

## HOUSING

“...Americans with disabilities are entitled to the same range of choices and opportunities as other citizens. This includes being able to decide where and with whom to live, and how to spend time. These simple choices, generally taken for granted, are not afforded to people with disabilities...”<sup>1</sup>

### Our Beliefs

One of the primary goals of the Missouri Planning Council for Developmental Disabilities (MPC) is to have “Individuals reside where and with whom they choose in non-segregated community settings with the availability of individualized supports.”<sup>2</sup> This goal was created from values that are gaining acceptance across the state and nation.

MPC’s Needs Assessment indicates individuals with developmental disabilities (DD) and their families feel that there are significant problems and challenges with insufficient accessible, affordable, and safe community housing; insufficient in-home supports and services; long HUD (Housing and Urban Development) housing waiting lists.<sup>3</sup>

#### MPC Values

- To assist the community to include all people with developmental disabilities (DD) in every aspect of life
- Improve the lives of persons with DD through programs and services which enable those persons to live independently and productively, given their individual needs and capabilities
- Supports community initiatives that result in persons with developmental disabilities having opportunities for housing.

Supported living is “the fastest growing residential option for persons with DD in the U.S.,” increasing 19% from 2002-2004.<sup>7</sup> Multiple studies conducted over the last 20 or more years, of people moving from institutions and into the community have found decidedly positive results. According to some studies, residents of institutions in other states sometimes said they did not want to leave the institution. **However after moving they reported strong satisfaction and happiness within their community home.**<sup>8</sup>

### The State of the State in Housing

In Missouri, a shared vision appears to be emerging across state agencies regarding the need for creative reform of Missouri’s long-term care system. In 2006, Missouri received a \$3 million dollar, 5-year federal grant targeting

transformation of long-term support services in Missouri that aims to recreate the system to improve outcomes for both consumers and providers.<sup>9</sup> Missouri Protection & Advocacy Agency (MO P&A) also supports community-based living and recommends “families should be involved at every step and decision point.”<sup>10</sup> *Show-Me Change*, a report produced in 1998 by MPCDD, determines all services and supports should be designed around

### What the Research Says

Research supports the nationwide trend to increase community-based living opposed to institutional care. The Olmstead ruling by the Supreme Court in 1999 states that it is a violation of the Americans with Disabilities Act (ADA) for states to discriminate against people with disabilities by providing services in institutions when individuals could be served more appropriately in a community-based setting.<sup>6</sup>

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

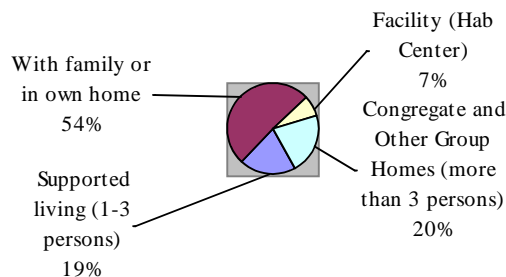
##### Needs Assessment Results

- 57% of respondents thought persons with Developmental Disabilities (DD) were *most likely* to live at home with family and friends
- 48% thought people with DD were *least likely* to live in a place of their own
- 70% of respondents rated community-based living opportunities as “inadequate” or “fair”

##### Challenges in finding a place to live included:

- Need for more in-home supports and services. Long waiting lists for HUD housing and other community programs
- Challenges of living on one’s own in the community
- Impact of community and housing industry perceptions

#### Place of Residence- Missouri, 2006<sup>5</sup>



achieving a maximum level of community inclusion, and the planning process should be truly “person-centered.”<sup>11</sup> Governor Blunt restated in 2006 that he supports “private-sector community placement through closure of the state-operated Bellefontaine Habilitation Center.”<sup>12</sup>

Despite the presence of numerous federal, state, and local programs and federal legal provisions

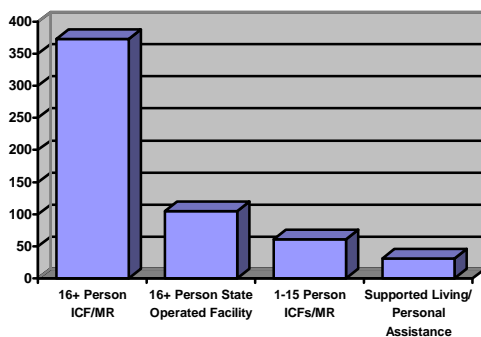
*“Because most people with disabilities have fixed incomes, we can’t afford apartments and we’re stuck. Even though I am working, I can’t afford my apartment and I can’t afford to move either.”<sup>13</sup>*

addressing housing, significant barriers still exist including: **1)** the lack of available, accessible housing, **2)** the number of persons waiting for these programs, and **3)** consumer

understanding of the programs and of their legal rights. Here are the facts from 2004:

- Missouri is one of only eight states that reported a decrease in spending for supported living and personal assistance.<sup>14</sup>
- Missouri ranks within the 10 lowest states for use of 1-6 person residential settings.<sup>15</sup>
- Cost of care to adults with DD in Missouri steadily decreased across all settings; supported living with personal assistance being on average the least costly to implement.<sup>16</sup>

**Cost of Residential Options in Missouri FY2004<sup>17</sup>**



■ Annual Avg Cost of Care Per Resident (in thousands)

- Missouri still ranks 38<sup>th</sup> in average daily number of residents in institutions.<sup>18</sup>

- Use of nursing facilities for Missourians with DD was 58% greater than the nationwide rate.<sup>19</sup>

***Dilemma of Aging Caregivers.*** It is estimated that in the United States 75% of people with developmental disabilities live at home with their families, with the primarily caregiver being over the age of 60 in 25% of these homes.<sup>20</sup> In Missouri, 15,201 persons with developmental disabilities were estimated to be living with caregivers over the age of 60.<sup>21</sup> This number signals an emerging crisis within the state as aging caregivers become unable to care for their loved ones with developmental disabilities and out-of-home placement becomes necessary, given the already crowded waiting lists.

*“Biggest area of concern is ‘What happens when we are gone?’, and ‘My son lives with me but I am concerned about his care when I am gone.’<sup>22</sup>*

**What We Recommend**

These recommendations are meant to enhance the objectives already stated within the Transformation Grant and other current housing initiatives.

- Priority should be placed on expanding the availability of accessible, affordable and safe housing options within the community.
- Locate affordable and accessible housing options in places that optimizes access to community resources and services.
- Separate funding for housing from funding for supports to maximize individual control
- Explore blended funding to increase housing and support options for people.
- Develop a plan to meet the housing and support needs for individuals with caregivers over 60 years of age to prepare for the fiscal demands required to meet the impending need.
- Increase access to HUD Section 8 vouchers.
- Work with other partners such as Centers for Independent Living and Comprehensive Psychiatric Services to coordinate state, federal, and local housing initiatives.

**HOUSING ENDNOTES**

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- <sup>2</sup> Missouri Planning Council for Developmental Disabilities. <http://www.mcpdd.com>
- <sup>3</sup> Rinck, C., Graybill, T., Berg, R., Horn, W. (2006). "The Missouri Planning Council for Developmental Disabilities Statewide Needs Assessment".
- <sup>4</sup> Ibid.
- <sup>5</sup> MRDD Databook. (June 2006).
- <sup>6</sup> "The Olmstead Fact Sheet". Missouri Department of Mental Health Department of Mental Retardation and Developmental Disabilities. Accessed at <http://www.dmh.mo.gov/mrdd/issues/olmstead/factsheet.htm>
- <sup>7</sup> Braddock, D., et al. (2005). The State of the States in Developmental Disabilities Preliminary Report. Department of Psychiatry and Coleman Institute for Cognitive Disabilities: University of Colorado, Boulder.
- <sup>8</sup> Conroy, J.W., & Bradley, V.J. (1985). "The Pennhurst Longitudinal Study: A Report of 5 Years of Research and Analysis". Pennhurst Study Report PC-85-1. Philadelphia, PA: Temple University Developmental Disabilities Center/ UAP. Boston: Human Services Research Institute.
- <sup>9</sup> Missouri Department of Mental Retardation and Developmental Disabilities. Retrieved from <http://www.dmh.mo.gov/mrdd/transform/thansformation.htm>
- <sup>10</sup> "Policy Statement on the Future of Missouri's Habilitation Centers and Community-Based Support for Persons with Developmental Disabilities". (Spring 2005). *Alliance*. Missouri Protection and Advocacy Services.
- <sup>11</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>12</sup> Tuft, C. & Mahr, J. (December 20, 2006). "Blunt Clashes with Parents Over Closing State Home". Accessed at [www.stltoday.com](http://www.stltoday.com).
- <sup>13</sup> Rinck, C., Graybill, T., Berg, R., Horn, W. (2006).
- <sup>14</sup> Braddock, D., et al. (2005).
- <sup>15</sup> Ibid.
- <sup>16</sup> Ibid.
- <sup>17</sup> Ibid.
- <sup>18</sup> Ibid.
- <sup>19</sup> "Missouri Division of MRDD System Transformation Initiative". (2005). Application for Real Choices Systems Transformation Grants. Missouri Department of Mental Health Division of Mental Retardation/Developmental Disabilities. Available online at <http://www.dmh.mo.gov/mrdd>
- <sup>20</sup> Heller, T., Caldwell, J., & Factor, A. (2005). Supporting aging caregivers and adults with developmental disabilities in future planning. *Disability Research Brief*. Rehabilitation Research and Training Center on Aging with Developmental Disabilities. University of Illinois: Chicago.
- <sup>21</sup> Braddock, D., et al. (2005).
- <sup>22</sup> Rinck, C., Graybill, T., Berg, R., Horn, W. (2006).