

## Managing Risk while Empowering Choice

Few endeavors in life, if any, can be accomplished without some risk of harm. Moreover, taking a risk, such as starting a business, can have positive as well as potential negative consequences. Surveys of persons with disabilities demonstrate that the ability to make choices which may have positive or negative consequences enhance the quality of life. 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 possible negative consequences. Perceived or actual risk to the health and safety of people with disabilities or others in the community can undercut efforts at community integration. Fear of people with disabilities was one of the initial reasons why they were institutionalized. A common belief is that closing institutions in the late '70s to '90s resulted in persons with disabilities being forced into homelessness, particularly those with psychiatric disabilities, and such individuals remain feared and shunned today by the majority community.

Continuing efforts to provide persons with disabilities real control over decisions affecting how they participate in all aspects of community life with non-disabled persons has caused varying degrees of concern. These concerns arise in a variety of contexts. State and county governments, providers of disability services, family members and people in the community believe there is a potential for harm to people with disabilities and others resulting from unrestricted community integration of people with disabilities. The State and its counties are responsible to ensure safety of "vulnerable adults". Providers fear bad publicity and litigation will result if persons with disabilities are harmed while participating in community living on their own say-so without restriction or supervision. Studies show that family members rank safety of their disabled loved ones as more important than the quality of life desires of their disabled relatives. Many communities protest when a group home is proposed to be opened in their neighborhood out of fear for their property, property values and even their own safety.

Many of these concerns arise from myths, fears and stereotypes about disability and disease. For this reason, disability rights advocates crafted the ADA to permit public and private disability programs to exclude only those persons whose disabilities posed a significant risk of 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. Risk to self is not a permitted statutory basis for exclusion of a person WITH A DISABILITY under the ADA.

Notwithstanding the ADA's strictures to the contrary, 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 of people with disabilities. Many persons with disabilities are perfectly able to accurately assess risks and rewards without assistance and without someone looking over their shoulder to second-guess 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 people with disabilities, has abilities and limitations occurring on a spectrum from non-existent to very high. Each of us has a large combination of strengths and weaknesses which enable us to be good at some things and not very good at others. Disability does not equate to total inability. One need only recall the athletic feats of the athletes in the 2012 Paralympics to realize the truth of the statement. Persons with multiple, severe disabilities may exist at the very low end of the spectrum, just as the paralympians would be placed at the very high end of the spectrum. Thus, any risk management policy must be appropriate and flexible enough to meet the needs of persons with disabilities living on the extremes as well as the greater number of people with disabilities whose abilities and limitations combine to put them in the middle of the spectrum.

Therefore, a valid risk management policy must be applied on an individual, case-by-case basis. Generalizations about people with various diagnostic classifications are not a lawful basis for risk management. Moreover, one also must evaluate on an individual basis whether some form of accommodation, service, or support, which, if provided, would enable an individual with a disability to safely perform an activity or achieve a personal goal.

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

**Recommendations:**

1. 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 harmonized to conform to applicable law including the ADA.

2. 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.
3. DHS should use internal and external stakeholders to decide what private and public entities should address individual safety and health concerns regarding a specific individual with a disability without undue delay. Qualification criteria and certification of individual responders should be required.

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