

# The State of the State for Missourians with Disabilities

## COMMUNITY RESOURCES AND SUPPORTS

“It is NOT reasonable to deny even one person the right to live among us in the community, where services and supports can be provided.”<sup>1</sup>

### Our Beliefs

A principle belief of the Missouri Planning Council for Developmental Disabilities (MPC) is that all people with developmental disabilities (DD) belong in their community. In order to achieve community inclusion, people with DD and their families should be informed, active and equal partners in policymaking.<sup>2</sup>

#### *MPC Beliefs*

- *People with DD are supported in their communities near families and friends.*
- *Community based services and supports promote a positive image and awareness of people with DD.*
- *Community based services and supports provide opportunities for people with DD to be valued members of the community, making contributions as well as receiving needed supports.*
- *The system should promote the use of community resources, and, in so doing, build community capacity.*

### What the Research Says

When the role of the case manager was created in the 1970's, this person was intended to be a powerful monitor, advocate, and service coordinator for people with DD. However, modern case managers are limited in being able to fulfill this role, not because they don't want to, but because the evolving demands of their jobs do not allow them to do so. These new roles ask case managers to change the balance of power and control, and turn the decision-making authority over to the consumer and their family.<sup>3</sup>

Modern case managers are also required to provide information about resources to assist persons with DD through the system as they age, a job that is critical due to the current limited resources. In the age of the internet, demand for easily accessible online resources is constantly increasing.

### The State of the State in Community Resources and Supports

Within the top five strategies the Needs Assessment participants listed for bettering communities for persons with DD was the need for more information and resources for persons with DD and families.<sup>5</sup>

MODDRC. The Missouri Developmental Disability Resource Center provides information, peer support, and volunteer leadership opportunities for Missourians with disabilities, their families, and for community providers. Peer mentorship is provided by connecting parents, self-advocates, and professionals throughout the state with “matches” for ongoing and immediate support, via the Sharing Our Strengths (SOS) program. This program has shown a 14% increase from 2005 to 2006 in requested support matches.<sup>6</sup>

Several of the organizations in the state that provided lending libraries of information about DD have ceased lending materials. It appears that only two sizable, online lending libraries now remain—MODDRC servicing the entire state, and Special School District of St. Louis County Family and Community Resource Center (SSD FCRC) servicing St. Louis County.

MODDRC reported 872 requests for information from persons across the state in FY2006, a 5% decrease from the 921 requests in FY2005.<sup>8</sup> In comparison, the SSD FCRC, servicing one county, reported a total of 2,819 contacts for 2006, a 40% increase over 2005. Increases were attributed to planned outreach activities, including a comprehensive, systematic distribution system; email communication; and targeted outreach to underserved areas.<sup>9</sup>

*“They need to find a way to unite families to share information with each other.”<sup>7</sup>*

Public Awareness. MPC provides partial funding for Regional DD Advisory Councils across the state. These councils are knowledgeable about local needs and service gaps in their region and provide a

#### *What Missourians with DD and Their Families Are Saying<sup>4</sup>*

##### Statewide Needs Assessment Results

When asked to rate resources and supports provided by civic organizations, faith-based organizations, social service organizations, and family/friends:

Respondents thought people with DD were *most likely* to use:

- Family/friends (61%)

Respondents thought people with DD were *least likely* to use:

- Civic organizations (60%)

##### Adequacy of Options

- (76%) Civic organizations rated inadequate/fair
- (60%) Social service organizations rated inadequate/fair
- (77%) Family/friends rated good/excellent
- (57%) Faith-based organizations rated good/excellent

##### How supportive are communities?

- (40%) Somewhat supportive
- (56%) Not supportive or only somewhat supportive

Participants clearly indicated that increased services and supports, beyond that covered by Medicaid, were necessary to attain an improved quality of life.

grassroots planning and advocacy for improvements in supports and services for persons with DD. The Regional Councils are also the main advisory group to each of the Division of Mental Retardation and Developmental Disabilities' (MRDD) eleven regional centers. The authors of *Show Me Change* (1998) noted the need for Regional Councils to become accountable for incorporating person-centered principles and recommended the Regional Councils communicate with Regional Centers to infuse those principles into the provision of supports and services. This appears to still be a need today.<sup>10</sup> One of the top concerns identified in the Needs Assessment final participant comments<sup>11</sup> was the need for increased community understanding of DD in order to address attitudes and perceptions. For example, it is difficult for the general public to understand transportation issues that are unique to persons with disabilities. Education is needed in order for the general public to understand the importance of accessible transportation that is available when people with disabilities need it.

The need for public awareness takes two forms:

1) Education of self-advocates and families on topics of importance, in order to create informed leaders that can effectively increase community awareness; and, 2) Education of the public regarding the need for opportunities for persons with DD to participate in community activities, recreation, employment, housing, and so forth.

Regional Centers. The 11 regional centers in the state are the entry and exit point for consumers. The centers provide screening and diagnostic services for both children and adults, evaluate the need for services and arrange for them, and assess consumers' progress.

Although families and providers were generally satisfied with Service Coordination (SC) according to the Needs Assessment, they both noted inconsistencies in quality across Service Coordinators (SCs) with no built-in opportunities for providing feedback.<sup>12</sup> According to a recent report, large caseloads are the norm for SCs and workers report high levels of stress and general job dissatisfaction. Staff also report too many job responsibilities and paperwork burdens. These factors contribute to a perceived shift away from person-centered care due to limited time to focus on the "consumer".<sup>13</sup>

A frequently noted concern was the "wait lists" for MR/DD services through the Regional Centers, which are viewed as a direct result of inadequate funding.<sup>14</sup> Concerns voiced in a recent Regional Center review regarding waiting lists centered around the fear that the Department of Mental Health (DMH) and MRDD have become a Medicaid-only system.

**"—if an individual is not eligible for Medicaid, that person will not receive services and may languish on the waiting list. It was stated frequently that individuals and families on the waiting list must go into crisis and then services may be approved. There was a great deal of frustration expressed about this, explaining that some temporary or interim type of service might avoid a crisis and the ensuing disruptions for families and consumers."<sup>15</sup>**

Senate Bill 40 Boards. The Senate Bill 40 Boards (SB40) or "County Boards" were formed to distribute special tax levies, or "mill" taxes, that were passed by county residents to benefit people with DD. These taxes have historically been used to support, care for, or provide employment, transportation, or residential living of persons with DD. Over 80 counties in Missouri and St. Louis City currently have this tax in place. 93% of persons with DD in Missouri live in counties serviced by SB 40 boards; 7% (or 7,100) of the estimated 101,000 Missourians with DD in 2003, do not have a SB 40 board in their county.<sup>16</sup>

**"There are no apartments or anything in Stone County. Other counties have them because they live in counties with SB 40 Boards."<sup>17</sup>**

Senate Bill 40 funds are viewed as a potential source for improving such services as person-

centered planning and implementing pilot programs. However, concerns in recent testimony were noted regarding: 1) disparities in SB 40 boards and the services they offer across various regions of the state; 2) need for better oversight and accountability of county usage of SB 40 funds.<sup>18</sup>

### **What We Recommend**

It is now well known that simply placing persons in the community does not automatically equate to acceptance by the community, inclusion in the community, and improvements in quality of life. The following recommendations support needed improvements in community resources.

- Promote self-direction of services for individuals with DD as the primary way that services are managed and delivered in Missouri. Increase availability of self-directed services and provide education and training regarding these options for policy makers, self-advocates, families and the provider community.
- Encourage efforts that lead to all services and supports that individuals with DD receive, maintain, or increase community inclusion.
- Decrease services coordination caseload size to a 1-50 ratio to ensure quality service delivery.

- Support efforts to raise the level of respect of direct care staff and use the College of Direct Support to meet the needs for ongoing training and credentialing as well as to improve recruitment, retention, and compensation for direct care staff.
- Support and advocate for the DMH's budget requests for community based services in order to increase funding and meet the needs of individual and families on the MRDD waiting lists.

## **COMMUNITY RESOURCES AND SUPPORTS ENDNOTES**

"Shattering Myths". (2005). Missouri Developmental Disabilities Network and People First of Missouri. Accessed at <http://www.mpcdd.com/>

<sup>2</sup> The Missouri Customer Leadership Initiative. (1998). "Show Me Change: Building a Participant-Driven System for Missourians with Developmental Disabilities". Retrieved 01/07, from <http://www.mpcdd.com/pdfs/LeadershipInitiativeFinalReport.pdf>

<sup>3</sup> Amado, A.N. (2005). "Evaluation of Case Management Model Hennepin County Developmental Disabilities Program 2004-2005". University of Minnesota institute on Community Integration. <http://rtc.umn.edu/docs/HennepinCountyReport.pdf>

<sup>4</sup> Rinck, C., Graybill, T., Berg, R., Horn, W. (2006). "The Missouri Planning Council for Developmental Disabilities Statewide Needs Assessment".

<sup>5</sup> Ibid.

<sup>6</sup> FY2005 info provided by MODDRC staff.

<sup>7</sup> Rinck, C., Graybill, T., Berg, R., Horn, W. (2006).

<sup>8</sup> FY2005 info provided by MODDRC staff.

<sup>9</sup> "Parent Education: Standard Program Evaluation". (2006). Special School District of St. Louis County. Retrieved 1/07 from [http://www.ssd.k12.mo.us/about\\_SSD/program\\_eval/assets/05\\_07/Parent\\_Education.pdf](http://www.ssd.k12.mo.us/about_SSD/program_eval/assets/05_07/Parent_Education.pdf)

<sup>10</sup> The Missouri Customer Leadership Initiative. (1998).

<sup>11</sup> Rinck, C., Graybill, T., Berg, R., Horn, W. (2006).

<sup>12</sup> Ibid.

<sup>13</sup> "Missouri MRDD Home & Community Based Services Organizational Review". (2006). Jefferson City, MO: Missouri Department of Mental Health. Retrieved 1/07 from <http://www.dmh.mo.gov/mrdd/rcreviewreport.doc>

<sup>14</sup> "A Report to the Governor on Building a Safer Mental Health System: Issues and Recommendations". (2006). Jefferson City, MO: Missouri Mental Health Commission. Retrieved on 1/05/07 from <http://www.dmh.missouri.gov/spectopics/MHCreport.pdf>

<sup>15</sup> "Missouri MRDD Home & Community Based Services Organizational Review". (2006).

<sup>16</sup> "Annual MRDD Community Program Funding Report by County for Fiscal Year Ending June 30, 2003". Jefferson City, MO: Division of Mental Retardation and Developmental Disabilities. Accessed at <http://dmh.mo.gov/mrdd/provider/fy03annualreport.pdf>

<sup>17</sup> Rinck, C., Graybill, T., Berg, R., Horn, W. (2006).

<sup>18</sup> "A Report to the Governor on Building a Safer Mental Health System: Issues and Recommendations". (2006).