



Ask Cathy...

An Open Dialogue With A Mother and Special Needs Architect

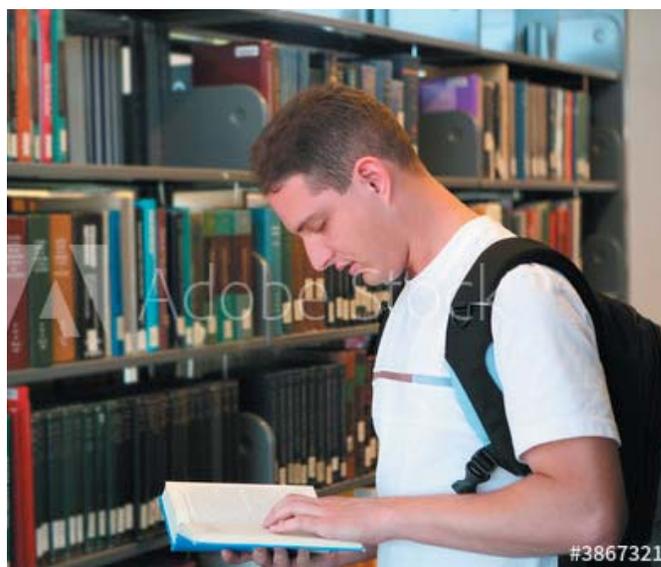
Q: Can you tell me how old your son was when you started thinking about his adulthood?

A: Yes, he was about eight. As the regular education school work became more and more difficult for my son, I stopped worrying about his ability to add three-digit numbers and became focused on the development of life skills. When my son was in middle school and his teachers sent homework home, I did not “do” my son’s work for him. I wanted his team to understand how difficult and, at times, ridiculous the work was. I set a timer and left him to try to complete the work. He rarely got past his first question.

My son is gifted in many ways but the work was not geared towards his gifts. I cared that he knew how to use a calculator. I cared that he could read. I cared that he knew right from wrong and how to be compassionate and faithful. I also knew that for him, independence skills were important. I taught him how to use the phone, make a call, look up a number, use the library, take the bus, shop independently in the grocery store, fold laundry, cut the grass, vacuum the house, iron his clothes, etc. I taught him how to pack a grocery bag. Even something so simple was not simple. The first time he did this, the bread went on the bottom and got smashed. The intuitive thinking was simply not present for him. He didn’t connect that heavy weight ripped the bag. He didn’t connect that eggs are fragile. These are things he needed to be taught. So, at the age of eight, my entire focus was on his independence skills and his adulthood. And today at 25, these lessons have served him incredibly well.

Q: I’m trying to get services for my son through our school system. Can you share any tips with me?

A: First, I would say the most important thing is to fully disclose everything—the good, the bad and the ugly. I find many parents hide the realities of how stressful things can be on the entire family. Being very direct about the complexities and challenges with your entire team—teachers, IEP coordinators, social workers and medical professionals—is paramount. Documenting every event that is



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difficult for you and your other children and insisting on support is the only way to get heard.

Second, work from the top down. Figure out who’s in charge and call on them...even if that means contacting your state’s governor. Be the squeaky wheel and the passionate mom.

Lastly, and most importantly, READ THE LAWS. Know your child’s rights. Be able to make concise arguments. You want to be an educated and fearless advocate.

Q: My son has difficulty making choices. At times it can be so aggravating for the other children because they want to get on with the day. Do you have any recommendations for how I can help son make up his mind about things?

A: Yes, we learned this about twenty years ago. The trick is not to ask open-ended questions. Rather, provide three options in your question presentation. For example, don’t ask, “What color would you like to paint your room?” Instead ask, “Would you like to paint your room green, tan or yellow?” This narrows the options drastically and removes the pressure to come up with an answer. We still use this technique today with our son being 25 years old. If left to his own decision making process, he would take 10 minutes to order a meal. This prolonged indecision can be stressful for the entire family. Because I know what he likes, I’ll often ask right after we sit, “Do you want a burger or a cheeseburger?” Done! ◀

SPECIAL NOTE: Cathy’s responses come straight from her own personal experiences. It’s important to note that each child on the spectrum is unique and will have their own set of needs.

CATHY PURPLE CHERRY, AIA, LEED AP...

...A special needs architect and founder of Purposeful Architecture, Cathy Purple Cherry is the mother of an adult son on the autism spectrum and the sibling of a Down syndrome brother. Through her lifelong interactions and observations of her brother and son, she has an acute awareness of relevant triggers and environmental issues that impact individuals with disabilities. In addition to the numerous articles she has written on the topic, Cathy speaks nationally on Purposeful designs that support the academic and therapeutic needs of individuals with disabilities. She engages her audiences and enables them to consider design applications and concepts that enhance their practice by creating environments designed to meet the needs of individuals with disabilities. She is tireless in her efforts to improve the quality of life for people with disabilities through Purposeful Architecture™. For more information, visit www.purposefularchitecture.com.