

## Essential Elements of Family-Professional Collaboration

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## Sources for Presentation

- ◆ > 40 years experience, SCERTS Model
- ◆ research - experience of ASD in the family
- ◆ “Reflecting on the Journey” - 19 years of weekend parent retreats – learning from parents
- ◆ Dr. Elaine Meyer – Director, IPEP, Children’s Hospital- Boston and the Harvard University Medical School

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## Why Focus on this Topic?

- Very little, if any training for MOST professionals in ASD (exceptions: Social Workers and some Psychologists)
- Skills in teaching and therapies do not guarantee ability to communicate with and support families, especially around stressful circumstances and “high-risk” times

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**Why Focus on this Topic?**

- Parental attitudes about professionals vary greatly depending on parents' culture, past experience and understanding of ASD
- School and agency staff have a long-term enduring impact on the child and family
- "Trust must be earned"

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**Family-Centered Practice**  
(Prizant, 2008)

Family-centered practice has as its primary goal, empowering families with the knowledge and skills to make the best choices for their child and for the family. In family-centered practice, professionals collaborate with families in decision-making about specific goals and objectives, as well as educational/treatment approaches.

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**Family-Centered Practice**  
(Prizant, 2008)

Parents are respected as experts regarding their child, and professionals consider each family's unique strengths and needs, as well as its cultural and religious values.

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*Challenges for Families*

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*Major Sources of* **Stress**  
*for All Human Beings*

**Uncertainty**  
**Unexpected Events**  
**Lack of Control**

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**Challenges for Families**

1. Suspecting something is not right & searching for answers
2. Post Diagnosis - Understanding autism (ASD), and beginning the journey

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**Suspecting something is not right & searching for answers**



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**Challenges for Families**

- 3. Explaining ASD to others – dealing with judgmental reactions in public
- 4. Who to believe in the face of discrepant opinions/information (diagnosis and treatment)?

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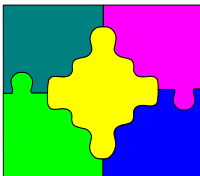
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**Understanding Autism and Explaining Autism to Others**



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### Challenges for Families

- 5. Which treatments to choose or approaches to take?
- 6. Coping with future uncertainty, transitions and change

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### Who do we believe?



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“Professor Marvel never guesses, he knows!”



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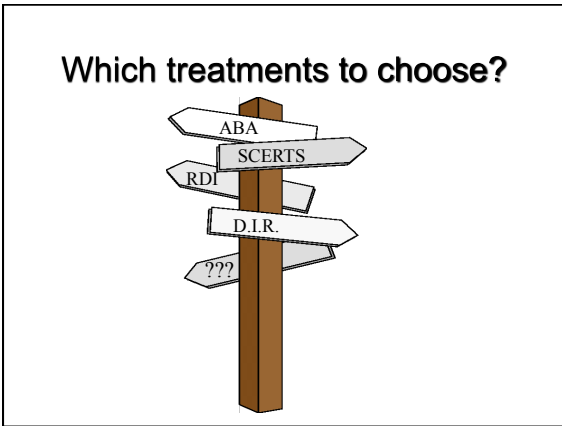
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**Transitions- Specific Challenges**

- Who will be working with my child?
- How will my child react to a new environment, new activities?
- Letting go and shifting trust to new staff
- New expectations for my child as he/she gets older (“no longer my cute little one”)
- Transitions require a future perspective, which may cause anxiety

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**Challenges for Families**

- 7. Finding balance - attention to the child, marriage, siblings and employment

“Juggling a million balls at the same time”

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“Juggling a million balls at the same time”



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**Challenges for Practitioners**

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**Challenges for Practitioners**

- 1. Working directly with children vs. supporting parents' competence and knowledge.
- 2. Respecting parental priorities and wishes about treatment options while trying to provide services based on effective practices.

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**Challenges for Practitioners**

- 3. Dealing with recommendations from professionals that are discrepant with one's own philosophy and practice.
- 4. Resisting the compulsion to "fix and rescue". Learning how to "bear witness".
- 5. Developing trusting relationships in a short period of time, and then "letting go".

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**Essential Elements of Family-Centered Practice**

- 1. Build Trust
- 2. Encourage collaboration
- 3. Communicate clearly and listen well - nonjudgmental
- 4. Demonstrate loyalty
- 5. Be humble

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***Successful Family Support  
begins with Trust.***

**A Major Source of Trust for  
Parents is the Interpersonal  
Characteristics of Program Staff**

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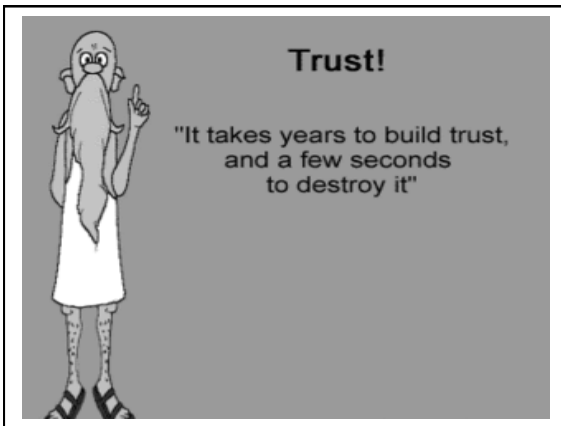
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**Interpersonal Characteristics  
that Engender Trust**

(Prizant, 2008, adapted from S. Covey, 2006)

**Character Indicators**

- 1. Talk straight**
- 2. Demonstrate respect**
- 3. Create transparency**
- 4. Right wrongs**
- 5. Show loyalty**

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**Interpersonal Characteristics  
that Engender Trust**

**Competence Indicators**

- 6. Deliver results
- 7. Get better – grow professionally
- 8. Confront reality but “keep hope alive”
- 9. Clarify expectations

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***Listening to Parents***

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*“I never learned anything  
when I was talking”*

- Larry King



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***We all benefit from support, and require support in our lives.***

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***“In order to survive, a human being needs to live in a home furnished with hope”.***

- Maya Angelou

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***“The people who have been most helpful to us are those who do not take away our hope. We have learned to keep away from the ‘doom and gloom’ crowd”.***

- Father of a 8 year old boy

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**What do parents find helpful?**

- 1. Honest and accurate information, resources
- 2. Quality services for child & support for family
- 3. Strong partnerships with professionals
- 4. Good night of sleep
- 5. Learning “tips” from other parents
- 6. Social support & sharing experiences with others
- 7. Respite opportunities

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**Conversations with Parents**

- 1. Be a good listener
- 2. Ask about the parent’s priorities and agenda
- 3. Try to understand the parent’s perspective and level of understanding
- 4. Collaborate with parents on assessment - validate their expertise

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**Conversations with Parents**

- 5. Focus on the child’s strengths as well as areas in need of improvement
- 6. Be a trustworthy partner
- 7. Reduce uncertainty – talk about upcoming activities and recommendations
- 8. Engage in transition planning in a collaborative and comprehensive way

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**Transitions Require Thoughtful Planning and Support**

- Major source of stress – uncertainty, unexpected events, lack of control
- First major transition - diagnosis
- Recurring transitions throughout the school years and out of school

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**THE “SCERTS” MODEL**  
(Prizant, Wetherby, Rubin, Laurent & Rydell, 2006)

**S - SOCIAL**  
**C - COMMUNICATION**  
**E - EMOTIONAL**  
**R - REGULATION**  
**T - TRANSACTIONAL**  
**S - SUPPORT**

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**How do we infuse Family-Centered Principles in The SCERTS Model**

**Assessment – first opportunity to develop trust**

- detailed caregiver questionnaire
- observe direct interactions at home, school
- develop consensus of child’s strengths and needs – include parent’s perceptions and have them validate assessment results
- document parental concerns and priorities

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**How do we infuse Family-Centered Principles in The SCERTS Model**

**Program planning and intervention**

- Collaborative goal setting
  - functional, meaningful skills
  - address family priorities
- Program for strengths and motivations
- Address objectives across home, school and community contexts
- Validate progress as “authentic progress”

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**How do we infuse Family-Centered Principles in The SCERTS Model**

**Program planning and intervention**

- develop Educational Support plan for each family with a choice of activities
- develop Emotional Support plan taking into account natural supports as well as other support activities

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**Trust and support allow parents to “reframe” and develop alternative perspectives about the experience of autism in the family**

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**“Despite living in New Hampshire for a few years before we had kids, we never hiked until the boys had autism. One day, about 3 years post-diagnosis, we found ourselves in a state park with time to kill.**

**We did a fast one-mile trek and it calmed the boys down, and gave us a family activity we all could share. We were hooked and ever since find ourselves devoting family time to rugged outdoor pursuits.”**

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**“I think about our journey and the “Mountain Climbing” metaphor often, and keep the attached photo mounted on the wall as my own symbol of the rewards of the journey. As I go about my day with its usual demands and frustrations, I see the phenomenal 9 miles of mountain ridge that my sons climbed - a climb their OTs questioned they could do - and feel immensely proud of us. It’s my own reminder that one fine day we accomplished a goal I’d always wanted not just in spite of autism, but because of it.”**

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**“While not everything works perfectly, I’m amazed at how many possibilities exist despite the dis-abilities.**

**That itself is a fine lesson that all of us special parents have learned, and that guides us through many a dark moment.”**

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**A Departing Thought**

***There are smaller lives and larger lives. The surest gauge of the scale of a life is how many other lives it touches.***

***Thank you for all you do!!***

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For more information and resources:

**WWW.BARRYPRIZANT.COM  
WWW.SCERTS.COM**

Coming in 2015

***Uniquely Human:  
A Different Way of Seeing Autism  
(Simon & Schuster)***

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