

A READER'S COMPANION



The Narrow Bridge
PRESS

Thoughts for Educators and Practitioners

For Families with Autistic Children

Excerpted from *A Miracle of the Heart: A Father and Son's Autism Journey*

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An autism diagnosis can be incredibly frightening for a family. There is still so much that is unknown about the condition — what causes it, and what lies ahead for the autistic individual and his or her family. Given the dramatic rise in the number of children being diagnosed as autistic, families may be overwhelmed and confused by the "noise" in the media, online, and in the press.

As a father whose child was diagnosed when he was two-and-a-half years old, I know what it is like for a parent to hear that his child is autistic and to be overcome by pain and fear.

Recently, I met with a group of early child intervention clinicians and shared these thoughts about communicating with parents and family members of newly diagnosed autistic children.

FOR PRACTITIONERS

What to Say to Parents

① *Your child is not broken*

- No matter how many unusual things your child does and how strange they seem to you, what your child is doing has meaning and a purpose for him or her.
- Our goals should not be to make your child "unautistic."
- Together we will work to bring out the best of your child and help him or her reach the best of his or her potential.

② *Your child's differences and difficulties are not your fault*

- You are not a "refrigerator mother."
- There is no clear evidence that vaccines cause autism or Tylenol taken during pregnancy causes autism.
- In fact, researchers are still searching for the causes of autism, and there may be multiple interlocking causes.

③ *We are with you*

- We are with you.
- We will be honest with you.
- We will give you a plan and help you every step along the way.
- Come to us with questions —
 - It is hard to screen out all the autism "noise." We will help you figure things out.
 - If we don't immediately know the answer, we'll figure it out.
 - Model affective behavior — show strong emotion through voice and gestures.

④ *This is a collaborative effort*

- We will work with you to find a network of practitioners in different disciplines and explore different educational settings and opportunities.
- We also have names of disability attorneys who will help ensure that your family receives the support you are entitled to according to the Individuals with Disabilities Education Act (IDEA) — which requires that children with disabilities be educated in the least restrictive environment. See: [ed.gov — Individuals with Disabilities Education Act](https://www.ed.gov/individuals-with-disabilities-education-act)

⑤ *You are not alone*

- According to the latest findings of the Centers for Disease Control, one in 32 children is currently being diagnosed as autistic.
- There are so many families who are facing the same situation.
- There are tremendous resources out there — we will help you find them.

⑥ *Honesty and Hope / Hope and Honesty*

- It may be a long road.
- It is hard to know the outcome.
- But we will work with you to make your child the best version of him or herself.
- We will be with you every step of the way.

What to Hear from Parents

1 *Autism is frightening — help us understand*

- Autism is like the monster under the bed.
- Its symptoms are strange and can be different for all individuals. Increasingly, individuals are determining that they are autistic when they are adults.
- The loss of connection with our children is not only frightening but heartbreaking as well.
- We don't know why this happened to us.
- We live in a world of magic pills and medical solutions. But there is no pill or shot for autism.
- We don't understand this — we want to know why this happened and we want to make it better.
- **Thus —**
 - **Take the time to explain what it means** in words that parents and family members can understand.
 - Recognize that families and individual family members will react differently.
 - Be aware of the potential and existing emotional impact.
 - Recommend supportive services for other family members — but only if requested.
 - Be appropriately available to family members — email, cell in an emergency.

2 *We need more than a diagnosis*

- In English — in words we can understand.
- Help us understand what this will mean for our child — how it will impact his or her life today and, in the days to come. Saying that it is a sensory processing issue or a developmental delay may not clarify things for us.
- Knowledge and understanding will empower us. Confusion and lack of clarity are disabling. Take the time to explain the issues to us with words we will understand.

Help parents, be sensitive to our needs, but remember who the client is. Don't let us off the hook. Push us, challenge us. Keep us on task. We must be the main protagonist if our child is going to get better.

3 *Be sensitive to our needs — but put us to work*

- This is a challenging time for us. But give us homework, work we can do at home. For instance:
 - Teach us how to be the best Floortime partners we can be.
 - Tell us what we can do at home to address our child's sensory needs.
 - Share diet recommendations with us.
 - We need to know good home habits — for instance, TV watching and video game playing. What outdoor activities are productive? What do we need to know about travel?
 - What equipment should we purchase for the home?
 - Empower us to be advocates on behalf of our children, and embolden us to be subversive when we need to be.

4 *Be honest — but be gentle*

- "Always tell the truth — but know how to tell it."

⑤ *Give us appropriate hope*

- Balance challenges and hope.
- Discuss a treatment plan.
- Have a list of highly regarded clinicians in different fields to recommend.

⑥ *Don't give us platitudes*

- Such as:
 - "When life gives you lemons, make lemonade."
 - "Challenges will make you stronger."
 - "God doesn't give you challenges you cannot overcome."

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