CDCS Update: A Need for Consumer-Directed Supports

The Arc of Minnesota has supported and fought for consumer-directed services like Consumer-Directed Community Supports (CDCS). We were the lead agency that fought against changes to CDCS rules and budgets that adversely affected families.

In spite of our efforts, changes to CDCS did take effect. Since then, families have had varying experiences. According to some advocates, families with young children have found that CDCS works well for them, with adequate budgets and flexible supports. Some parents of adult children have had different experiences. While we don't have good data at this point on how CDCS families as a whole have been affected, we do know that a number of families with adult children have struggled. Here are stories from three of those families.

JEFF'S STORY

Jeff Skwarek is legally blind, has never been able to talk, and has cerebral palsy. Before CDCS, he lived in foster homes and large congregate settings that ranged from institutional-type facilities to a nursing home to a community group home. Staffing in these settings was inconsistent, and support for the staff was inadequate, so he spent more than 25 years being misunderstood and mistreated. He was tired of living this way, and five years ago, he refused to continue living away from his family.

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Fortunately, CDCS had just become an option for families. Deborah Denning, Jeff's mother, brought him home to Minneapolis and helped create a budget specifically designed for him. Virtually all of the monies went to individualized supports. The budget paid for staff who could help with Jeff's assistive technology to help him communicate and have more control over his daily life. The budget covered speech pathology services that could support Jeff as he communicated with others in the community. Jeff thrived under CDCS. He was learning money management by running errands, and he was learning to ride the city bus. He served on the Minnesota Governor's Council on Developmental Disabilities and staffed its exhibitor booth. He had a volunteer job that was getting him prepared for paid employment.

Then the CDCS changes came, and Jeff and Deborah were told that their CDCS budget would be cut by 54%. In order to keep Jeff at home, they dropped CDCS and went back to licensed services. Their budget for services stayed roughly the same as the old CDCS budget; however, $16,000 (or about 10%) of the money Jeff used for his unique supports under CDCS now went to the provider agency. The $16,000 for the provider went for services that Deborah was already providing and Jeff didn't need, such as recruiting and training staff. Deborah believes Jeff is now "intellectually dying" because he doesn't have the same support to help him develop his skills and continue to be as active in the community. She calls the current budget "fiscally irresponsible."

Deborah fears that the $16,000 she no longer has for Jeff's staffing may mean salary cuts for the staff still working with him. This could mean less stability for Jeff, which is what he went through before CDCS and wants to avoid now. If Deborah needs to spend more time with Jeff, this, in turn, could affect her ability to keep her job.

THE GONNELLAS' STORY

The Gonnellas were given a new, state-set CDCS budget that was 38% less than the previous year. After that, Pam Gonnella found out that she had breast cancer. She is now undergoing treatment (see page 2 for an update) and is no longer able to help with daily care for her daughter Sarah, who has severe disabilities.

The Gonnellas were forced to leave CDCS and use personal supports under the MR/RC Waiver. These supports were funded at a higher level than the new state-set CDCS budget. However, the actual number of hours for Sarah's direct care support is 300 less than the family used the year before, due to greatly increased administrative costs.

More money now goes to the fiscal agent. Pam says this entity is providing basically the same payroll service they did under CDCS the year before, but at nearly twice the cost. The increased administrative costs mean the State of Minnesota is not saving any money, and in a year when the family needs more help for Sarah, it is getting less support than in any of the years the Gonnellas were on CDCS.

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The Gonnellas have tried to adjust to the new budget. Volunteers from Pam's church are providing meals three times a week, and one volunteer is coming in once a week to help with Sarah's care. For some of Sarah's care, they also rely on Sarah's 82-year-old grandmother. However, because of the loss of 300 hours of help, caring for Sarah is still harder than last year, even if Pam didn't have cancer to deal with. Even with the extra volunteers, Pam said, "I don't know how long we can continue to care for Sarah at home. We are struggling

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right now and can't handle more cuts."

THE JOHNSONS' STORY

Cindy and Greg Johnson received such a significant cut in their CDCS budget that they replaced CDCS with personal supports under the MR/RC Waiver. This gave them more dollars for their daughter Jenna's supports than there would have been under a reduced CDCS budget. Their experience with personal supports hasn't been positive.

Under the Johnsons' current waiver budget, they are receiving fewer services than they received under CDCS. This is due to the higher administrative costs taken by the licensed provider – 20% of the waiver budget versus 10% administrative costs when the Johnson's used the CDCS option and were employer of record. These extra administrative costs have cut into staff hours. Cindy estimates that they have lost 700 hours of direct care staff time for this year (an average of two hours a day).

With more money now taken out for administration, the family has to pay a number of expenses from their own pocket – like medical supplies, copays for some OT and PT visits and medications; expenses for first aid training for new staff; maintenance on Jenna's power wheelchair, liftvan and other equipment; day program expenses; and office supplies for record-keeping – all costs previously covered under CDCS. With the new Medicare Part D drug program, they also pay the copays for Jenna's prescriptions.

The higher administrative costs have not meant an increase in the level of service from the provider, though. Cindy still does staff training, recruiting, hiring, supervision, firing, and time sheets. "For us, nothing changed except there is less money and less options to cover necessary support services and supplies," Cindy said. By not having the option of using CDCS, the cost for Jenna's care will be much greater to the system.

Jenna needs 24-hour care a day, and the Johnsons can't provide this under their current allowed waiver budget. This added financial burden has forced the Johnsons to appeal their waiver budget and ask for an increase.

Of the families who were on CDCS, more of them saw CDCS budget decreases than budget increases, according to Cindy. "I don't personally know many families who stayed on after they received their new CDCS budget," she said.

This includes many of the families that have met at the Johnsons' home over the years to talk about CDCS and other issues affecting their children and their supports. Three of these families placed their child out of home and into group homes, because they couldn't get needed services under their reduced budget, nor could they step in themselves and provide all the care their child needed.

KEEP CDCS

These stories show that CDCS can be a far better option for families who have used this service than if they had to find other ways of providing supports. The positive experience of parents of young children under CDCS, the negative impact of taking adult children off CDCS, and the higher administrative costs that some have experienced after CDCS all show the need to continue it. Cindy summed it up well: "The impact of gutting CDCS program has had a very negative effect on many persons with disabilities and their families, and it has forced them to choose much more costly and more restrictive options!"

The Arc of Minnesota is working to help turn the service system around and move it again towards greater consumer direction. Cindy Johnson is a member of a task force whose goal is to develop a new method of calculating CDCS budgets. Staff members are providing input to a DHS task force that is looking at innovations in residential services (see page 8). We will also push for legislation in 2007 to move the service system toward greater consumer control. ■