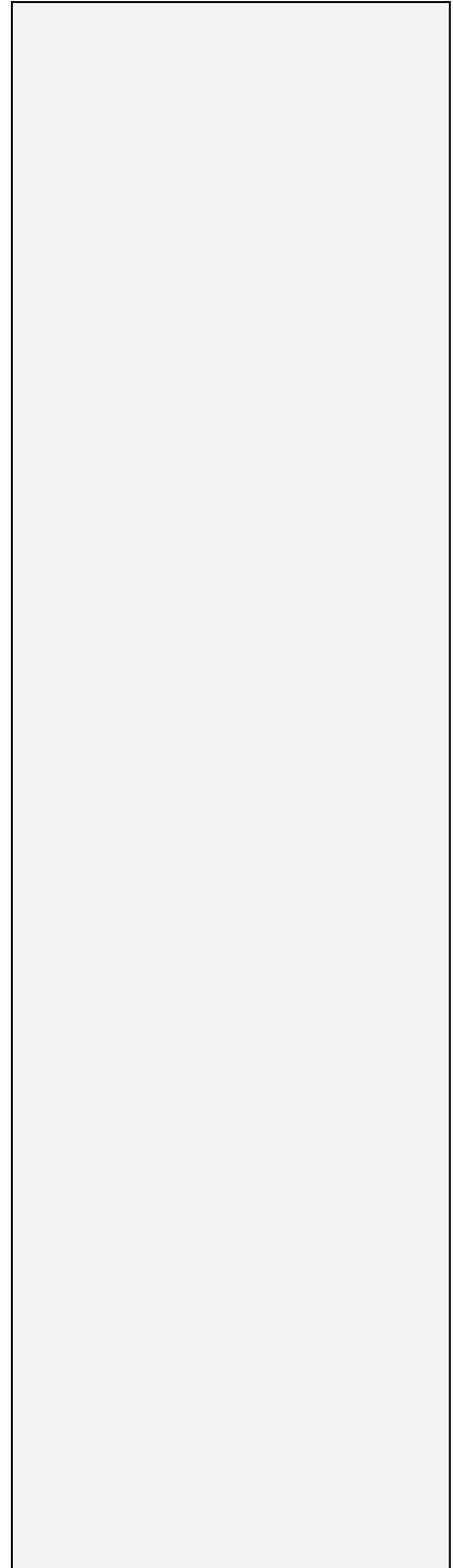
treatment.

5. After my child's evaluation, will the treatment plan be discussed with me and how long will it take until treatment begins?

- Often programs have wait times between the evaluation and the start of treatment. You want to make sure the suggested timeframe works for your family.

6. How do you assess my child's medical status, nutritional status, skill & ability level, and behavior/psychology status?

- **Medical:** If it's an intensive program, the best programs offer medical testing onsite or they have access to quality providers who they routinely work with to fully understand a child's existing medical status. Often children will require tests such as an endoscopy, gastric emptying study, video swallow study, allergy testing, motility testing, etc. Look for a program that has the onsite expertise or access to specialists who have expertise.
- **Nutrition:** The best programs have a registered dietitian nutritionist on the team who should do a thorough nutritional assessment, which includes a food log, and ask other detailed information about your child's nutritional status.
- **Feeding Skill:** The best programs have specialists; occupational therapists and speech and language pathologists, who thoroughly understand a child's skill level. They will perform oral-motor tests, sensory tests, and a praxis test that are essential to obtaining reliable and valid



information. In some instances, children will need diet modifications to match their skill level. For example, a three year old may only have the skills to eat pureed food.

- **Psychosocial:** The best programs have a psychologist and/or a board certified behavior analyst to assess and advise on the parent/child interaction during mealtimes and understand the behavioral components that may be influencing mealtime behaviors, both good and bad.

7. How do you evaluate progress toward feeding goals and how am I included in the evaluation process?

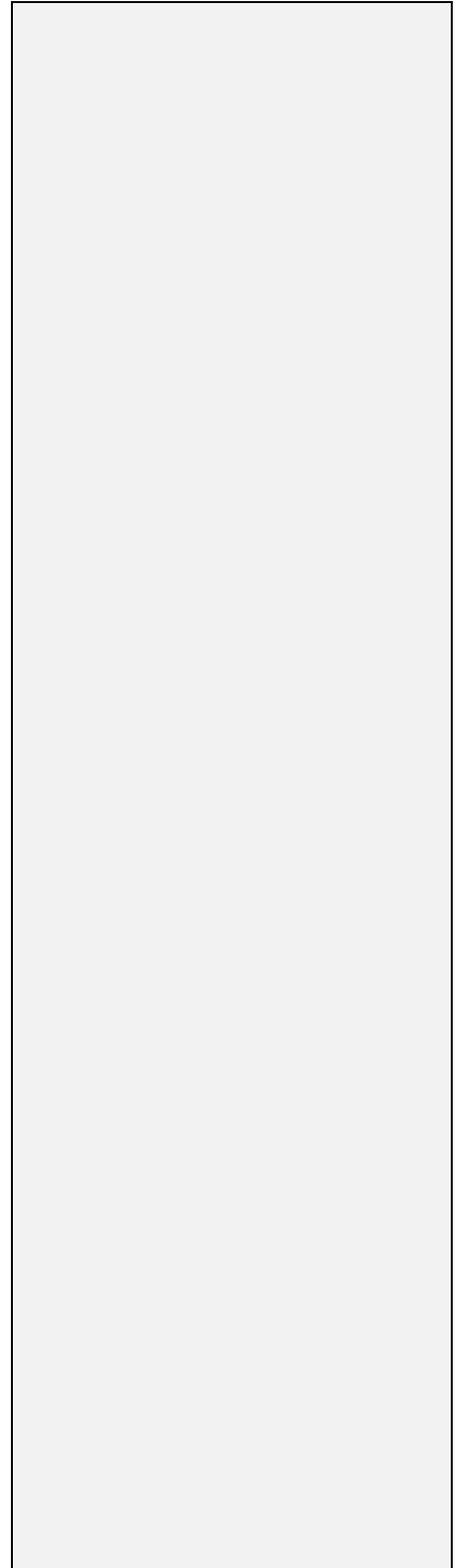
- Look to see how progress is assessed and how often it is measured. The best programs will meet at least once a week and will include you as well as all other practitioners who are treating your child as part of the meeting in real time.

8. What does a typical day in the program look like?

- Make sure you understand the frequency of meals and what type of support you may or may not receive on the weekends. You should also ask about what types of other activities are provided for you and your child. Activities such as school time for an older child; a place to nap for a younger child; parent support groups for you, etc.

9. What type of housing is available for out of area families?

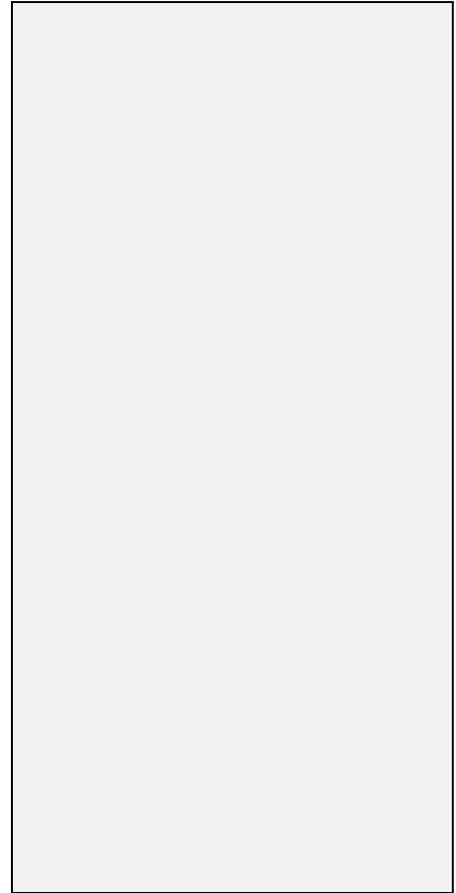
- Look for affordable options such as a partnership with Ronald McDonald house, hotels that offer



discounts for families being treated; special rates for apartment rentals, etc.

**10. What follow up care do you provide after discharge?
How do you support a family once they go home,
particularly if they live out of state?**

- The program should also prepare you for your home life environment when you are possibly with other kids, animals, parents that both work full time, etc.
- Look for a program that offers follow up to ensure progress continues to be made. You should have a set schedule for future contact with the full team.
- You want to make sure they are willing to collaborate with other providers for your child's ongoing care and have a set schedule for future contact.



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