

What Professionals Say. . .

What Parents Hear

Barbara Cohen, M.A.T., M.A.

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Disclosure

I declare that neither I, or my immediate family, have a financial interest or other relationship with any manufacturer/s of a commercial product/s or service/s which may be discussed at the conference.

Our children are supposed to:

- Move our DNA forward
- Love us and be loved by us
- Express our best traits
- Redeem our shortcomings
- Grow up to reflect positively on us

My child is perfect from the moment
of birth.

Every conversation about autism challenges my child's perfection

- My child will not grow up to give me children.
- My child will not grow up to redeem my shortcomings.
- My child will not grow up to proclaim my excellent parenting.
- My child may not grow up and out into the world at all.

Expressions of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Based on the work of Elisabeth Kübler-Ross and David Kessler. Text on the following five slides taken from David Kessler on www.grief.com

Denial

Denial is nature's way of letting in only as much as we can handle.

Anger

A connection made from the strength of anger feels better than nothing. . . . Anger is just another indication of the intensity of your love.

Bargaining

Guilt is often bargaining's companion. The "if onlys" cause us to find fault in ourselves and what we "think" we could have done differently.

Depression

We withdraw from life, left in a fog of intense sadness, wondering, perhaps, if there is any point to going on.

Acceptance

Acceptance is often confused with the notion of being “all right” or Okay with what has happened. This is not the case. . . . We may start to reach out to others and become involved in their lives. We invest in our friendships and in our relationship with ourselves.

First Conversation

- Professional: *I'm concerned that Sam is not meeting some of her developmental milestones, and I think it would be a good idea to have her evaluated.*

First Conversation, Cont.

- Parent:
 1. *I am so glad that my concerns are not being dismissed.*
 1. *How dare you suggest that my perfect child is not perfect? You know nothing about my child. Are you trying to tell me that my child's future is a black pit?*

Evaluation

- Professional: *Tell me about the pregnancy and birth. Were there any significant stressors? How was your health?*
- Parent: *I did something wrong. I was too anxious; I let myself catch a cold; I drank a glass of wine before I knew I was pregnant. This is my fault.*

Evaluation, Cont.

- Professional: *When did Sam say her first word? When did she start crawling? Walking?*
- Parent: *This doctor is conducting an evaluation that is designed to show Sam in her worst light. Being late talkers runs in our family and we are fine.*

Discussing the results

Professional: *Looking at the evaluation results, you can see that Sam is behind in her development in pretty much every area—her speech, her motor skills, her level of independence. Her behaviors are consistent with a diagnosis of autism.*

Discussing the results, cont.

Parent:

- 1. You and your invalid tests are wrong.*
- 2. I did something wrong. Or maybe my partner did something wrong. We shouldn't have let the baby cry himself to sleep; or, maybe we should have let the baby cry himself to sleep.*
- 3. My child's life is over.*
- 4. My life is over.*

Discussing the results, cont.

Professional: *Early intervention is the most important thing you can do for your child. Research is conclusive that autistic children who start receiving treatment early have the best outcomes.*

Parent: *I have failed my child by waiting so long.*

Discussing the results, cont.

Parent: *What is the prognosis for my child?*

Professional: *I have seen children respond amazingly well to therapy and accomplish things that their parents never thought possible. We just don't know.*

Parent: *You won't answer because the prognosis is so dire. My child is gone.*

Discussing the results, cont.

Parent: Where does my child fall on the spectrum?

Professional: Some score better in some areas, some score worse in others. It's a spectrum.

Parent: Why won't you tell me we are at the top? You are telling me this will never be good.

Future visits

Professional: *How are the therapies going?*

Parent: *You think I am not doing enough and you have no idea how exhausted I am.*

Questions that never go away

- What does the future look like?
- What did I do wrong?
- What more can I do?
- I'm exhausted. What happens if I don't do more?

Guidelines for speaking with parents of autistic children

- Present information without normative statements.
- Do not declare a terminal prognosis or suggest that a window has closed.
- Find something to state positively—but skip the comments about patience and saintliness.
- Never assume full acceptance.