

Will the special session help people with special needs?

by Michelle K. Wolf

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The current California developmental disabilities system, once a model system for the entire nation in providing individualized, community-based care for children and adults with intellectual and developmental disabilities, is starving for funds to keep programs going. Because Gov. Jerry Brown signed next year's \$115.4 billion budget without the needed funding, our last chance for help may be in the upcoming special session of the state Legislature, which will be focused exclusively on health care issues. Without an influx of new funds, many providers will have to shut down their programs and services, and lives will be endangered or even ended prematurely.

Right now, the lines on the charts are all heading in the wrong direction:

- Since mid-2011, 435 residential homes for adults with developmental disabilities have closed, representing a loss of nearly 2,300 beds.
- In the same period, 57 day and work programs closed their doors, affecting 1,200 people.
- And 15 supported employment programs ended, a loss of 176 opportunities to work in community settings.

How did it ever get this bad? In the late 1960s, a group of parents in California who had children with Down syndrome, autism, cerebral palsy and other developmental disabilities (DD) joined together to create an ambitious new alternative to the state hospitals, which at that time were the expected destination for their children. The parents challenged the medical establishment's status quo, which said their children needed to be "put away" out of sight, and out of their communities of family and friends, for the "good of the rest of the family."

Out of frustration with forced institutionalization and given no support to keep their kids with DD at home, these parents became fierce advocates, working with disability rights champion Assemblyman Frank Lanterman from Glendale to sponsor civil-rights types of legislation. They succeeded in getting the California Legislature in 1969 to muster bipartisan support and passed the Lanterman Developmental Disabilities Services Act, or Lanterman Act for short. This landmark legislation declares that persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other persons by federal and state constitutions and laws, and charges the 21 regional centers in California with advocacy for, and protection of, these rights.

So far, so good. But as the years have gone by, the number of eligible children and teens has increased, driven especially by the dramatic spike in autism cases. Meanwhile, California's reimbursement rates for services have remained essentially flat for two decades, while the costs to provide services have grown.

This funding gap was widened by the Great Recession, when legislators slashed funding for the DD system by more than \$1 billion. As a Contra Costa Times newspaper editorial said, "The system that supports roughly 280,000 individuals with developmental disabilities is in a crisis that few outside that community understand."

Leading the charge to finally "bend the curve" is an umbrella group of nonprofits and providers that serves the developmentally disabled, called the Lanterman Coalition. The coalition is pushing for a 10 percent one-time across-the-board increase in provider rates, as well as a 5 percent cost of living increase annually until there is a systematic reform of rates and, most important, a complete review and overhaul of those rates. Paying the staff who work directly with adults with developmental disabilities little more than minimum wage makes it very hard for provider agencies to hire qualified staff in the first place, and also leads to high employee turnover, which is very detrimental to those needing care but who often take a very long time to trust someone new.

For parents or other family members, having to constantly build a new relationship with an assigned service coordinator at the regional centers also is exhausting, frustrating and time-consuming. My family has had four

different service coordinators assigned to our son in just the last two years because of these funding cuts. At one point, I had to call a supervisor every day for a week just to get a call back to find out who was our assigned person; our current saving grace is that our son is still in high school and therefore needs fewer services from the regional center system than he will after he completes his education.

As I mentioned above, we have one last chance left to fix this crisis. State Sen. Jim Beall (D-San Jose) has introduced a bill for the upcoming special session to increase rates for regional centers and the purchase of service vendors serving individuals with developmental disabilities. Joined by state Sens. Bill Monning (D-Carmel) and Fran Pavley (D-Calabasas), this bill will also call on the California Department of Developmental Services to create a financial sustainability plan to ensure the community-based developmental services system is working effectively. It's time for the rest of the Legislature to support this bill and to begin to restore the system for our family and friends with developmental and intellectual disabilities.

Michelle K. Wolf writes a monthly column for the Jewish Journal. Visit her Jews and Special Needs blog at jewishjournal.com/jews_and_special_needs.