

Early Childhood Intervention (ECI)

INPUT, INFLUENCE, AND IMPACT Texans with Disabilities Driving Advocacy

Introduction:

The Coalition of Texans with Disabilities (CTD), with the help of a variety of organizations and advocates, developed three online surveys to collect data on topics that directly affect the disability community. Statistical and qualitative data was collected from January 30, 2015 to March 13, 2015 on disability employment, early childhood intervention, and personal attendant services by CTD's developmental disability policy Fellow. CTD's fellow is part of Texas Council for Developmental Disabilities grant-funded program that supports a policy-focused staff member to develop professional experience on disability issues.

CTD estimates as many as 20,000 people with disabilities, their families, and supporters received (multiple) notifications of the availability of the surveys and their importance for the policy Fellow's research. Outreach was conducted via word-of-mouth, social media, newsletters, and online methods. Many of CTD's partners were gracious in sharing the outreach efforts.

Unfortunately, the numbers of submitted surveys were extremely low and not statistically significant. Therefore, inferring any conclusions or contrasting the survey data with nationally collected statistics would be inappropriate. However, the open-ended questions provided invaluable input and insight for CTD staff members during the 84th Texas legislative session. These responses helped CTD staff members to understand individual challenges and omnipresent barriers that Texans with disabilities face on a daily basis.

Respondent answers have been edited minimally by correcting spelling errors and formatting. All respondents were anonymous and responses have been randomized to protect each respondent's privacy. Several respondents filled out paper surveys (Appendix A) or were scribed by the policy fellow.

Current Situation:

[Early Childhood Intervention \(ECI\)](#) is a program coordinated by the Department of Assistive and Rehabilitative Services (DARS) that provides a variety of parental training and support services such as physical therapy, occupational therapy, speech therapy, screenings, and assessments for children with disabilities from birth to three years old. The services are typically delivered in a family's home (or another location) via health service contractors.

ECI is a crucial resource for the parents of children with disabilities. A multitude of studies have shown early intervention services to be important to the development of children with disabilities and to be extremely cost-effective by reducing the need for future long-term services.

The program has undergone many changes in provider qualifications, services hours, and cost sharing over the past several years. These changes have had a significant impact on the children who qualify for services, and for the growing number of children diagnosed with disabilities that would have met program qualifications in the past, but no longer qualify for these services.

Survey Data:

The Early Childhood Intervention (ECI) survey consisted of 20 questions (Appendix A). 14 Texans with disabilities began the survey, but only 9 people completed it. Of those 9, 8 were family members or parents and one was a consumer who received services in California in the late 1970's. The participants' responses to the open-ended questions provided useful insight to the limitations of the ECI program and delineated areas that were the most helpful or restrictive) to consumers.

The Basics:

Who?

- 89% of the respondents **were parents** of a child who received ECI services from DARS.
- 1 person was a consumer of ECI services as a child who currently lives in Texas but received services out-of-state.

Outreach?

- 63% of the respondents found out about ECI services via **their own research**; 37% were provided with a **referral**.

Family Cost-Sharing?

- 44% of the respondents **participated in** the "family cost-share system," 11% **did not**, while another 44% **did not recall**.
- 11% of the respondents stated that their family cost share **was a burden**, 22% stated that it **was not**, while 67% **did not recall**.
- 83% of the respondents stated that their family was responsible for a family cost-share amount of **less than \$25/month**, while 17% stated that their share **was more than \$401**.

After ECI?

- 67% of respondents stated that their child participated in **Preschool Programs for Children with Disabilities (PPCD)** after ECI services stopped, while 33% **did not respond**.

- 50% of the respondents stated that their **child's services changed** after stopping ECI, while the remaining 50% stated that their child's services **did not change**.

Consumer Satisfaction?

- 67% of the respondents stated that they **were very pleased** with the ECI services they received, 11% stated they **were somewhat pleased**, and 22% respondents stated they **were not at all pleased**.
- 67% of the respondents stated that the **hours of service** that they received **were sufficient**, while 33% stated that the hours **were not enough**.
- 67% of the respondents stated that **ECI services were helpful** to them and their child, while 33% stated that they **services were not helpful**.

In-depth:

When did you receive ECI services?

Answers varied widely, as each of the 6 respondents stated a different timespan for the services they received.

Responses	1	1	1	1	1
Dates	1973 - 1976	2003	2004 - 2005	2007	2011 - 2015

Where did you first learn about the availability of ECI services for your child?

Responses	2	1	1	3	2
First learn	Internet search	Agency	Medical professional	Family or friends	Other

Where do you think ECI services should be delivered?

Respondents' answers varied greatly with no consensus on the locations at which ECI services should be delivered.

Responses	36%	36%	18%	10%
Location served	Family's home	Childcare facility	Offsite location	Other

What were the differences in your services when ECI was over?

Two participants responded to this question with the following statements:

- a) "Services provided at a greater frequency, and included A.B.A. [Applied Behavior Analysis] (out of my own pocket of course)."
- b) "No longer received services in the home. Son only received services at school, so not as much access to parent training."

Were there significant transition challenges?

Most respondents did not state any transition challenges, but one parent stated, "They were significant - basically non-existent and an appropriate plan was not in place when my son turned 3."

Further Clarification:

The respondents stated the reasons for their preferred delivery locations as follows:

- a) "I think services need to be offered in a variety of settings so that generalization of skills can be built in immediately. Also a service delivery model that relies mostly on training parents to implement the vast majority of the therapy is not realistic, stressful and emotionally draining."
- b) "Easier for my child to be in a comfortable place to work the best."
- c) "My son wouldn't break away from me or his things in our home."
- d) "My work schedule is from 8-5 Monday to Friday, my child spends most of the day at daycare and I prefer services there so the teacher can also work with her outcomes/goals."
- e) "Because I had the opportunity to be present in-home, and so I was able to learn a lot of the techniques to help my child."
- f) "Child spends most at the day at daycare while I work."
- g) "Babies are supposed to be nurtured at home -- safest environment."

In Their Own Words:

Respondents were asked to share their experiences and insights about the ECI program.

- a) "They helped me get her SSI and set up for school. They referred me to a wheelchair company for my daughter. They cared about what we thought and listened to our questions and concerns. Very friendly and gave us pointers on what else we can do at home when she doesn't have therapy."
- b) "I can only share that the therapists were well intentioned but felt constrained by the severe limitation on services offered to families of children with significant disabilities like autism."
- c) "We are US tax-paying citizens and our child was not provided ECI services because no one saw the disability until he was 3years old and he was officially diagnosed to have Autism at age 4. We already missed ECI."

- d) "Early intervention made a huge impact for my child's progress. I believe it was key in helping him overcome many of the symptoms of autism, and it taught me invaluable lessons to help my son and myself to cope with his diagnosis."
- e) "Coppell ISD's Child Find is not working properly. They are not doing their job."
- f) "Look at New York for a far far better service delivery model. They have recommendations for intensity and frequency of services and provide services such as ABA and DIR Floortime that is not provided by ECI Texas. You can also put your toddler in a small preschool setting with various ratios depending on the nature and severity of the disability and all of it is provided by ECI."
- g) "I participated in ECI in California, which has many different rules. But I was pleased with my services and I remember that I learned to walk and was prepared to enter school with these types of pre-k special education services."
- h) "Need more physical therapists and more time for physical therapy. Some kids need more than two times a week and for 30 minutes. An hour of therapy time for some kids is just right. 30 minutes some just start working 15 minutes in."
- i) "I think more children up to the age of three need to be screened by an ECI professional."
- j) "The services were so minimal they were wholly ineffective and we had to fight to try to get more and do more privately and tremendous personal expense. Also transitioning from Part C services to Part B services was horrible."
- k) "My son could not speak and was offered speech 1 time per month during working hours/working days. Overall there was no benefit as the devices were ridiculously limited, and often canceled last minute by the provider."
- l) "I did not have a family cost share but the maximum charge's seemed economical."
- m) "Our child missed the early intervention in 2004 - 2006. Our child was born in 2003. He wasn't officially diagnosed until 2007. So we missed ECI services. We missed a lot of the early intervention."

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