
“I Don’t Know”

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

Three little words—“I love you”—are considered the most important words we can say. But three *other* little words—“I don’t know”—could also have a profoundly important effect on the lives of children and adults with disabilities and their families. They could prevent the death of dreams, equalize relationships, open up worlds of possibilities, and much more. The use of these words by parents, physicians, educators, service providers, and anyone else who touches the life of a person with a disability could radically change that person’s life!

Let’s start at the beginning—D-Day—the day of diagnosis. Many, if not most, physicians who diagnose developmental disabilities in children are usually pretty certain in their prognoses: they tell parents what their child will never do. The physician’s words have the power to turn the dreams of the parents into a nightmare of hopelessness and fear.

Some parents never recover, and their children, sadly, suffer the consequences of their parents’ emotions and the physician’s prescription: a lifetime of treatments, interventions, and services to “cure” the child or minimize the effects of the condition; limited opportunities to experience a full life as a child or adult; segregation in special programs; low expectations; and more. Other parents, however, discover the doctor was wrong the first time their child *exceeds* the predicted low expectations. But this discovery might take years—years in which hopelessness, fear, and the never-ending merry-go-round of services and treatments have taken over the family’s life. These parents may be able to chart a new and better future for their children, but they may never recover their original hopes and dreams. The physician’s predictions created a wound of despair that’s too deep.

The erroneous prognosis may lead to another negative outcome: mistrust. Many parents may sarcastically laugh about the ignorance of the “dumb doctor who didn’t know what he was talking about,” and they

also learn not to trust *any* “experts.” Their operating principle—with just cause—becomes, “Fool me once, shame on you; fool me twice, shame on me.” Parents may be reluctant to enter into positive, trusting, equal partnerships with *any* professionals.

A physician’s dire predictions about a child *may* be the result of the doctor’s ignorance. After all, diagnosing physicians are usually *pediatric* specialists who have little or no real-life experience with, or knowledge about, adults with developmental disabilities. Thus, they *don’t know* what’s really possible! In addition, physicians may spew the “worst-case” scenario to protect themselves from future lawsuits: they fear being sued by parents if they predict a “rosy” future for a child and it doesn’t come to pass.

How could all this change if diagnosing physicians realized they don’t have all the answers and said, I DON’T KNOW more often? Instead of prophecies of doom and gloom, what if the doctor said something like, “I don’t know if your child will [do this-or-that]...” which could be followed by:

- “Anything’s possible...” or
- “If your daughter is not able to [walk or talk or whatever], we can look at some great assistive technology devices that could help...” or
- “Let’s focus on what’s really important for your child: that she feels good about herself, that you believe in her, and that you have dreams for her...”

And *how* the physician delivers this message would be critically important. Saying, “I don’t know...” tinged with a look of pity or sympathy would negate the spoken words.

While this type of message might not cause the parents to jump for joy (they still might feel concern for their child’s future), it wouldn’t strip parents of the hopes and dreams all parents need to successfully raise their children. The doctor who diagnosed my then four-month-old son with cerebral palsy was certain

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in his doom-and-gloom prognosis. But the second doctor we saw routinely said, "I don't know..." or "I'm not sure..." and his words helped restore some of the hope the first doctor had stolen. Like most parents, I wasn't looking for guarantees or promises, only a more realistic and truthful appraisal. And when it comes to forecasting the future of a child or adult with a disability, I DON'T KNOW *is* the most honest statement that can be made!

What about others adopting the I DON'T KNOW response? Parents of very young children don't yet have the wisdom borne from experience, so the words of therapists, service providers, and other early childhood staffers can have great influence on how mothers and fathers think about their child and her future. During these early years, parents are looking to the experts for reassurance and hope. Instead, many professionals seem to routinely dole out fear-generating warnings, such as, "If your child doesn't do [such-and-such] by [certain age], then [this awful situation will result]..." These are someone's *opinions*—not facts! So those who work with young children and their families can omit harmful opinions, and use responses similar to those recommended for physicians.

Moving on to school-aged children, teachers, administrators, and others in the school system can also learn to say I DON'T KNOW more often. Special ed teachers, principals, and others in the educational arena also have the power to crush the dreams of parents and their children. Consider parents who are hoping their young child with a disability will enter a general ed classroom in kindergarten or first grade, instead of an ungraded, segregated special ed classroom. What if, instead of automatically saying, "No," to this request, a principal responded with, "We might not know exactly how to do this, but we'll work together and figure it out..."

We could apply the same scenario to adults with disabilities, regarding where and how they live and work. Instead of assuming a person couldn't be

successful in a real job or living on his own, what if service providers said, "We don't know for sure that this will work, but we're sure gonna' give it a try..."

Finally, what about parents? While others may routinely dash *our* hopes and dreams for our children, do we, in turn, do the same to our precious sons and daughters? If a child with a physical disability wants to play on the park and rec softball team, do his parents tell him, "No! You use a wheelchair—you can't do that!" What about a teenager with a cognitive disability who says he wants to go to college or a young adult who wants to marry his true love? What happens when parents say, "No" to these ordinary—but very, very precious—hopes of their children? Instead of trying to "protect" their children (and crushing their dreams at the same time), what if parents let go of their fears, and wondered to themselves, "I don't know if this is possible, but it might be..." In turn, they could say to their child, "We're not sure how this would work out, but we'd like to hear your ideas about it..."

I DON'T KNOW—said out loud or silently in our heads—can open our minds to solutions and possibilities! We really don't know what's possible, what's do-able, what will work or won't, until we try! Here are some phrases that can exercise our mouths *and* our brains:

- I don't know...let's talk about it.
- I don't know, but anything's possible...
- I don't know...what do you think?
- I don't know, so let's figure this out together.
- I don't know—we've never done this before, but we can give it a try!
- I don't know, so let's get some others involved to see what we can come up with...

If you think it might be difficult to say these words, practice in your head or in front of the mirror when no one else is around—practice makes perfect, right? Then when the time is right, you *will* be able to say the words and *mean them*, and a world of possibilities will be opened!