

Sarah Thompson

Early Intervention Parent Liaison



## INTRODUCTION

As a parent of a child with a disability and a professional in the Early Intervention system, I have learned from personal experiences how important building personal relationships with Providers and the family are. Healthy personal relationships aid in family engagement, better understanding of parent sensitivity, and effective communication.

Early Intervention has Key Principles. The top 4 key principals that have directly impacted my life are:

1. Infants and toddlers learn best through everyday experiences and interactions.
  - I have come to learn I am my child's best therapist.
2. Families, with the necessary supports, can enhance their children's learning.
  - I have learned to develop a voice on behalf of my child. I have learned how to be an advocate. I have learned the confidence to develop both of these characteristics.
3. Early intervention needs to be individualized to reflect family preferences.
  - I have learned that Providers need to meet the family where they are at. By doing this, it positively impacts where the parent is in their child's development. This has allowed me less personal resistance in working with Providers and less guilt if we aren't all on the same page of professional vs. personal decision making.
4. IFSP outcomes must be functional and based on children's and families' needs.
  - Realistic expectations has probably been the hardest concept for me to develop over time. Denial may be a contributing factor? But at the end of the day HOPE is what I cling to.

As a Parent Liaison I educate Providers to help understand how they and families can work together in achieving the Mission of Early Intervention.

## THE NEED TO ACHIEVE THE EARLY INTERVENTION MISSION

As a Parent Liaison part of my job for the past 4 years has been to survey families during their process with EI. I have also conducted trainings with Providers on the parent perspective based on my personal experiences, ongoing interactions with EI families and Parent Liaison surveys.

The feedback has shown there is still work to do in the field of disability. There is a gap that needs to be bridged between family and Provider perspectives.

Educating Providers on the parent perspective helps to achieve the EI mission. Not all diagnoses are the same but there are very similar ranges of emotions these families face. There are daily challenges that are unique to families raising a child with a disability. This all factors in how "receiving" families are of ongoing Provider services.

## OBJECTIVE

The objective is simple: Education on bridging the gap between families and Providers.  
What factors are impacting the "GAP"?

### Family Priorities

- Understanding what they are. Sometimes just getting through the day.

### Trigger Words

- Remembering person first language

### Grief

- ROLLERCOASTER of emotions
- Guilt
- Denial
- Depression

### Previous Negative Provider Interactions

- Thinking outside of the box. Theory vs. being realistic

## Early Intervention Parent Liaison Satisfaction Survey

*Survey developed by Sarah Thompson, Parent Liaison*

Surveys are conducted by phone monthly. Questions are based on the families current level of participation in the Early Intervention system.

Level of participation includes:

- Intake into the EI system
- Ongoing direct services
- Transition out of EI on the child's third birthday.

1. DO FAMILIES FEEL THEY HAVE A VOICE AND UNDERSTAND THEIR RIGHTS IN EI.
2. DO FAMILIES FEEL THEY ARE A VALUABLE MEMBER AND TREATED AS AN EQUAL ON THEIR CHILD'S EI TEAM.
3. HAS THEIR EI TEAM HELPED TO EMPOWER THEM TO BE AN ADVOCATE FOR THEIR CHILD.
4. DO FAMILIES HAVE CLOSE WORKING RELATIONSHIPS WITH MEMBERS ON THEIR CHILD'S EI TEAM.
5. WERE THEIR QUESTIONS AND/OR CONCERNHS HANDLED APPROPRIATELY.
6. HAS EI MET THEIR EXPECTATIONS.
7. WOULD THEY RECOMMEND EI TO A CONCERNED PARENT.
8. WHAT WAS THEIR CHILD'S GREATEST ACCOMPLISHMENT DURING EI.
9. HOW SATISFIED THEY ARE WITH THE LEVEL OF SERVICE THEY ARE RECEIVING.
10. WHAT SUGGESTIONS FAMILIES HAVE ON IMPROVING OUR SERVICES TO THEM.

## NEXT STEPS

FAMILY TO PROVIDER CONTINUED EDUCATION TO ADDRESS THE "GAP" TO BUILD GOOD RELATIONSHIPS.

- a. Co-facilitator of trainings with the Early Intervention Training Program
- b. Trainings with Providers outside of CFC #16
- c. Future work with the Department of Health & Human Services

## THE NEED TO ACHIEVE THE OBJECTIVE

As a Parent Liaison I have found family feedback I get is different than what is given to Providers. I am seen as a relatable parent rather than a professional. With me, families more freely share their honest feelings and quality of services they are receiving. Working in EI as in interdisciplinary team All sides of feedback is important to learn the full family picture. THIS knowledge improves better quality of service.

## FINDINGS BASED ON FEEDBACK

### COMMON PARENT EXPERIENCES IN RAISING A CHILD WITH A DISABILITY

- Anxiety
- Grief
- Sense of urgency in obtaining services
- Lack of communication with Providers
- Feelings of being overwhelmed
- Reliability of Providers

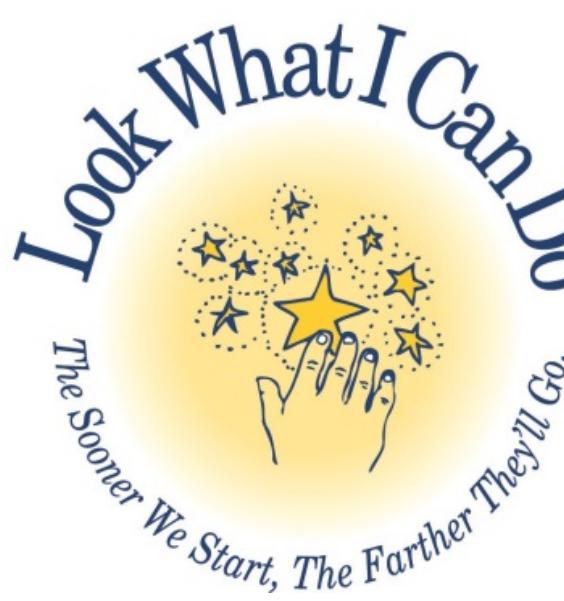
### COMMON CHALLENGES PROVIDERS FACE WORKING WITH FAMILIES

- Lack of active engagement and follow up on the part of the family.
- "Fixing" the child
- Lack of Communication with the families

## CONCLUSIONS

### FAMILIES AND PROVIDERS FACE COMMON CHALLENGES

- A. Communication
- B. "Fixing" the child
- C. Expectations
- D. Frustration
- E. Active engagement



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