

How A Father Sees Life For His Daughter: Thoughts From Jeff Strully

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How we think about people, how we describe people, and how we work for desirable futures is what this is all about. I'd like to take you on a journey. When I look at my daughter Shawntell I don't see a "half empty glass." I see a "half full glass." For years and years my wife and I were good parents. Good parents were described as people who would take their children to physical therapists and do these little exercises, and have their children walk up steps that went no place, and then walk down the steps.

From my daughter's point of view it was like "Why did you get me here if you didn't want me to stay?" We did everything that people told us to do: early intervention, preschool; we bought the right toys; we worked day in and day out. One day I woke up to discover something. That my daughter wasn't broken. And I didn't have to fix her. Perhaps what we need to do is to change the way we talk and think.

I've begun to think, "What supports do people need to lead a valued life?" Now in Shawn's case some of these supports are medical. You can't be successful when you are choking 9 out of 10 times, right? She takes only two bites of food. The question becomes "Does she never go out with her friends to eat because she only takes two bites of food?" The answer is "No." You see, the skills, the competencies aren't the prerequisites to having a good life. Whether she's toilet trained or not, whether she chews or not, whether she uses communication or not is not the entrance requirement to have a decent life. The only requirement is breathing - and sometimes some people need assistance with that. Other than that, what's possible is in our mind's eye.

One of the things I want to emphasize - if nothing else - is that people have dreams. We need to have families reclaim the dream that for so many years they were told was lost or couldn't exist. "Your child will never..." "Your child will never..." And after a while, families stop having dreams. That is probably the most disabling thing that disability is all about.

What's my biggest fear as a parent - that Shawntell will never walk right, or talk right, or go to the bathroom, or chew? No, that doesn't scare me as a parent. Do you know what scares me as a parent? Loneliness, isolation, victimization. Shawn and some of her friends came to my wife, Cindy, and me and said, "We think we're going to backpack through Europe this summer."

And I said, "Well, hold it guys. Shawn doesn't walk real well." (She has this toddler gait, and God forbid there's a thread on the carpet: she falls. I mean her knees are constantly being damaged).

"How are you going to backpack through Europe?" I asked.

"Don't you understand, Jeff?" they said. "No, I don't understand."

They responded, "Well Jeff, people will pick us up because Shawntell can't walk!"

This made me feel so much better.

Leslie was Shawn's integration facilitator. She is a friend, and a recovering Special Education teacher. The question we have to figure out is how to work collaboratively, because no matter how good I am as a parent, without Leslie's help, I couldn't do it. This means we have to work in partnership.

Partnership truly means that we listen to each other and we work together. Since Shawntell is over 18, she has to be the decision maker. Because she has to make decisions she's going to make mistakes, she's going to make errors, and she's going to make some bad choices along with the good choices she makes. What we need to do, it seems to me, is we need to think about things with a new paradigm. Trust me when I tell you that it wouldn't take anyone in this room less than one microsecond, if Shawn walked in, to say:

"There's a person with severe mental retardation. There's a person with multiple handicaps." That shouldn't change Shawntell's need to have a wonderful life. Having a 13 IQ didn't change anything in my mind about the wonderful life she should have and about the dreams, hopes, and desires.

Shawn, my daughter, happens to be a person who is Hispanic. She took a class called Hispanic Studies and her Professor knew that she had started to do facilitated communication. He said to her, "Well Shawn, you better make sure you get into the library and get the books, because we are expecting you to take my midterm. We expect you to take the midterm and do the best you can."

The first question on the midterm - the only question Shawntell was able to answer - was, "A Hispanic family has a Hispanic son who rejects the culture. Another Hispanic family adopts an Anglo son who embraces the culture. Please comment.

Shawn typed out, "The first doesn't want to be labelled, the second one wants to belong."

I don't know what mental retardation is anymore. Things are changing so quickly in our world and our understanding of what's there and what isn't there. I would like to suggest to you that maybe we need to rethink some things - like, is it possible that mental retardation isn't what we think it is? Maybe people have things in their heads and they haven't yet figured a way to get it out. If that's the case, maybe we should take a very conservative approach about where people should be living and what they should be learning. I would hope that all of you would work with families and people with disabilities to create desirable futures. We have to struggle with letting go and figuring out how to support people to have desirable futures.

Today, we are into microwave thinking. If we can't lose weight in three minutes, or we can't cook it in three minutes, we aren't interested. We need to be there for the long haul. And, I think we have to see this as a long haul. The world is not going to change quickly. We must help find outside support for families and individuals who do not want or believe that desirable futures are possible. Far too many people have been told over and over that their children can't walk, can't talk, can't see, can't do, can't believe, can't... And we need to rethink that.