



FY 2009 Budget Priority Testimony Presented to the Division of Services for People with Disabilities (DSPD) Board

Overview

The Disability Law Center's (DLC) testimony to the DSPD Board is intended to help the Board better align DSPD policy and budget priorities with prevailing federal and state guidance, as well as the Division's own goals and objectives. Our testimony highlights the belief that the need for community-based services is a shared, yet solvable, problem. We therefore present critical questions we feel are fundamental to any sustainable solution. Finally, our answers to these questions inform and shape our short- and long-term policy recommendations.

Federal, State, and Agency Guidance Favors Community-based Services

"A public entity shall administer services, programs, and activities in the **most integrated setting appropriate** to the needs of qualified individuals with disabilities."

- 28 CFR Section 35.130(d)

"There is no other **equally effective** course of treatment available or suitable for the recipient requesting the service that is more conservative or **substantially less costly**."

- Utah Administrative Code R414-1-2(18)(b)

"Promote Opportunities and Provide Supports for Persons with Disabilities to **lead self-determined lives**."

Values:

- We respect and support personal choice and personal responsibility
- We value the preservation of family and other natural supports
- **We believe in stewardship and wise use of public resources**
- We respect and support personal choices.
- We believe people deserve high quality supports and services
- **We believe funding should be needs based and should follow the person**

We Will...

- Continue a person-centered philosophy
- Work collaboratively to dissolve barriers to quality service
- Support a full spectrum of service options
- Support self-determination by assisting persons to exercise and develop their ability to make choices and experience a) freedom to make informed choices from among available options of services and supports, **b) authority to control a defined amount of dollars to purchase only**

what is needed and valued, c) support to nurture informal relationships that might augment, if not replace, some purchased services, and d) responsibility to give back to the community”

- DSPD Mission and Values

Enhancing and Expanding Community-Based Services is Crucial

- We must allocate and expend our limited resources as wisely as possible.
- Approximately 1,900 individuals and families who currently receive no supports need to know if and when they are likely to get the help they need so they can plan for the future.

The Need for Community-based Services Can Be Met

- In order to do so effectively and efficiently, we need to confront the "black hole" mentality associated with the waiting lists and face the fiscal realities of the Utah State Developmental Center. There is no "hole" when long-term needs and costs are known.
- We must develop and implement a long-term, comprehensive and financially sustainable long-term plan comprised of evidence-based strategies to meet the needs of individuals and families.

Critical Questions Help Identify and Frame Priorities

- How are an individual's and/or family's needs likely to change over their lifespan?
- How do we respond to the various demographic factors impacting the issue, including the growth in and the aging of the population?
- How can we best support persons with disabilities and their families in their effort to live as independently and productively as possible?
- How do we develop the infrastructure needed to support these individuals and their families in their communities?
- How do we promote the growth and stabilization of the workforce needed to support these individuals and their families in their communities?
- How do we strike a balance between providing supports that help individuals and families meet their basic needs and providing a full array of services to individuals in institution- and community-based programs?
- How many individuals would choose to move from institution-based to community-based care if given the option? How can we facilitate their choice?
- What is the existing and potential demand and cost for institution-based care compared to community-based care? How is this balance likely to change over time?

Recommendations Include a Variety of Policy and Practical Strategies

- Encourage our congressional delegation to expand the Deficit Reduction Act's (DRA) shift away from institution-based and toward community-based services in Medicaid.
- Follow Washington and Oregon's by employing a "global budget" which consolidates institution- and community-based funding into a single line item, allowing the money to follow the person rather than the person following the money.
- Make cost-effective proactive and preventive services more widely available by taking advantage of sections 1915(i) and 1915(j) of the Social Security Act.
- Fund the Family Opportunity Act, which enables families with a medically needy child, income up to 300% of poverty, and private insurance to purchase Medicaid as a wraparound to meet their child's additional needs.
- Facilitate personal responsibility and accountability by adopting a sliding premium and/or fee scale, such as that employed by the Medicaid Work Incentive, to the extent allowed by federal law.
- Establish a public-private partnership utilizing a trust fund, AmeriCorps volunteers, work-study students, or another mechanism to provide a portion of the 525 individuals and families waiting for respite care with services.