

**ECI WEBINAR SERIES:
PRACTICAL STRATEGIES FOR
WORKING WITH CHILDREN WITH
AUTISM**

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PART 1: ESTABLISHING RELATIONSHIPS WITH FAMILIES AND BECOMING AN EFFECTIVE COACH

- Let's start by talking about some issues that are common in families of children with autism.
- Depending on your level of experience, you may be aware of these issues already.
- Others you may not have given much thought.
- Sources for this discussion include some new research:
 - *Helping Families Caring for Children with Autistic Spectrum Disorders* (2009) by Ghanizadeh, Alishahi, and Ashkani
 - *Family Adaptations, Coping and Resources: Parents of Children with Developmental Disabilities and Behavior Problems* by Jones and Passey



FAMILY ISSUES TO CONSIDER

Mothers

- In the first study, the mothers of children with ASD had poorer mental health than the general population.
- The burnout effect of having a child with an ASD is stronger for mothers than for fathers.
- Mothers do better when the child with autism has fewer maladaptive behaviors and fewer social impairments.
- Mothers who have difficulties in family adaptability and cohesion have higher levels of depressive symptoms and anxiety.



FAMILY ISSUES TO CONSIDER

Siblings

- Siblings can play an important role, especially with opportunities for social interactions.
- However, the stress level for siblings may be high. When children with autism have behavior problems, their siblings may have social problems as well.
- Relationships with their friends may also be impacted.



FAMILY ISSUES TO CONSIDER

Coping

- Couples with children who have autism have more conflicts and sometimes less family cohesion.
- When a family's coping mechanisms are not as strong, there is a higher level of stress and tension.
- **However, the coping strategies of the parents change over time.**
- Acquiring social support is a coping strategy which should be encouraged and families need a social network.



FAMILY ISSUES TO CONSIDER

Sleep

- Children with autism often have sleep problems.
- Screening and management of their sleep problems improves family functioning.
- The parents of children with autism suffer from greater sleep problems than those of typically developing children.
- Sleep quality of the parents is poorer and their sleep quantity is lower than the parents of children without ASD.



FAMILY ISSUES TO CONSIDER

Feeding Problems

- Feeding problems and gastrointestinal disturbances are more common in children with ASD and their parents might be worried about these problems.
- Common issues are resistance to trying new foods and being a “picky eater.”
- Parents need help with these issues in order to decrease family stress.



FAMILY ISSUES TO CONSIDER

Sensory Problems

- Sensory impairments such as taste, smell, visual, and auditory process problems are common to many children with autism.
- Sometimes, these problems are not reported by clinicians but are reported by the parents.
- Children may also be defensive to tactile or auditory stimuli.
- When developing programming for young children with sensory issues, parents' observations and concerns should be addressed.



FAMILY ISSUES TO CONSIDER

Quality of Life

- In developed countries, the quality of life of families with children who have autism may be more of an issue than even financial problems.
- In some cases, even the health of parents can be impacted.



FAMILY ISSUES TO CONSIDER

Economic Problems

- The families of children with ASD may have a lower level of income. In the study cited, the families were more likely to have financial problems and often needed more money for medical care for their children.
- Depending on where families live, families may or may not have good access to specialized care for their children and themselves.



FAMILY ISSUES TO CONSIDER

Mental Health

- In the study cited, the authors estimated that the lifetime financial cost for a child with autism in the U.S. is \$3.2 million and is rising.
- The mental health care service system is sometimes inadequate to provide the help that families need, especially when the child's ASD impacts their employment status.

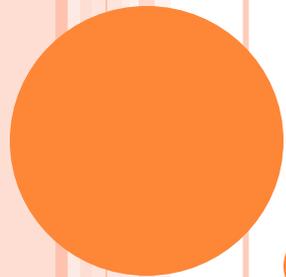


FAMILY ISSUES TO CONSIDER

The Parent-Child Relationship

- The mother-child relationship is impacted by the lack of social reciprocity and the presence of repetitive behaviors when the child has autism.
- **Teaching the parents improves their positive relationships with their children, increases their social interactions with their children, and decreases parenting stress.**
- Mothers who accepted the diagnosis of autism had some higher levels of engagement, especially supportive engagement in play interactions with their children.





ANY QUESTIONS?

We will take a few minutes to allow you to submit questions.



QUICK REVIEW

Which of these characteristics of autism can cause stress for the family of a child with autism:

- A. Sleep problems
- B. Feeding problems
- C. Sensory problems
- D. All of the above.



IMPORTANCE OF THE FAMILY'S COPING STRATEGIES

- The second study examined not just coping strategies but “locus of control.” This refers to one’s view of events as either outside of one’s control (external locus of control) or within one’s control (internal locus of control).
- Coping strategies associated with *reduced stress* included:
 - Maintaining family integration
 - Cooperation
 - Optimism
- Parents who feel effective in their parenting role and in control of their child’s behavior tended to have lower levels of stress.



EXAMPLES OF FAMILY STRESSORS

- The majority of parents in the second study found that dealing with friends and family on a daily basis was extremely stressful.
- The significant challenges faced were consistently related to a lack of knowledge and understanding by others.
- Most parents felt that explaining their child's disability and specific difficulties to others as the most beneficial strategy to reduce this stressor.



OTHER FAMILY STRESSORS

- Parents reported difficulties in obtaining a diagnosis or gaining accessible and understandable information about their child's disability by doctors.
- Once help *was* received, parents reported challenges in obtaining consensus from professionals about future services and appropriate supports.
- The majority of parents reported the need for perseverance and determination when acquiring supports for their children as well as getting second opinions and further information to support their decisions for their children.



KEY FINDING OF THE SECOND STUDY

- *Parents emphasized that although professionals are knowledgeable and essential in providing support, parents know more about their child's needs than anyone else.*



OTHER IMPORTANT FINDINGS FROM THE SECOND STUDY

- For parents to become competent and effective in their parenting, *services must assist them in feeling a greater sense of personal control* over their child through teaching, training, and further information.
- Various parenting approaches and coping strategies need to be recommended and taught to parents, including opportunities to promote family cohesiveness and cooperation, through parental support groups and respite for parents.



WHAT TO TAKE AWAY FROM THIS RESEARCH



No wonder when you show up, what the parents may feel like they need is this!!

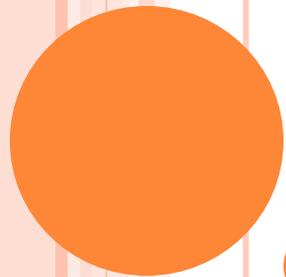


WHAT TO TAKE AWAY FROM THIS RESEARCH (IN ADDITION TO HOW THE CAT FEELS)

Here's what I take away from these two studies:

- When you first meet the parents of a child with autism, they will be tired, stressed, worried, and often, already frustrated.
- The mothers will likely be experiencing the highest levels of stress.
- Their children may not eating, may demonstrate serious behavior problems, may be over-reacting to sensory stimuli, and may never sleep at night.
- Unless you deal with these challenges, you are unlikely to make much progress teaching the child or the parents.





ANY QUESTIONS?

We will take a few minutes to allow you to submit questions.



QUICK REVIEW

If the situation is as described for families, what does this mean for your approach?

- A. It would be a good idea to ask the parents about the stressors that are impacting their family life, even if they seem mundane or ordinary.
- B. Getting to know the family situation is a great idea!
- C. Even if you don't start to teach the child skills right away, if you are getting to know the family and what they see as important, that's just as valuable.
- D. All of the above.



Getting the Conversation Started

Based on the information presented so far, what are some questions that you might want to ask families who have a child with autism during your first few visits?

Is there any information that might help you as you not only try to understand their child but also understand their situation?

For example, I might be asking questions like these:

- *“How is your child sleeping? “And how much sleep are you getting?” “Does he have a bed time?” “How is that working?”*
- *“Do you have any family support?” “Is there anyone who is helping you?” “How about in the community?” “Do you know what resources are available?”*

What are some other questions you might suggest?

- “.....?”
- “.....?”
- “.....?”



BECOMING A COACH

- Because your role is to work with the family, especially parents, and not just with the child, it is critical to learn how to coach and support the family.
- Remember some of the points from the research:
 - **Parents do better when they have a sense of control and effectiveness about what they are doing.**
 - **Parents who feel effective in their parenting role and in control of their child's behavior tended to have lower levels of stress.**
 - **Teaching the parents improves their positive relationships with their children, increases their social interactions with their children, and decreases parenting stress.**
 - ***Parents emphasized that although professionals are knowledgeable and essential in providing support, parents know more about their child's needs than anyone else.***



WHAT MAKES A GOOD COACH?

Some of the basic literature on coaching suggests the following essential steps:

- ***Setting the foundation***, including meeting ethical guidelines and professional standards
- ***Co-creating the relationship***, including establishing trust and intimacy with the family
- ***Communicating effectively***, including active listening, powerful questioning, and direct communication
- ***Facilitating learning and results***, including designing actions, planning and goal setting, and managing progress.



SETTING THE FOUNDATION

- Of course, as an ECI professional, you have clear procedural and ethical guidelines that you must adhere to at all times.
- Your level of professionalism will encourage parents to trust you.
- Part of your role as a professional is to know when other resources are needed and to refer families when it is appropriate.



CO-CREATING THE RELATIONSHIP

In order for parents and families to trust you, you must create a safe and supportive relationship. You can do this by:

- Demonstrating concern
- Demonstrating personal integrity, honesty, and sincerity
- Establishing clear agreements and following through with what is expected
- Demonstrating respect for the family's perceptions, learning style, and personal beliefs
- Providing on-going support for new behaviors and activities, including those that may involved risk taking and fear of failure.



COMMUNICATING EFFECTIVELY

Good communication skills are essential. It is important to:

- Focus on the family's agenda, concerns, goals, values, and beliefs
- “Read” the tone of voice, body language, and words
- Summarize, paraphrase, and mirror back what parents say to ensure clarity and understanding
- Integrate and build on the family's ideas and suggestions
- “Bottom line” and help the client get to the heart of the issue rather than get bogged down in details.



COMMUNICATING EFFECTIVELY

In addition, good communication involves:

- Asking questions that reflect active listening and an understanding of the family's perspective
- Asking open-ended questions that create greater clarity or new learning
- Asking questions that evoke discovery, insight, and commitment or action
- Giving clear and direct feedback
- Re-framing and helping the parents understand from another perspective when they are uncertain
- Using language that is respectful and appropriate, without a lot of jargon.



FACILITATING LEARNING AND RESULTS

There are several issues related to this step, including:

- Creating awareness of multiple sources of information, so that the family has access to several perspectives
- Maintaining an open mind and not losing your own perspective
- Helping families identify their underlying concerns
- Identifying major strengths and major areas for learning and growth. Both are important!!



FACILITATING LEARNING AND RESULTS

- Brainstorming and assisting families as they define actions that will enable them to help their child even more----not getting stuck
- Engaging families to explore alternative ideas and solutions, which may mean they apply skills they have already learned
- Celebrating success and chances for further growth.
- Helping the parents “Do it now.” during the coaching session, with your immediate support.
- Creating plans that are attainable, measurable, and specific, and especially targeting early successes that are important to the family.



WE WILL LOOK AT A VIDEO CLIP

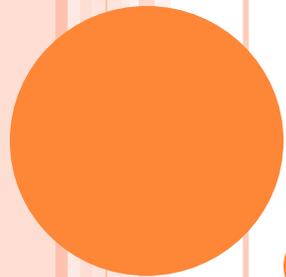
EXAMPLE

Some things I noticed about the coaching relationship:

- Mom's body language looks like she has trust and confidence.
- Both adults celebrate success.
- Mom shares information openly.
- Even though she is busy, the interventionist listens and asks questions.
- Mom's interactions with her child have increased.

What do you see?





ANY QUESTIONS?

We will take a few minutes to allow you to submit questions.



QUICK REVIEW

What are some strategies you can focus on to improve your coaching skills with families of young children with autism?

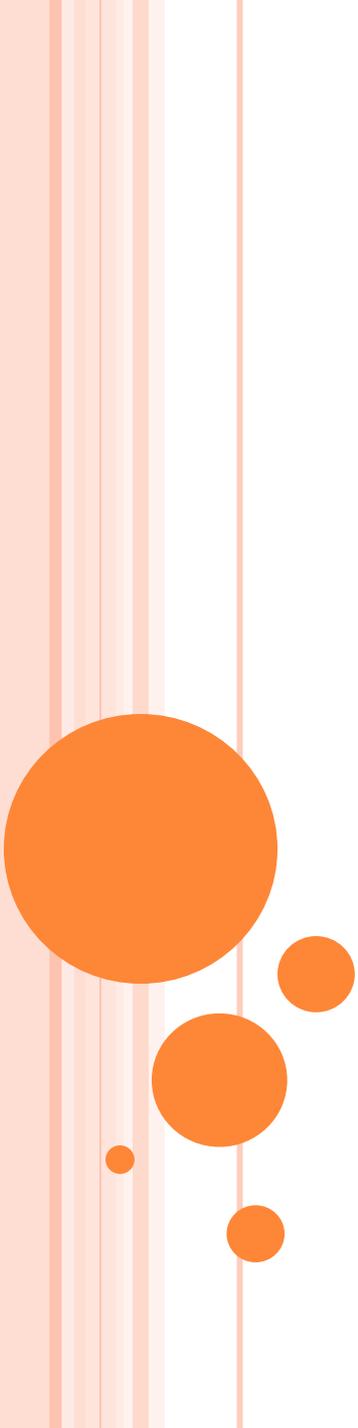
- A. Help them identify strengths and areas of need.
- B. Give clear and direct feedback.
- C. Summarize and mirror back information so you are sure that they understand.
- D. All of the above.



SUMMARY

- The families of young children with autism face many challenges. Some are unique because of the nature of autism.
- In order to work effectively with families of young children with autism, start by recognizing how they are feeling and thinking.
- To establish a coaching role, you will need to focus on setting foundation, co-creating a relationship, communicating effectively, and facilitating learning and results.





LOOKING AHEAD

Our next webinar will be on Monday, July 19th at 9:00 a.m.

The topic will be *Structuring the Environment for Young Children with Autism.*