Parent Experiences with Early Steps

By Cheryl Miller

Mother of two boys with special needs

Child advocate

Positive Experiences/Views

- Overall concept of early intervention
- Dedicated & compassionate employees
- Lots of great advice, knowledge on local resources
- Having someone in the home is very helpful-what is there that we can use?
- Free service, no matter what!
- Consistent/convenient

Vinny and Alex

Infants & Toddlers with Down Syndrome

Importance of Feeding Therapy

- Why Alex needed it/I needed it as his mother
- What happened the first day?
- What happened after 6 months?
- All children with Down Syndrome
- Children that don't get significant intervention 0-3
- Where we are now?

Importance of Feeding Therapy

- 2 Medical outcomes for children with no feeding therapy intervention from age 0-3:

1) Failure to thrive, repeat aspiration leading to ongoing pneumonia & other respiratory issues

2) Feeding aversion (results from forced feeding when the child is incapable)

Importance of Feeding Therapy

- Social and Emotional outcomes:
1) Caregiver stress (stressed parent=stressed child)
2) Social delay due to not being able to eat in the same manner as or with same age peers

Recommendations

- Need for flexibility & work directly with the parent (not school)
- What is the biggest concern for the parent? (How will that be addressed with the new focus on social/emotional outcomes?)
- If you don't know the answer, say so
- Don't overstep your role, parents see providers as experts

Recommendations, cont.

- Refer out to other providers, pediatrician
- Parents of special needs kids are exhausted, it should not have to be a fight
- Don't say "higher functioning"
- Get parent input on the Battelle, every single question-don't assume
- How is Early Steps presented by providers
- Documentation in a timely manner

Beckman Protocol

- https://www.beckmanoralmotor.com/index.php
- Lots of oral motor exercises
- Some internal, some external
- It's not just for children with DS

Thank You!