

How Do I Decide What Approach to Take With My Child Who Has Autism?

by Dee Blöse

Revolutionary Common Sense from Kathie Snow, www.disabilityisnatural.com

That's a big question, and a very important question. Your decisions can have a life-long influence on your child's life.

First, picture your hopes for your child's future. Start at his death and work backwards. I'll share the picture for my son. On David's deathbed, I hope he'll think thoughts like these:

I had a wonderful life. I'm proud of what I accomplished. I have helped others. I felt loved by my family and friends. I was fulfilled.

During David's adult years, I hope he'll think thoughts like these:

I make a difference in this world. I have a meaningful job that is important to me. I have family and friends who love and support me. I am respected for my opinions and I'm responsible for my choices. I am happy with where I live.

During David's childhood, I hope he'll think thoughts like these:

I love school. I love to learn. I enjoy my friends. I can communicate with my friends, teachers, and family. I can get my point across! I have fun! I am included and never feel separated. I feel whole. I do not feel I am "sick" or "inferior" to others, just because I am different. My family loves and respects me for who I am. I am David—maybe I'm a little different, but I'm just as beautiful and wonderfully-made as all other kids. So I have autism—you wear glasses and have a goofy nose!

Second, think about what it will take to turn hopes into realities. What are the barriers? What will your child need to learn to achieve the pictures you've described?

My process went like this: David has two particular needs that may be potential barriers: communication skills and social skills. I know that behaviors are tied to social skills. I also know that

his behaviors are considered "less socially acceptable" when he cannot communicate with others. I know he's smart. I need to support his thinking skills, while simultaneously enhancing his communication and social skills.

If David cannot communicate with *everyone*—not just people who know him well—he won't have a chance in the real world. If he cannot maintain "socially appropriate behavior," he will not be successful outside of our home or other "protected" environments.

Third, what kind of environments will be needed to support the development of your child's needed skills? In our case, environments must be responsive to David's needs. Sometimes he needs simplification, such as reduction of sensory distractions and transitions, as well as not overloading him with too much information. Sometimes he needs to be encouraged to achieve a goal, while simultaneously having a support to fall back on if he feels over-challenged. Environments need to support his successes, not failures. Whatever enables him to experience success needs to be in place.

Most of the time, David needs to be with others, including people who know him *and* those who don't, as well as people who know how to support him, *and* those who don't. That's the real world! He needs to learn, in his own time and space, how to succeed in the real world. He needs to learn to recognize when he is being overwhelmed and how to take appropriate actions. We need to respect his communication in this so he will not fail. That is the best method for achieving "socially appropriate behavior." Will it always be pretty? No. When is the best time to work on it? When he is young and the world is the most forgiving. This is one thing we cannot save until later, because learning "social appreciation for others" is a long process.

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David needs an environment that *requires* him to communicate. Does he need supports? Yes. Visual supports, communication supports, and continuity across all environments are critical while he's learning to communicate effectively.

Fourth, what approaches will provide your child with the tools he needs to be fulfilled and happy in the real world?

In our case, the people in David's life who are responsible for "helping" him (teachers, service providers, family members, and others) need to support him to be successful in all that he does. Support techniques must always be respectful of him, and his needs and wants—never humiliating, demeaning, abusive, harmful, or hurtful.

Others should be respectful of the fact that each of us has "a bad day" now and then. Approaches must always be humane, and must never resemble the inhumane methods that are sometimes used on prisoners or animals.

David needs to be included in *everything* with other kids his age, including school and other activities—not stuck in a corner with adult helpers. And he needs individually-designed supports to ensure his success. He does not need to be singled out as "special;" that contributes to him feeling "different."

David also needs to be given the same opportunities as other kids: the opportunity to "mess up" and to learn from mistakes so he knows that failure is part of life. He needs the opportunity to be "laughed at" (just like other kids, and within

reason), so he can strengthen his backbone. David needs the opportunity to be with others who have wants and needs, so he can learn the world doesn't revolve around him. He needs opportunities to be helpful, so he can learn concern for others.

Children *without* disabilities learn these things through typical life experiences in natural environments. *David needs to learn these things in the same ways.* He will not learn real-life experiences in an artificial, fake environment. We all learn by really "being there." Any child, if isolated from the real world, will suffer the consequences. David is no different. The key to his success is to ensure he's supported in the natural environments of the real world.

Finally, the best gift you can give your child is love—and not just love for him, the love for your family and friends. One day you will be gone. Will you leave him a lasting legacy of family and friends who love and care about him after you're gone?

Or will he be alone, because he depended only on you for everything, and neither he nor anyone else has any idea how to support his needs? Worse, will you leave bitter children who feel, "All Mom ever cared about was my brother with autism."?

Think about the future and consider all these things. Think about your whole family. You may feel your other children don't need you as much as your child with autism does. But that's not true. They need you just as much, and their futures are also at stake.

Listen to your heart. Don't embrace information you feel uncomfortable with. Take care of all your children. And when you die, you can say, "I gave it my best. I had a good life. I am fulfilled."

***The ones who matter most are the children.
They are the true human beings.***

Lakota Proverb

Dee and Keith Blose are the parents of Amy, David, and Justin. At the time of this writing, David was a 13-year-old seventh grader; today, he is a successful 19-year-old who is living in his own place! Dee is Executive Director of Youth and Family Services in her Oklahoma community, and is also a Family Faculty Adjunct Professor and co-instructor in the web-based PT/OT Master's program at the University of Oklahoma. Dee originally wrote this article at the request of OU Early Intervention personnel, to provide parents of young children with autism with information to promote long-term thinking. Dee added, "I have been dismayed by much of the information distributed to parents of children with autism. I feel many of the interventions being promoted are short-sighted, don't consider the entire family, and are basically inhumane to the child. My thoughts are not meant to bash any program or intervention method, but to ask parents to think about the future of their whole families in making long-term decisions." My thanks to my friend, Dee, for allowing me to share her story with others.

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