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Fixations #3: Nothing's Broken - Everything's Fixed

By Carmen Sanchez

Two months before our son's fifth birthday, we thought we had found the magic pill that would cure his developmental disability. The exact hows, whats, and whys of our situation don't matter. What does matter is that for a couple of weeks we woke up thinking that maybe his disability was a bad dream – each morning would be the start of the day when the pill would do its magic. In those two weeks, as I fantasized about the child that would emerge, I came to realize just how little I had come to terms with Ben's disability. I wanted it gone, out of his body and his mind forever, a disease for which there was a cure. I thought I had grappled with the disability, had come to terms with its place in my son's life and the way it had helped make him the person I know. All I could think about was that my son would be "fixed."

The story does not have a miraculous ending. The pill didn't work. Ben made progress in those two weeks, like he did in the weeks before, and he continues to make in the years since. He didn't seem any worse for the experiment, pretty much oblivious to our expectations and clearly immune to the pill's wonders. And when nobody looked, I cried for the child I had lost again.

More than three years later, I still have trouble listening to stories of miracles, of children who have been cured. I feel happy for the parents and the children, and I wish them long joyful lives. But I wonder if in telling these stories in a culture where everything can be "fixed," we aren't devaluing the lives of people with disabilities. Our culture values self-improvement so highly that, unintentionally, disability seems to be

equated with failure. So much in 21st century America centers on making ourselves better – from self-help books, to cosmetic surgery, medical technology, and "designer" babies – where does having a perfect child who also happens to have a disability fit in?

I also realize that the enormous gains that have been made in improving the lives of people with disabilities would have been impossible without a single-minded focus on finding cures, the fixes for a "problem." On a daily basis, my son benefits from the struggles of other people before him who pursued their dreams of

improving their lives and the lives of people with disabilities. Most parents, and here I include my husband and myself, pursue all the medical and therapeutic options we have to make our children healthier and stronger. However, over time, I have come to question whether choosing medical procedures and therapies is really about

maintaining my son's health or chasing elusive fixes for his disability because it satisfies my needs.

Several years ago, I heard Norman Kunc speak about how he once turned down an offer to be "cured" of his disability. Kunc is a sharp and funny advocate for people with disabilities. What he said took me aback at first; who would turn such an offer away? Yet, he went on to speak eloquently about how his disability was as much a part of him as his abilities and his right to decide the shape of his own life. He also spoke about how a disability is really only a part of a

"...enormous gains [that] have been made in improving the lives of people with disabilities."

person's life and how getting to know the person puts the disability in its proper perspective.

His comments helped put into focus how I could best help my son. I could give him a life that made him feel happy, valued, and loved for who he is, not for whom he could be. I could teach him to have a voice, so when the time comes for him to live independently, he can shape his own life. I stopped focusing on fixes. Instead, my husband and I consider therapeutic activities in terms of Ben's life and our life as a family. As he gets older, Ben has had a greater say in what he will do. Eventually, Ben will be the one who decides what he does, because it's his body and his life. Ben goes to conventional therapies to learn new things and keep his body strong and supple, and we have our regular round of doctors' appointments. But he also is

learning how to ride horses, swing a bat, sing pop songs, and dance with all the girls in his class. He's learning how to play the piano, not because it's therapeutic, but because his sister plays and music is important in our family.

He has finally made his clueless mother understand that he doesn't need to be fixed – nothing's broken. I've come to realize that his spirit is indomitable, full of the everyday magic and promise we all hold.

Fixations was a three-part series by authors with personal experience with disability. The mother of a middle-school aged son (Fixations #1), a young adult with a physical disability (Fixations #2), and the mother of several young children, one of whom has a disability (Fixations #3).

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