



Meet Lillian

(as told by her mother, Nichole)

In 2018, having recognized that my daughter, Lillian, was definitely in need of speech therapy, I began the tedious process of trying to obtain an evaluation for her. I had to send in a request for evaluation three times to our school district. I physically dropped a copy off, faxed a copy to them, and mailed one in as well. An evaluation was finally setup in November 2018 after I physically returned to the district office with my fax confirmation.

From the day of actual evaluation to the day services for Lillian actually began took 'SO LONG'. In April 2019, Lillian finally started receiving the speech services she was deemed eligible for on her IFSP.

Lillian is very delayed in her articulation. She becomes very frustrated when we cannot quite make out a word or phrase she is trying to say. As a parent this absolutely breaks my heart. She has now begun to say she is *stupid, and not smart*. I always tell her how brilliant she is. And that her tongue just needs to keep getting help so her words come out better. If her evaluation would have happened sooner, she would definitely be further along on her speech. I feel that every month missed is like 6 months behind for a child's growth.

Four year old Lillian understands that she needs to work on her language skills although, she still doesn't fully grasp why. I am very pleased that this year for Kindergarten she was accepted into a special program for children in need of speech services called STEPS. I believe all the students need some form of speech therapy. And even though we are under remote learning, Lillian seems super confident. She has said, "Mommy (child's name), sounds like me. They need help with their tongue," with a huge smile.

So while I am frustrated that it took so long for her initial evaluation to take place, I am pleased with how far along her abilities have come.



A PARENT'S *Perspective*

A Mother's Response to the Bureau of Early Intervention's Exit Survey

If you have recently exited Early Intervention, or are getting ready to exit, there will be a survey coming to you. It might seem like extra work, but please consider writing a letter to accompany the survey. It might prove to be beneficial and make the Department of Health see that there is more than just configuring data on a LIKERT Scale, because in this case this research will not bring forth the problems that exist.

My reasoning for adding this letter is simple. Quantitative data for this program doesn't highlight the deficiencies that exist. A qualitative survey would give better feedback because the questions would have to be open ended.

To Whom It May Concern:

I recently received the exit survey for the Early Intervention program. I understand this survey attempts to compile data using a Likert scale system; it does not allow addressing the issues that exist within the program altogether. For many parents, especially in the Monroe County area of New York State, this survey does not allow the parent to address any deficiencies within the program. The state will understand the needs that are not being addressed with proper solutions. You will find attached responses to all questions in the survey. I hope that you will take the time to understand the complexities and deficiencies that parents face because of the funding issues in the state.

Survey Questions and Responses:

1. Understand how the Early Intervention system works.

Upon exiting the program, I fully understand how this program works, including the complexities and the provisions written in USC §1400-1470. Without research, this would not have been possible.

2. Understand the roles of the people who work with my child and family.

When my child was enrolled in this program, this was not always possible as wait times prevented providers from working with my child. As a parent and a former DSP at Finger Lakes D. D. S. O., it was not hard to know the role that the service coordinator plays or to understand the part of the providers when my child was put on a provider's caseload.

3. Communicate more effectively with the people who work with my child and family.

Communication is a vital piece of this program from start to finish. There are currently two versions of the New York State Public health law: the legal and state personnel version, the other version for the public. New York State Public Health Law §2545 does not give the 30-day time limit when looking online, but it does to the legal team that works in the Assembly.

4. Be able to evaluate how much progress my child is making.

Evaluating my child's progress has been seen throughout the year in Early Intervention when the necessary services began being delivered to my child.

5. Know About my child's and family's rights in Early Intervention.

About this subject of knowing my rights and child's rights within the program, it took countless hours of research, contacting IDEA, speaking with other parents, talking to advocates through The Children's Agenda, becoming a member of the LEICC, and working with local and state legislators.

6. Get the services that my child and family need.

Waiting on a capacity list for months did not achieve this goal for an extended period. Once services started, and new relationships formed with new providers, progress began to take shape for my child. The wait time exceeded a full IFSP time frame.

7. Feel that I can get services and supports that my child and family need.

To address this matter, I, as the parent, never stopped advocating and fighting for services even when my child was on the capacity list. I obtained speech services from private providers with insurance paying for the service. My child participated in clinical services that were provided by a clinic through Nazareth College. From January 2019 – August 2019, speech therapy was not included in the IFSP. Speech Therapy was crossed off of the initial IFSP because there was thought that Special Instruction was more critical, even though she was not talking at the time, and was a primary issue with her development and behaviors because of the inability to communicate effectively.

8. Know where to go to get supports to meet my child's needs.

As previously stated in response to question 5, knowing my child's and family's rights in Early Intervention because of my involvement with other parents and programs in the community, I met this. I continue to advocate for my child in the preschool setting.

9. Know where to go to get supports to meet my family's needs.

Please reference the response to question 5 and question 8. This question is redundant.

10. Understand my child's special needs.

Understanding my child's special needs was achieved by the partnership of her providers over the last year.

11. Feel more confident in my skills as a parent.

Not applicable

12. Feel that my efforts are helping my child.

My efforts help depend on the day and sometimes are entirely ineffective, every parent encounter this. This issue does not solely fit into the realm of a parent of a special needs' child.

13. Be more effective in managing my child's behavior.

This is a work in progress, and there is no choice on the Likert scale that fits.

14. Make changes in family routines that benefit my child with special needs.

This is answered on the survey

15. Do things with and for my child that are good for my child's development.

Please consider the choice of words for this question. It is non-specific, and I, like other parents, do "things" that are good for my child's development.

16. Do activities that are good for my child even in times of stress

Please reference the survey

17. Improve my family's quality of life

Please reference the survey

18. Keep up friendships for my child and family.

Please reference the survey

19. Feel that my child will be accepted and welcomed in the community.

Please reference the survey

20. Feel that my family will be accepted and welcomed in the community.

Redundant question, combine with question 19

21. Know about services in the community.

Please reference the answers for questions 5, 7, and 8.

22. Participate in typical activities for children and families in the community.

Due to Covid-19, this has not been entirely possible.

23. Think back on your child and family's time in the Early Intervention Program. If your child received Telehealth services, they worked well. Telehealth services mean your child received services through a computer, tablet, or smartphone.

This question assumes that the services worked well. The services did not work well for an extended period because of the change from in-person to telehealth. Constant forms of bribery rewards to convince my child to engage, reduction in services provided, and challenges with having other children around wanting to participate with their sibling make telehealth extremely hard.

24. Think back on your child and family's time in the Early Intervention Program. Telehealth services may not have been available to your child and family. If they were available, would you have used them? Telehealth services mean your child received services through a computer, tablet, or smartphone.

Please reference the answer given for question 23.

During the time my child spent in the Early Intervention Program, the language, the lack of direct support when pressed about time frames even from the BEI, made it hard in the beginning. This unique design helps children and families, yet the language and communication are not the best. Without the help of Disability Rights New York and ultimately, without other parents' support, the path of waiting would not have been as manageable.

Sincerely,

E.M.



Interfaith Collaborative's 2020 Advocacy Issue

The Children's Agenda's Interfaith Collaborative is a diverse group of faith communities throughout Monroe County dedicated to advocating for the changes children need most. For the third year in a row the Interfaith Collaborative has chosen Developmental Services as their advocacy issue.

Last year the Interfaith Collaborative collected and delivered 4,333 letters signed by members of 50 congregations requesting an increase in funding for Early Intervention and Preschool Special Education.

Due to COVID-19, this year's letter is in the form of an on-line petition. The petition asks the Governor and State Legislative Leaders to include a Covered Lives proposal and funding for families to aide with digital accessibility in the 2020-21 state budget.



Parent Survey Time

In last month's newsletter we shared the results of the Parents Helping Parents Coalition of Monroe County spring parent survey regarding telehealth services for Early Intervention and Preschool Special Education.

Last week they launched two follow up parent surveys to identify areas of progress and need in this new school year. **Monroe County parents** may access these surveys at the following links:

[PHP Early Intervention Parent Survey](#)

[PHP Preschool Special Education Parent Survey](#)

Following in their footsteps the Kids Can't Wait Campaign launched a similar survey to capture the same information from **New York State parents residing outside of Monroe County**. The Kids Can't Wait Parent Survey is available in both English and Spanish and may be accessed at the following links:

[KCW Parent Survey – English](#)

You do not have to be a member of one of the participating faith communities in order to complete the petition, it is open to all New York State residents. [Click here](#), if you'd like to add your name to the petition. And as always spread the word!

[KCW Parent Survey - Spanish](#)

Your survey responses are very much appreciated and they help guide our advocacy efforts to best meet the needs of children and families.

The Children's Agenda

1 South Washington Street Suite 120 | Rochester, New York 14614
(585) 256-2620 | communications@thechildrensagenda.org

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