

The Hidden Outcome of One Page Profiles

So...as we consider the ways One Page Profiles can be helpful and not just “garnish” or more meaningless paperwork...I have to share this perspective. I shared it with Michael Smull recently and he did what you know he always does...he said “you need to write that and share it.” Here’s my perspective on the one-page profile...

Through the years I’ve been to lots of conferences and seminars and seen lots of ways to help others know my child. Many of them, while great ideas, were overwhelming to me. I was already an exhausted Mom and caregiver, and now you want me to do WHAT??? I rarely followed through. The One Page Profile provides families a way to introduce their loved one in a simple and straightforward way, without having to invest hours and hours of time they don’t have. The fact that they can attend a one-day training and walk out with a good start on a profile is bonus!

But there’s a bigger outcome of one page profiles that we can’t overlook and it’s an outcome you may never see.

My son David is now 24 years old, and he is one of the Loves of My Life. But I have to be honest and say that I didn’t always feel that way. David was diagnosed at the age of 3 months with a rare disease I’d never heard of. We were given a very grim prognosis which included intractable seizures, intellectual disability, gross and fine motor delay...scary stuff for a brand-new, first-time Mom.

What the grim prognoses never mentioned were the behavioral and psychological issues that typically go hand-in-hand with the disease. I’ll spare you the awful details, but just know that life as I knew it changed. There is much I hate about this disease, but the behavior and psychological stuff was SO INCREDIBLY DIFFICULT - I hate it the most. Somehow, in those early years, I lost sight of my son in light of the hatred I felt for his disease and what it was taking from him, from me, from our family.

When David was about 5 years old, I met a now-dear friend named Kathie Snow (disabilityisnatural.com). Kathie asked me about my son, and like so many other parents like me, I flew into my detailed description of everything that was wrong with David, using the best medical, educational, and therapeutic jargon I could muster. You know...it was all about his “functioning levels”, and his “behaviors”, and his medical issues and therapeutic programs. Kathie stopped me mid-sentence and gently challenged me by asking “Yes, but tell me about your son. Tell me about David. Who is he? What does he love? What is he good at? What’s your favorite thing about him?”

I was speechless. Really. I mean speechless. I couldn’t answer her.

Kathie then challenged me to go home and begin re-defining who David was in my own mind. I remember it so clearly...sitting at the keyboard with my hands poised to start typing and not knowing where to start. I’m ashamed to admit it. *I honestly could not think of a positive thing to say.* It was a watershed moment for me; one that forever changed me. I finally managed to type these words:

David loves to laugh. He can tell you everything you ever wanted to know about trains...and bulldozers and backhoes...and angels. He gives the best hugs in the world. He loves life and the outdoors. He’s a terrific big brother.

So...Perhaps the most important outcome of a One Page Profile has nothing to do with introducing the loved one or helping that person get the supports they need. Perhaps The Most Important Outcome of a one page profile happens inside the person(s) writing it. Writing a one page profile gives parents, family members the opportunity to consider their loved one in a whole new light - the light of “like and admire”; of “Important To” and “Best Support”.

And THAT - to me - is a pretty powerful outcome, whether anyone ever reads the One Page Profile or not.

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