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## From Awareness to Respect

CATEGORIES: [Community Life](#)



*By Guest Blogger Commissioner Sharon Lewis, [Administration on Developmental Disabilities](#), U.S. Department of Health and Human Services*

The [Developmental Disabilities Assistance and Bill of Rights Act](#) considers the issues of “self-determination, independence, productivity, and integration and inclusion in all facets of community life” for individuals with [developmental disabilities](#). All of these values presume respect for people with developmental disabilities. Where respect is lacking, self determination and independence are often denied. Integration and inclusion without respect become merely symbolic. As we celebrate Developmental Disabilities Awareness Month 2012, it is clear we have achieved much over the past 50 years, but we still have far to go before we can claim full success.

In recent conversations with young adults with intellectual and developmental disabilities (ID/DD), I have heard many incredible stories about their college experiences, their great jobs and their wonderful apartments and shared living arrangements – lives that don’t sound very different from those of other twenty-somethings. The young woman from Massachusetts who graduated and is now working as a teacher’s assistant at competitive wages. The guys from Wisconsin who just moved into apartments in an inclusive community where they host football parties for their neighbors on the weekends, and are excited to be able to invite girls over (without the watchful eyes of their mothers!). The young woman from Iowa who is supported by her family in her efforts to run her own coffee shop – a popular local gathering place and a connection to the community. And my friend from Oregon who has worked for an independent bookseller for more than a decade, hiring his own staff and purchasing his own vehicle, despite having no verbal language and other significant disabilities.

Yet for each of these positive stories, I hear dozens and dozens more from youth and young adults who have not yet been able to experience the lives they hope for – people who have experienced abuse at the hands of a provider or a family member; been physically restrained or secluded in our schools; who want a real job but cannot escape the sheltered workshop environment; who want to live on their own or with friends but are stuck in an institution, group home or with family; who have significant communication or behavioral barriers and do not have access to the support they need in order to express their choices, let alone their dreams.

For nearly every one of these young adults, whether they are enjoying good opportunities or experiencing substantial barriers, the path to and through adulthood is still often fraught with discrimination, low expectations, limited opportunities and lack of respect for people with ID/DD. Despite decades of civil rights protections, we still have more than 115,000 people with ID/DD living in large congregate institutions, while more than 120,000 people wait for home and community-based services. The graduation rate hovers around 35 percent, less than a quarter of people with ID/DD work in competitive integrated employment and people with ID/DD experience disproportionately high poverty rates.

At the same time, we have recently seen media stories and difficult debates about wrongful birth lawsuits, growth attenuation treatments (medical treatments that involve administering estrogen in order to reduce growth) for the convenience of caregivers, continued use of aversive therapies, bullying among our youth and use of harmful restraints in schools. Just last week, autistic adults held a candlelit vigil to remember the life of a young man with autism killed by his mother in a tragic murder/suicide, while some wondered whether it was understandable for a mother to commit such an act.

What do these stories and these statistics tell us about ourselves and our society's assumptions about people with intellectual and developmental disabilities? How far are we from meaningful self-determination, independence, productivity, integration and inclusion?

At what point do we move from seeking simple *awareness* about intellectual and developmental disabilities to expecting meaningful *respect* for people with ID/DD?

Self advocates understand the difference. They are working tirelessly to eliminate the R-word, to expand home and community living options, to convince employers to give people with disabilities a fair chance at a fair wage, to empower youth with disabilities to speak for themselves, to help families understand why it is important to maintain high expectations...quite simply, to change our perceptions and fundamentally shift attitudes across this country about people with ID/DD.

Ensuring that we have a strong and vibrant self-advocacy movement across our country is a key priority for the [Administration on Developmental Disabilities](#) (ADD). ADD has been working with national self advocacy organizations ([Self Advocates Becoming Empowered](#), [Autistic Self](#)

[Advocacy Network](#), [National Youth Leadership Network](#)), our network ([Developmental Disabilities Councils](#), [Protection and Advocacy systems](#), [University Centers for Excellence in Developmental Disabilities](#)), and the [National Association of State Directors of Developmental Disability Services](#) to host a series of regional self-advocacy summits involving every state and territory. By bringing together state leadership teams, we hope to energize and guide our efforts to support the self-advocacy movement at both the state and national level, and ensure that the next generation of self-advocacy leaders has a solid foundation to build upon. We all have a responsibility to ensure that people with intellectual and developmental disabilities receive not only our care, but our respect. It is time to move beyond awareness.

*Sharon Lewis was appointed Commissioner of the Administration on Developmental Disabilities in March 2010. Prior to her appointment as Commissioner, she served as the Senior Disability Policy Advisor to the U.S. House Committee on Education & Labor and as a Kennedy Public Policy Fellow for the U.S. Senate Subcommittee on Children & Families. She is the recipient of numerous awards, including the 2010 Distinguished Leadership in National Disability Policy Award and the Consortium for Citizens with Disabilities Chairman's Award.*

*Commissioner Lewis also worked for the Oregon Developmental Disabilities Coalition, the Oregon Family Action Coalition Team, founded DisabilityCompass.org and managed the Oregon Partners in Policymaking Program. She is a parent to three daughters, including one with a disability. She is also a native of Michigan and a graduate of Washington University in St. Louis.*