

Appendix A

Categorizations of Family Survey Open Ended Questions

Please share any additional comments regarding your experience with early intervention:

Number of positive comments regarding experience with early intervention: 74

1. Supported my skill/confidence in my child's development (21)
 - a. "As a parent, it is very important to have a team that supports your decisions as parents and helps you achieve these decisions and goals."
 - b. "They helped and are still helping my family navigate this path. I am so grateful to our team."
 - c. "EI changed our family's life for the better and they helped educate and connect us in a way I feel a private service provider could not"
2. Child made development gains (9)
 - a. "My son has made amazing progress, and I'm sad to be ending services."
 - b. "Our EI team a great experience and I would never have been able to interact with my granddaughter life we do now."
 - c. "They gave us hope and pushed through goals that we wanted our son to accomplish! Things that we never thought he could do...they got him to do them!"
3. Overall positive experience (31)
 - a. "We were very satisfied with our experiences with EI."
 - b. "Early intervention was the best thing that could have happened for our son."
 - c. "EI services has truly changed her life and for the better!!"

Number of negative comments regarding experience with early intervention: 65

1. Total information provided (13)
 - a. "A lot all at once. Confusing/overwhelming"
 - b. "I was given a binder of information that included a list of EI programs"
 - c. "Always went above and beyond providing information"
2. Increase number of Services (8)
 - a. "summer was slow on services."
 - b. "no services available for him over the summer."
 - c. "I wish we had more visits than once a month."
3. Increase social opportunities with D/HH families (6)
 - a. "more resources to other families who have children with hearing loss/other challenges."
 - b. "important to have the support of other families"
 - c. "better play groups"
4. Poor Communication with EI (11)
 - a. "a lot of staff turnover and the transition to new providers was not communicated to us –a different person would just show up."
 - b. "a lot of change over in staff"
 - c. "they just forgot about us. (They were) supposed to come once a month and we just didn't hear from them."

Please share additional comments regarding any barriers to receiving services for your child.

1. Health care costs (31)
 - a. "Original hearing aid was covered by insurance future ones will not"
 - b. "Our private insurance involves high premiums every month as well as coinsurance payments and deductibles that can add up.
 - c. "The costs for congenital CMV are outrageous"
 - d. "My main concern is and always will be the ability to pay for all of the services he needs. Between copay's, deductibles and maximum out of pocket it has been very stressful trying to pay for all of his care. It is overwhelming for our family since our income is too high to qualify for help."
2. Distance from services(6)
 - a. "Long distance to go for testing -150 miles one way"
 - b. "We ended up traveling out of state for therapy and audiology."
 - c. "Many services are far away"
3. Unaware of all therapeutic services (12)
 - a. "Would've nice if the community knew of services."
 - b. "It was difficult at first because nobody had told us about some services."
 - c. "I do not remember hearing about all of the services but all the ones I did get were really helpful."

Knowing what you know now, what would you have done differently in obtaining early intervention services for your child?

1. Sought alternative resources (17)
 - a. "I would have switched to pediatric specialty providers earlier."
 - b. "I would not solely rely on government early intervention services."
 - c. "I probably would have stuck to only private therapies."
2. Asked more questions (11)
 - a. "I would have been more assertive in asking for resources related to the communication method we had chosen."
 - b. "Asked more questions about conditional services available."
 - c. "Ask for ASL instruction on day 1 of services!"
3. Met with other families or deaf mentors (14)
 - a. "I would have been more open to parent support groups or DHH gatherings."
 - b. "Looked more into finding other children that are DH/H. Connecting with parents."
 - c. "Made attempts to meet w/ other cochlear kids sooner."
4. Sought services earlier (31)
 - a. "We started early intervention when our child was 8 months, starting around 4 months of age would have been a better choice as we would have put on hearing aids sooner."
 - b. "Started private speech sooner."
 - c. "Would've started AVT sooner"

What is the most important advice you would give a parent whose child has recently been diagnosed with hearing loss regarding early intervention and family supports?

1. Don't wait, start early (22)
 - a. "Use the help offered and don't delay."
 - b. "Don't wait for people to contact you, be proactive."
 - c. "get aids on at the early possible age and stay with it. Give your child all they need to hear and succeed and trust in them."
2. Ask for your child's needs (53)
 - a. "ask for referrals"
 - b. "ask for price reduction/free services"
 - c. "You are and will forever be the best advocate for your child. If you think something is off -keep going until you get answers."
3. Connect with other parents of DHH children(12)
 - a. Have a parent who went through it call the new parent to let them ask questions on what works and what doesn't work and share their story."
 - b. "Find and talk to other parents who have been through your situation, and who have pursued a similar outcome that you desire."
 - c. "Take advantage of opportunities to meet other parents of DHH kids."
4. Become informed about support and services
 - a. "Support and free services are available and important to start early."
 - b. "My advice would be to try to push things along as quickly as you can because the earlier your child has been diagnosed the earlier you can get him/her aided and in therapy."
 - c. "Get in contact with EI! They will help you with everything you need whether it is support, education, or where to go next as your child advances and gets older."
 - d. "Get informed!! Utilize all resources (medical professionals, support groups, state services, the internet, etc.) to learn about D/HH children and the needs they have. Advocate and never be afraid to question what you are being told. Your child is relying on you to get them the equipment and services they need."