

## **Changing the Service System to Empower Individuals with Disabilities**

Since the 1970's society's views of people with disabilities has been evolving to recognize the uniqueness of an individual's abilities and limitations. Despite forty years of improvement, lack of employment and resulting poverty frequently cause individuals with disabilities to enter into the social services system. While the requirement for an individualized assessment and response is a cornerstone of disability policy this is not always reflected in the service system. Although person centered planning is considered a "best practice" often times individuals feel like their choices are not honored. Authorization for services and supports comes from a "case manager".

There are certain prerequisites if individuals with disabilities are to be empowered:

- Every individual should be presumed competent, unless declared otherwise by a court, to direct the planning process, make choices, achieve his or her goals and outcomes, and build a meaningful life in the community.
- Every individual has strengths, can express preferences, and can make choices.
- Every individual with a disability should have his or her choices and preferences accurately assessed and understood using a formal assessment process which is regularly updated. Currently, DHS is implementing Mn CHOICES as its assessment tool.
- Every individual with a disability should be provided a budget for housing and services which he or she can use to make choices, with, as appropriate, the assistance of family and significant others.
- Every individual should be able to have the timely assistance of an advocate such as a certified peer specialist, peer integration specialist or self-advocate.
- Every individual contributes to his or her community, and has the ability to choose how supports and services enable him or her to meaningfully participate and contribute.
- Through the individualized planning process, an individual maximizes independence, creates community connections, and works towards achieving his or her chosen outcomes.
- An individual's cultural background is recognized and valued in the individualized planning process.

### **Empowering Choice While Managing Risk**

Unfortunately, empowering individuals to live their own lives in the community of their choosing, as mandated by Olmstead, raises complex issues around the issue of risk of harm and potential liability. Few endeavors in life, if any, can be accomplished without some risk of harm. Moreover, taking a risk can have positive as well as potential negative consequences. However, the ability to make choices

enhances the quality of life of persons with disabilities. Most people weigh the potential benefits and the potential negatives when considering a course of action, whether or not this is done consciously or unconsciously.

When it comes to disability, however, risk taking is often viewed as having only potential negative consequences. Perceived or actual risk to the health and safety of people with disabilities or others in the community can undercut efforts at individual empowerment and community integration.

Continuing efforts to provide persons with disabilities real control over decisions affecting how they participate in all aspects of community life raises concerns in a variety of contexts. State and county officials<sup>1</sup> providers of disability services, family members<sup>2</sup> and people in the community sometimes believe there is a potential for harm to people with disabilities and others resulting from unrestricted community integration of people with disabilities.

Many of these concerns arise from myths, fears and stereotypes about disability and disease. For this reason, disability rights advocates crafted the Americans with Disabilities Act (ADA) to permit public and private disability programs to exclude only those persons whose disabilities posed a significant risk of substantial harm to others which could not be mitigated by some form of mandated accommodation which would not impose an undue burden or alter the nature of the program in question.<sup>3</sup> Risk to self is not a permitted statutory basis for exclusion of a person WITH A DISABILITY under the ADA.

However, perceived or actual fear about the health and safety of persons with disabilities and others in the community can and will torpedo efforts at integration unless they are effectively dealt with. There are many policy complexities to the appropriate management of risk in the context of community integration. Many persons with disabilities are perfectly able to accurately assess risks and rewards without assistance and without someone second-guessing their decisions. People with disabilities should not be subjected to risk management policies which are not applied to non-disabled adults in similar circumstances.

Moreover, every human being, including a person with a disability, has abilities and limitations. A valid risk management policy must be applied on a case-by-case basis to evaluate whether some form of accommodation, service, or support, which, if provided, would enable an individual to safely perform an activity or achieve a personal goal.

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<sup>1</sup> Hall-Lande, J.; Hewitt, A.; Bogenschutz, M.; Laliberte, T., "County Administrator Perspectives on the Implementation of Self-Directed Supports", *Journal of Disability Policy Studies*, Feb. 16, 2012.

<sup>2</sup> Assistant Attorney General Thomas E. Perez, Testimony Before the U.S. Senate Committee on Health, Education and Pensions, June 21, 2012, p.5

<sup>3</sup> The ADA Title II (state and local governments) regulatory restriction permitting exclusion of a person with a disability only if the disability would pose a direct threat to others and not to self is found at 28 C.F.R. § 35.109. Similar ADA language applicable to private places of public accommodations, including social service agencies, may be found at 42 U.S.C. § 12182(d)(3) and 28 C.F.R. § 36.208.

Finally, an effective risk management policy must be able to respond to systemic barriers created by fears of risk of harm to self or others. Fear about the possibility of litigation, bad publicity, or individual liability must be adequately addressed on a systemic as well as an individual basis.

Recognizing that different disability populations have developed unique strategies regarding peer supports it is important to support multiple strategies to assist individuals with disabilities. For example, while self-advocates serving persons developmental disabilities and certified peer specialists serving people experiencing mental illness are closely related in terms of outcomes achieved they employ different successful practices. The OPC supports throughout its recommendations the expansion of peer supports for all disabilities. Thus, one of the recommendations below is to develop a new peer support called a Peer Integration Specialist. A certified peer specialist or a self-advocate could also be a Peer integration specialist. The key idea is to make peer support a critical component of the new service system.

**Recommendations:**

- The State should involve persons with disabilities, their families and advocates in the implementation and evaluation of Mn CHOICES to ensure it accurately identifies the abilities and desires of all people with disabilities.
- The State should develop a process to ensure that there is enforcement of consumer choice by all providers including but not limited to case managers as well as service providers.
- The State should provide regular training on empowerment of individuals with disabilities, their right to live in a community of their choice, as appropriate and the options for housing, services and supports which are generally available. Such training should be offered frequently to all stakeholders including people with disabilities and their families.
- The State should review laws and rules including the Vulnerable Adult and Nurse Practices statutes to ensure they do not reduce individual choice.
- The State should address risk management policies and standards in a consistent manner. Currently, the State Quality Council and several private entities are considering policies and standards for risk management. Best efforts should be made to ensure that existing and proposed risk management policies and standards are reviewed and do not conflict with applicable law including the ADA.
- The State should ensure that all laws and rules address the balance of choice versus risk and insure that choice is given more weight than risk is given.
- The State should provide ongoing training to stakeholders on applicable risk management policies and standards to ensure that concerns about empowering individuals with disabilities to be fully integrated into the community is not derailed by unwarranted health and safety concerns.

- The State should support the development of a position called a Peer Integration Specialists that helps train and support individuals with disabilities to learn to speak for themselves, understand their rights, and express their preferences. This will include funding to support the training and coordination of a network around the state, and payment to assist other individuals with disabilities in making choices and moving to the most integrated settings. Some funding will be dedicated to supporting peer integration specialists to meaningfully participate in workgroups and task forces that effect services and the evaluation of quality.
- The State should support a self-advocacy network in Minnesota that helps train and support individuals with developmental disabilities to learn to speak for themselves, understand their rights, and express their preferences. This will include funding to support the training and coordination of a self-advocacy network around the state, and payment to self-advocates to assist other individuals with disabilities in making choices and moving to the most integrated settings. Some funding will be dedicated to supporting self-advocates to meaningfully participate in workgroups and task forces that effect services and the evaluation of quality.

**Goals:**

- The State should, over the next 5 years, hire and train 1,000 Certified Peer Specialists to assist individuals in understanding, making and implementing their choices.
- The State should, over the next 5 years develop a network of 500 paid Peer Integration Specialists to perform the same functions as the Peer Specialists with individuals whose primary diagnosis is other than mental illness.
- The State should, over the next 5 years, develop a network of 500 paid or volunteer self-advocates to perform the same functions as the Peer Specialists with individuals whose primary diagnosis is other than mental illness.