

The State of the State for Missourians with Disabilities

SAFETY AND QUALITY ASSURANCE

"We are Americans too! We want to be included in all communities in our great nation and to have all the rights and responsibilities of full citizenship. We need to be safe and free at the same time. We know how to do this. Few American communities are listening."¹

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) and other Missouri advocates feel the responsibility of protecting individuals with developmental disabilities (DD) is not only a legal responsibility but a moral responsibility.²

The Division of Mental Retardation and Developmental Disabilities (MRDD) supports individuals with DD by engaging in person-centered planning which helps to identify and provide optimal programs and services; thus enabling individuals with DD to live a safer life in the least restrictive setting given their individual needs and capacities.

The results of MPC's Needs Assessment indicate that individuals with DD and their families feel there is still much variance in acceptance in the community and inclusion of people with disabilities. Many people expressed concern that the attitudes and lack of understanding of persons with DD lead to individuals being excluded from the community.³

What the Research Says: *The State of the State in Safety and Quality Assurance*

Four of Missouri's cities recently received national recognition for their economic strength and quality of life.⁵ The current realities of quality of life for Missourians with DD, however, do not seem to match this positive report.

Funding. Many individuals who provided testimony in 2006 to the Missouri Mental Health Task Force felt that budget cuts have significantly affected decision-making in the Department of Mental Health (DMH).

Consensus was that DMH cannot continue to stretch its dollars and still provide safety and quality assurance for the Missourians with disabilities that it serves.⁶ While the MRDD Systems Change Transformation Grant will increase access to community services, the ability to create new services and to maintain those that already exist will be difficult given the direct support crisis.

Safety and Quality Assurance Administration.

Some Missourians have expressed concern that competition, rather than cooperation, exists between services provided through state operated facilities and community-based programs, pointing to differences in standards of care expected from

contracted provider programs versus state operated programming.⁷ Some Regional Center staff feel that the current MRDD Quality Assurance (QA) system may be inefficient and/or time consuming, while some providers view it as intrusive and ineffective. MRDD's internal processes were also cited as an area of larger concern.⁸ The Missouri DMH visions for 2007-2012 include establishing new approaches to quality assurance and highlight regional center reform.⁹

MPC Values and Goals

- Persons with DD belong in their community.
- Quality of life is as essential as safety in regard to an individual's right to choose to live in the community.
- Freedom from abuse, neglect, exploitation and violation of human rights.

MPC Beliefs

- People with DD have the same rights and responsibilities as other citizens, including the opportunity and responsibility to direct their own lives.
- People with DD are listened to and treated equally as other citizens without assumptions based on their disabilities.
- The system is an active partner with people with DD and families by providing helpful and accurate information about choices.
- Resources for supports in the state of Missouri must be allocated and expended from a person-centered perspective rather than a provider-centered perspective. Individuals must be in control of their allocated resources for services and how they are delivered.

What Missourians with DD and Their Families Are Saying⁴

Statewide Needs Assessment Results:

- Generally speaking, 20% of people surveyed reported awareness of some type of abuse/neglect of persons with disabilities in their community, either physical, sexual, financial, or human/legal rights violation.
- 59% of respondents felt that people with disabilities were very safe or mostly safe in their community.
- However, 41% felt that people with disabilities were only somewhat safe or not safe at all in their community.

Challenges in quality assurance for community inclusion:

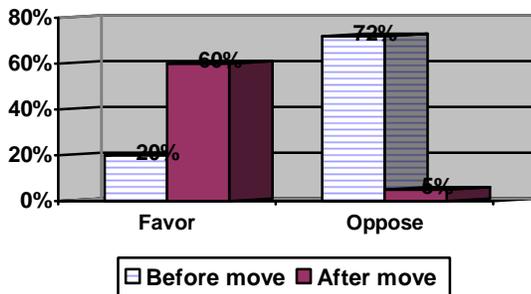
- People with disabilities were most often felt to be included in community life through 1) support and involvement of community organizations and businesses, and 2) through attitudes of acceptance from within the community.
- However, barriers of attitude and lack of understanding were also often stated as important factors in why people with disabilities are excluded from community life.
- Many people felt that persons with DD and their family members are included in planning that affects their lives. Family and friends most often supported them to participate in the planning process.

Quality assurance for decision-making regarding community inclusion involves effective person-centered planning. Indeed, the MPC has recommended that any movement of individuals from habilitation centers must be done from a person-centered approach by allowing the planning process to be directed by the individual with assistance as needed from a representative.¹⁰ Yet, Regional Center workers statewide report perceiving a move away from person-centered care and toward mere compliance with health and safety directives, as opposed to finding a balance between the two.¹¹

Abuse and Neglect Prevention. Between 2000-2005, at least 23 deaths linked to abuse and neglect at privately run homes and state-run centers under DMH's watch were reported in Missouri.¹² The 2006 Mental Health Task Force examined records of abuse and neglect from July 2005-June 2006. While the needs of residents and amount of services they received varied, data showed that residents of state-operated facilities were abused and neglected at a greater frequency (14%) than persons in community-based settings (5%).¹³ Studies in other states have also found decreased allegations of abuse after community placement.¹⁴

Although abuse and neglect have been recently publicized in Missouri, parents of the residents show concern regarding the potential closure of habilitation centers, and possible impacts on their loved ones safety. Similarly, a large majority of the parents of residents of the Pennhurst Institution in Pennsylvania did not wish to relocate their children into the community. Nevertheless, following the move, families shifted to a strong support of community placement, as depicted in the chart below, and noted that their loved ones seemed happier living in the community.¹⁵

Shifts in Pennhurst Parent Opinions Before and After Community Living Experiences



Direct Service Providers (DSP)-Lack of a Quality Workforce. An important barrier to making personal choice a reality for people with disabilities is the lack of a stable direct care workforce. A study by DMH in 2002 estimated the annual turnover rate of DSPs to be 68%.¹⁶ Lack of DSPs has been primarily attributed to low wages and poor benefits. Studies indicate a decrease in staff turnover rate with increased rate of pay.¹⁷ Decreases in turnover were found when persons with DD in the Missouri Independence Plus Pilot program were given control over their funds and could choose to increase wages.¹⁸

Participation in the Voting Process. Today, in most democracies, the right to vote is granted as a birth right without any qualifying test. The MPC works to increase participation of Missourians with developmental disabilities in the voting process through the encouragement of people with DD to register to vote, obtain voter identification, serve as an election judge, or call voters.¹⁹

What We Recommend

These recommendations are offered to supplement that which was already stated within recent reports on abuse and neglect.

- Promote efforts to support individuals and families in receiving services which will allow them to provide care for their family members in their home or a community setting of their choice.
- Develop options to include acute and emergency services including a community crisis response system for individuals

in crisis and to prevent more restrictive placements.

- Promote efforts to increase flexible funding systems that allow dollars to truly follow the individuals to the community and in the community.
- Increase early access to services prior to individuals reaching a crisis point and potentially reducing the need for more costly services.
- Provide critical supports for direct care staff including training, credentialing, and adequate pay to ensure safe, quality supports for individuals receiving services.
- Support efforts to fund and expand the College of Direct Support as an excellent vehicle for providing better supports for direct care staff.
- Promote quality of life as an essential component of safety and advocate to prevent safety from becoming a means to limit an individual's right to choose a life in the community.

SAFETY AND QUALITY ASSURANCE ENDNOTES

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- ⁶ "Missouri Mental Health Task Force Report to Governor Matt Blunt". (2006). Jefferson City, MO: Missouri Mental Health Task Force. Retrieved 1/07 from <http://www.dmh.missouri.gov/mmhtaskforce/documents/MOMentalHealthTaskForceReport.pdf>
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