
DO DISABILITY ORGANIZATIONS PRESUME COMPETENCE?

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

This is the second of three articles on this topic. The first article is “Presume Competence: Challenging Conventional Wisdom About People with Disabilities,” and the third article is “Eliminating the Presumed Incompetence Paradigm.”

It’s 1990. I’m the mother of Benjamin, a three-year-old with a disability, and a participant in the extraordinary Partners in Policymaking leadership development program. I’m also a board member of a local cerebral palsy association (CPA). In Partners, I’m learning awesome best practices about inclusion, employment, and other issues related to people with disabilities. But as a CPA board member, I’m a novice regarding the realities of Disability World.

At my first CPA board meeting, staff members present their quarterly reports. When the Transportation Director gives his report, *I can’t comprehend what I’m hearing*. He describes a “serious” issue and asks for help: while picking up “clients” at nursing homes for their weekly “outing” (Wednesday-Night-Bowling), several people were not able to go because the nursing home staff had not dressed them to go out, so what can he do to make sure this doesn’t happen again? A cacophony of voices collides with suggestions.

My neophyte mind is spinning with questions. What are people with cerebral palsy doing in a nursing home? How old are they? Do they only leave the nursing home to go bowling? What if they don’t like to bowl? And why are we, as an advocacy organization, focusing our efforts on *this*, instead of helping people find real jobs, so they can live in the community and get out of the nursing home? “Excuse me,” I interrupt, and ask my questions. Stony silence follows, and all eyes turn to the Executive Director who sternly replies, “They *can’t* work and that’s not what we do here, anyway!” This Director, and perhaps most of the CPA board and staff, believes the people we support are incompetent. I attempt to share what I was learning in Partners about employment, but to no avail. Making sure the nursing home staff dresses people so they can go bowling once a week is of the utmost importance!

Fast forward to 2007. Similar occurrences (with or without bowling, the sport-du-jour for people with disabilities) are still happening from Podunk to Cucamonga. Organizations which claim to represent the interests of children and adults with disabilities often create, promote, operate, and/or fund services and activities that perpetuate the PRESUMED INCOMPETENCE of people with disabilities. Many organizations started as true grassroots efforts, but with growth and expansion, some shift their underlying purpose and come to resemble players in the service system. This resemblance—and the outcomes—can be alarming.

The service system (early intervention, special education, adult services, vocational-rehabilitation, therapies and interventions, etc.) seems to be built on the presumption that people with disabilities are inherently incompetent. The result? Two unequal classes of people (“providers” and “consumers”) and one “solution” as described by John McKnight in his essay *Professionalized Service and Disabling Help*, (published in *Disabling Professions*): “As *you* are the problem, the assumption is that *I*, the professionalized servicer, *am the answer*. *You* are not the answer. *Your peers* are not the answer. *The political, social and economic environment* is not the answer...*I*, the professional, produce. *You*, the client, consume.” So, we can acknowledge the existence of the PRESUMED INCOMPETENT paradigm (along with many other unintended, negative consequences) inherent in the system.

But what about other organizations, such as non-profit agencies, advocacy or parent groups, etc.? Most are not officially part of the system (although some *do* become service providers), yet it seems many have inadvertently adopted the PRESUMED INCOMPETENT mentality. Shouldn’t we expect better, and do these groups represent the best interests of children and adults with disabilities and their families?

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The newsletters of organizations often tell the tale. A headline in one screams, “Join the ‘End the Waiting List’ Campaign.” Advocates are exhorted to attend the rally at the capitol, sign petitions, and more. Yes, we need to effect systems change. But is ensuring government assistance our highest hope for people with disabilities? Doesn’t this reflect an underlying PRESUMPTION OF INCOMPETENCE?

Wouldn’t greater outcomes be generated if an organization rallied its troops (and its board members) to spend their time and energy helping individuals with disabilities find real work for real pay? Then they wouldn’t need to be *on* the waiting list!

Many parent group newsletters are filled with information about special (segregated) camps, sports, etc., for children with disabilities. (And many of these activities were *created* by parents!) This sends a powerful and negative message: children with disabilities are not competent to participate in ordinary (and inclusive) activities. Thus, parents who look to such groups for guidance may believe their children can never be included—the leaders’ voices say so.

What if a parent group embraced inclusion and the PRESUMED COMPETENT paradigm? Parents who *created* special, segregated activities could *disband them*, and put their prodigious energies into working with community activities to ensure all children are welcome. Newsletters could share strategies parents can use to ensure the inclusion of their children.

The PRESUMED INCOMPETENT mentality is routinely on display at conferences. At many parent conferences, for example, presentations focus on “transition” from early intervention to segregated special education preschools. Why aren’t there sessions on the importance of inclusive early education, how a child can successfully stay home with mom, or other options? Is it because those who plan such conferences believe the only “solution” is professional help from the system? At some conferences, the vast majority of presenters are medical professionals who lecture parents on the latest research in cures or prevention!

Little or no attention is paid to inclusion or other issues that can lead to better lives for children.

Why don’t disability organizations spend more time and energy focused on inclusion, interdependence, the PRESUMPTION OF COMPETENCE, and other beliefs that can lead people with disabilities and their families out of the darkness and into the light? Their mission statements may include lofty sentiments which look good on paper, but which may never be realized. We talk the talk, but don’t walk the walk. Whether we’re leaders or participants in disability organizations, we can ask questions with a critical eye in order to move in a new direction.

Do the organization’s activities actively reject the PRESUMED INCOMPETENT mentality, and embrace and promote the PRESUMED COMPETENT paradigm? Does the organization reject the segregation of children and adults in any form, and embrace inclusion in all environments? (Some parent leaders have said, “We don’t support segregation, but some parents want to know about special camps for their kids. Shouldn’t we help them?” Yes, if we’re willing to assume responsibility for the continued isolation and segregation of people with disabilities in our society. If not, then leaders must take a stand, and help others learn why the PRESUMED INCOMPETENT mentality and the accompanying segregation are harmful to our children and our society as a whole.) Does an organization promote the values of, and strategies for, people with disabilities and families getting connected to the real world in order to use natural supports and generic services, so they can live real lives, included in their communities? Or do they focus primarily on helping people get more services (and more dependence, segregation, and isolation)?

Ask the hard questions. Make changes. Resist the howling criticisms of those who embrace the status quo. For every action, ask: “Does this demonstrate that we *PRESUME COMPETENCE* in people with disabilities?” Nothing less will get us where we need to be: a society where all are valued and all belong. Nothing less will do. Nothing less is ethical. And people with disabilities and families should expect nothing less.