

Self-Direction Comments

I'm Jim Karpe, the father of two special needs teen-agers who have self-directed budgets. Self-Direction provides us with slightly more flexibility and control, but only slightly. On a weekly basis, I find that my children's progress towards independence is hampered by complicated rules and narrow categories and bureaucratic procedures. Self-Direction claims to be a Person-Centered Program. It is not. Instead it is Rule-Centered. Here's the test: Whenever the interests of the Person collide with a Rule, the Rule always wins.

The accumulation of red-tape makes the Self-Direction system inefficient and difficult to navigate. The thicket of rules operates in direct opposition to the efforts of my son Eli and my daughter Sandy to become young adults with more independent-living skills. Most of the families that would benefit from Self-Direction will give up before they even qualify. That small percentage who fight their way through, find that they have entered a world of frustration and obstacles.

In brief, Self-Direction has been designed to fail.

Some concrete examples will help to illustrate. You will notice that each of the examples ends with "Self-Direction will not fund this."

My son Eli is now 19 years old, and his officially-sanctioned valued outcomes include learning how to care for himself and his home—the various Activities of Daily Living (ADL). This summer, I sent Eli to a wonderful eight-week program which houses young men and women in apartments, in groups of four, and teaches them ADLs. Eli's overall Self-Direction budget for the year has more than enough dollars to cover this service. But the program falls outside of all the narrow Self-Direction categories, and so Self-Direction will not fund this.

My daughter Sandy is an "Aspie"—a short-hand term for an individual with high-functioning Autism. Aspies tend to collapse into dependency after school is over. The way to prevent Aspie collapse is to provide them with cognitive skills. That is, they need training not in ADLs, but ADTs—Activities of Daily Thinking. Around

New York City, there are a small number of highly in demand specialists who are termed Executive Functioning Coaches. Sandy's budget has more than enough money in it to fund a weekly visit to one of these specialists. The skills that Sandy will learn could make the difference between dependence and independence. But the hourly cost for one of these coaches is much higher than OPWDD rate sheets, and so Self-Direction will not fund this.

My son Eli has the capability to become an independent traveler. He needs just a little more travel training. Because of high staff turn-over rate, no one who works with Eli knows how to deliver travel training. Fortunately, the Inter-Agency Council offers a three-day course to train staff, and Eli's Direct Service Professionals are willing to go through the course. The course will make them much more effective in helping my son reach his valued outcomes. But because during the course they will not be face-to-face with my son, Self-Direction will not fund this.

I could keep going with more examples, but you already get the point: The strict rules and narrow categories prevent progress. Perhaps those rules were meant to direct funds into the most effective places possible. If so, the rules have failed to achieve their goal, and should be scrapped. OPWDD officials often point at the requirements placed on them by the Federal agencies. That is, we have a Federal-Agency-Centered Program.

The answer is in the name—we call it OPWDD, but it is the Office of People with Developmental Disabilities. That office needs to advocate for the People it is devoted to. Put People and their outcomes back at the center of the programs. Not Rules, Not Federal Agencies. Focus on People, and find a way to eliminate the narrow categories and restrictive rules that prevent those People from advancing toward their goals.