

## **Transitioning to Adulthood: Getting a life**

The conversation had turned to transitions, and my friend, who had grown up with a developmental disability, suddenly looked glum. “Why is it,” he asked, “that people with disabilities get a transition, while everyone else gets a life?” I was stunned. I had never thought of it that way before. As a parent of young children with disabilities, I had always assumed that planning their transitions to adulthood would be a straightforward and clear-cut thing to do, an undeniable “key to success.” We had to work hard with the various funding streams to assure that goals were set and no gaps existed, that there would not be years of hanging out with the TV. But once adult services were in place, we could declare victory. Was it actually possible to create a successful transition in programs and services, yet fail our sons and daughters in the crucial activity of becoming an adult with an adult life?

Many years later and many gray hairs wiser, I understand what my friend meant about the need of young adults with disabilities to get a life. While access to appropriate services is vital, it is possible that the fight for services and the planning for future security (have we written our wills? created a special needs trust? will we need medical power of attorney?) can divert our attention from the simple fact that our sons and daughters are struggling to take on new and very different roles in their families and communities, and need our help and support to do so. Equating services alone, especially if they consist mainly in a continuation of the remedial activities found in most special education programs, with a successful transition to adulthood is a big mistake.

So what do people with disabilities need from their parents, teachers, and support staff to move successfully into a new stage of life, and not merely repeat and recycle the previous stage? First of all, they need us to see them as, and treat them as, the adults they are becoming. This may sound obvious, but everywhere we go we still contend with a long history of treating people with developmental disabilities as permanent children, incapable of making decisions about their lives, lacking in big dreams for the future, and content if their basic needs are cared for. These habits of thought are hard to break. They have become embedded and reinforced in a casual, pseudoscientific use of I.Q. numbers by many schools and service providers: we may be told that an adult has “the I.Q. of a three year old” or a person may be described as “a 10-year old in an 18-year old body.” Such misperceptions can lead to highly inappropriate transition plans and service delivery plans, to a failure to prepare people with the tools and information they need for navigating adolescence and adulthood, and to support staff assuming inappropriate parental roles with older individuals -- all to the deep frustration of everyone involved. I can see now that this is what my friend meant when he suggested that it is possible to get a transition – with all the bells and whistles – and still not get a life.

It is important to remember that who we are is always an aspect of our chronological age: an eighteen year old with developmental and intellectual disabilities, for example, has had eighteen years’ worth of experiences on this earth. He or she has the hormones and curiosity of an 18 year old, the growing need for independence and assertion of identity, the anxieties and insecurities of any young person transitioning to adulthood, the need for self-determination and respect in making future plans, and the need to relate to and be accepted by peers of the same age. Emotional and social growth does not come to a halt along some developmental timeline attached to an intelligence test. All people continue

to mature and change as they explore their possibilities and their world, make new connections, and learn from real-time and age-appropriate experiences.

As parents of children who require special education, we quickly learn the famous mantra: “Special education is a *service*, not a *place*.” As our children grow older, perhaps we need an updated slogan: “Transitioning to adulthood is about a *place in the world*, not just a *service*.” Many changes in expectations and attitudes are now moving us in the direction of more meaningful transitions that support people with disabilities to take on valued adult roles and responsibilities in their homes and communities. In the education system, a strong movement toward more meaningful transition planning is underway, and more families are insisting that it involve community-based job exploration and post-secondary education options, including access to college for non-traditional learners. “Employment first” is rapidly becoming a nationwide goal for students aging out of special education, supported by shifts in funding away from segregated day programs and sheltered workshops. Recent findings by the Department of Justice have put states on notice that placement of people with disabilities into those settings, rather than in real jobs at competitive wages, may violate the Americans with Disabilities Act as well as the Supreme Court’s *Olmstead* decision.

The practice of Person-Centered Planning, with its insistence on honoring what is important *to* (not just important *for*) the person served, is continuing to gain ground. And Person-Centered Planning, by its nature, leads us away from the limitations of “special” settings to the broader path of “everyday lives” and community inclusion. Self-determination is increasingly seen as a right for all, not a privilege for a few; new communication technologies and the growing awareness that behavior is communication make it increasingly difficult to argue that any person cannot engage in self-determination. Self-advocates, organized and trained, are becoming a force to be reckoned with nationwide. Their involvement and example is leading to a new willingness to be frank and supportive about issues such as sexuality in adult life. Methods of coercion and control are becoming increasingly disreputable, and are yielding to positive approaches. Even the widespread practice of guardianship, through which people with disabilities can be deprived of crucial civil rights as they reach adulthood, is falling into disfavor among many families and being questioned in recent court decisions. All of these changes increase the likelihood that people with disabilities will not just transition to new service systems, but get to live, work, and be respected as adult members of their communities.

Youth Advocate Program’s own “10 Best Practices,” compiled by parents, self-advocates and staff, offer further guidance to help assure that people with disabilities find a valued place in the adult world. We are advised to “focus on the person, not the label,” and to “presume capacity” – that is, the motivation and ability to move forward – rather than viewing the person as an endless consumer of remediation and “readiness.” The Best Practices also affirm that people with disabilities are the teachers and experts about their lives; this is a key insight that drives Person-Centered Planning. And can we ever remind ourselves often enough, after years of treating our kids like kids, that they are joining our adult world now and we must “interact age-appropriately”? Parents know that getting the relationship right, and slowly stepping back from the degree of control exercised with a small child, is crucial to launching a fully-fledged adult into the world. Last but not least, the Best Practices ask us to “Be open to lifetime opportunities for growth and development.” Keeping choices and options open means realizing that

the people we support will *always* be transitioning to new relationships, activities, and situations as long as they live, not just as they age out of school. A thoughtful, respectful transition to adulthood can create a template for many successful life transitions to come.

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9/19/14