

The Next Frontier in Civil Rights: Autism Spectrum Disorders

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For parents and families who have a loved one with an Autism Spectrum Disorder priorities change all of the time. When young the focus is on Early Intervention. This means obtaining effective therapies, appropriate education, social skills, reaching developmental milestones and the development of communicative language. Parents are busy insuring their children receive the best OT, PT, ST, ABA, teachers and school placements. Families are often consumed by busy schedules full of appointments and therapies. Staying very busy and very engaged, families are constantly looking for the interventions with the most promise and best track records in helping their children with Autism.

As children mature needs change, educational and school environments often become more complex and difficult to navigate. Social pressures on individuals in the spectrum increase with age causing various levels of stress and tension. Inappropriate behaviors and habits can be harder to manage in older individuals when they violate social norms and taboos (for example personal space, hygiene etc). Parents sometimes find resources shrinking as children move into their teen years and young adult hood. How many fundraisers focus on the needs of adult or teens on the Spectrum? Yet, if we cannot meet the challenges as children age what is the point of early intervention? Fundraisers, walks, awareness, news stories....they seem to love the focus on the young and autistic. What about the older individual now trying to live an independent or functional life? What about higher education? Work? Relationships? These issues are often considered part of "transitioning to adulthood" and have become a hot topic amongst autism advocates and organizations such as CARD dedicated to enduring the welfare of individuals with autism.

What I would like to offer today is a small glimpse at the future. Sometimes parents are so consumed in the moment when children are younger they don't consider the long term perspective. We do invest in prepaid college tuition programs, we fund savings accounts for future needs, we take out insurance policies to protect our families these are all strategies with a long view. But what about our kids in the spectrum? Are we adequately addressing the needs they will face as adults?

We all know at this point Autism is a spectrum in the broadest sense of the word. With skills ranging from intellectual genius to intellectually deficient, hyper verbal to non-verbal, savant to severely delayed there are times it is difficult to make the case for what we need to advocate for with Autism Spectrum Disorders due to the diversity of

individuals in the spectrum. However, there are some common themes which apply to all individual in these spectrum and these include:

- The basic human right to self determination
- Equal opportunity
- Freedom from discrimination based on disability

I do see a future where a civil rights platform for individuals on the spectrum may be on the horizon. As the numbers of children with ASD grow up, and many argue the “hidden hoard” of the first large wave of children with ASD are just reaching the age of maturity, society will feel the pressure of the special interests of individuals with ASD mount. Many organizations including CARD, Autism Speaks, the Autism Society of America and others have lobbied on state and national levels for the rights of children with autism for years. Now, we may see a future where individuals with ASD advocate for themselves, with the most able members on the spectrum speaking for those lacking in communication skills.

I welcome the day, when our political system and society as a whole recognizes that individuals with ASD have unique abilities and contributions to make to the world. I eagerly await the day our first political leader to step forward and share that he or she is on the spectrum rocks the world with their announcement. We know they are out there; we may even have hunches in the current political system about who is or is not on the spectrum. We may be able to surmise with considerable accuracy who these individuals are, whether or not they are willing to admit to or disclose a diagnosis. I know in my life time I will see the admission, “ yes I am on the Spectrum” announced from the office of a member of the House, the Senate, who knows...the oval office one day? This may in fact be the next frontier in Autism advocacy.