

# The Right to Risk

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The concept of the right to risk is vital to the nature of Interdependence. We deny people actions that are accessible to valued people, because we are concerned about their protection, yet in this denial, we can take away the very essence of life itself: freedom. Freedom to succeed is married to the freedom to fail.

The issue on the right to risk is important to understand. When a person is denied the right and opportunity to take chances, he is denied a vital outlet to learning. For most of us, critical learning is acquired when we take chances. Some people call this the “school of hard knocks.”

On the right to risk, the late theorist Wolf Wolfensberger suggested: “...it is dehumanizing to remove all danger from the lives of the ...handicapped. After all, we take for granted that there is risk and danger in our lives, and the lives of our non-handicapped children!” There is another factor in this question of control and risk that must be considered in the equation: the issue of liability. Like it or not, we live in a society that has embraced litigation. This has good and bad points. In the business of human services, however, liability and fear of litigation usually mean restrictions related to people with disabilities, and these restrictions typically play out in control.

There is no question in our mind that many programs designed for persons with disabilities in this country are control-oriented due to fear of liability. In fact, when asked to consult with organizations about Interdependence and how it may relate to their programs, one of the first issues on the table is that of risk and control. For many companies, especially the for-profit organizations, the window of risk and loss in promoting Interdependence is too great for them to embrace.

Although we differ with this decision, we can understand the company that chooses to sit out community inclusion programs. We cannot, however, respect organizations that conduct community inclusion programs, only to pervert them with control of their participants—directly and indirectly—to lessen their exposure to potential litigation.

Recognize that we are not berating organizations that consider exposure and liability. A company would be foolish to do anything less. However, there is concern about the creeping conservatism and control in programs that claim to be vested in community inclusion. Most of this action only leads to oppression and domination of the recipient of services.

There are ways that formal services can balance this dilemma between risk and control, but they demand a real sense of creativity. They also demand that the Interdependent paradigm be in place within the organization. The other paradigms just don't allow for this kind of participant control necessary to feel empowered.

Some actions that may be helpful in lessening risk are:

### **Discuss the Issue**

The right to risk is an issue that needs to be discussed and reviewed by all involved. Key aspects of risk and how the program or supports address risky situations should be covered. These discussions should be regular and immediate and include all players. That is, support persons and the person with a disability should hold discussions as close to the risky event as possible.

This factor of timing is a key dimension where the expert paradigms can fall short. Usually the expert paradigms follow a 9 to 5 work schedule. Paradoxically, risky events and situations often occur on weeknights and weekends. Thus, key staff are not always available for an immediate discussion. If they are, it is sometimes through a cell phone call and may be seen as an "intrusion" to the supervisor.

### **Document the Disclaimer**

After thorough review of the right to risk, a disclaimer should be developed, discussed, and signed by all parties. Although such documents may be inadmissible in court, they do reflect the importance and seriousness of the right to risk. These disclaimers should be reviewed and updated on a regular basis. They should be specific and tied to tangible, concrete situations.

Along with participants, family members, advocates, and funding representatives should all review and sign off on the disclaimer. If nothing else, the disclaimer can serve as a vehicle to raise consciousness and an understanding of personal responsibility for one's actions.

### **Establish Patterns of Support**

Perhaps the best approach in right to risk is found through adequate, reasonable, and responsible support patterns. In this area, the program needs to be detailed in support, but it should not be overbearing. These patterns of support must also be relevant and related to the lifestyle and interests of the person with the disability. Again, the micro paradigms have difficulty with patterns of support. Typically, organizations provide supports in classic shifts, much like hospitals. Schedule shifts make things relatively neat and tidy for the organization, but can fall short in meeting an individual's needs.

Although you can never fully protect against potential liability, one approach that has helped is found in the intersection of independent living and technology. In Pittsburgh, we have developed "smart homes" for residents who have some limitations that heretofore excluded them from independence. Partnering with engineers and technical experts we have purchased homes that, in essence, "think" for the resident. These homes are equipped with computer and smart technology that can alert the residents if the windows or doors are ajar, prompt them about medications, regulate water or room temperature, turn off water that runs too long, and allow residents to monitor porches, yards and outdoor spaces and the like.

Although these technologies will not prevent the possibilities of an accident or problem, they can greatly lessen some dependencies. In a way this is “Interdependence” not with people but with equipment. For most of you reading these words, this should not be an alien concept. I am sure your “smart phone” has bailed you out of many situations where your personal limitations might have gotten in the way.

Many programs under-support or over-support people based upon shifts, not participant needs. An open-ended support system that is not bound by shifts, job descriptions, and union issues, I believe, can greatly reduce the window of risk.

## **Conclusion**

In the end, life is about risk. Communities are not laboratories where variables are measured and controlled in the process. Rather, the dignity of life demands that people have control over their lives – and the ultimate control is the right to risk.

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