

**Supported Life,  
Some Ethical Considerations  
from the guy who signs the state contract  
and  
is the one staff responsible to  
the agency's Board of Directors**

by

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The task of administrating a program that supports persons with disabilities has always been an "interesting experience". With the development of a second generation of supported living programs well under way however, this job has taken on ethical challenges that I believe are unprecedented. I think frequently of a quote from Joel Barker as he discusses the dynamic of paradigm shifts. As I pondered the subject of ethics in our shifting from models of services to supports his thought that "when a paradigm shifts, everything goes back to zero", took on new meaning.

Ethics never seemed like a big deal before. I don't remember the scale of ethical concerns in the good old days of five years ago that we have now. Then we had ample licensure regulation to hide behind. "We can't do that because the state won't allow it" was a wimpy but effective tool to ward off those bothersome issues that potentially pitted individual rights against the rights of the agency (administrator?) to "control".

Today, as the metamorphosis of everyone's roles emerge, the status of our legal and ethical standing has forever changed. As we no longer have (some may say, enjoy) the role of "systems manager", we no longer direct groups of people to "program" other groups of people. Now we face daily the challenge of dealing with the individual with rights, living in a world where many people, but not all, truly believe in and support those rights. By accepting this one to one relationship, we leave our former manager status, perhaps forever. If we had them, we lose; **Power, Authority, Comfort, Control, Organizational Need, Safety, Protection, Rules/regulations,**

Our new role of "facilitator" offers a great deal less administrative comfort than our old roles. Now, not only do we have all the problems of the past, we also have the stuff of which potential law suits of unimaginable proportions are made; **Individual Planning, Self Advocacy, Choice, Empowerment, Support/facilitation, Dignity of Risk, Individual need, Natural Consequences, Risk, Quality of Life, Negotiation, Relationship.** **Some cases in point:** Innocently describing to our board the wonders of our latest supported living initiatives I was startled one evening to hear one member (an attorney and recognized legal scholar with a son receiving services in one of our homes) asked if this was a wise pursuit. He valued the supports his son was receiving and wanted nothing to happen that could put the agency's well being in danger.

### **What could happen. . .**

A few months after this meeting, one young woman who was her own guardian, was being lobbied by some of our staff to give more concern to safe sex practices. Knowing her as we had over the past few years it was clear that no one was going to tell her what was best for her. Trying to avoid the parental trap staff directed her to other community resources who could give her specific assistance in this area. Her family, some of our staff and concerned friends all wanted me to stop her. I could not of course do that.

**What else . . . ?** This same young woman was recently evicted from her apartment. She was evicted because she failed to pay her rent on more than one occasion. She didn't pay her rent not because she didn't have the money but because she used it to buy other items she felt, on impulse, were more important. It's quite probable that in doing this she defrauded the state by using her room and board monies for other than what they were intended. At this time we are giving mutual consideration to our support relationship. This consideration follows months of negotiating fewer supports and the choice of new support staff. We struggle to find an ever changing common ground as we deal with this and other individuals.

But, all is not lost. It's not the end of the world yet! To be sure the traditions of past service systems offer us little solace now.

So far I believe few "systems" work in this sphere. Values, personal relationships, and negotiation skills are more important resources now. "The answer" (was there ever really one?) I believe, is in fact that there are very few answers. Given that the book doesn't exist it would seem the survivalists thing to do is to organize an agency in such a fashion that it focuses on creative ways to work with consumers and their families to develop their unique "Life Plans".

We need, as well, more staff who seek creative solutions and who understand their primary function of personal advocacy. The term "level playing field" takes on new meaning in this context. Meeting as peers is a new experience. We are practiced with few skills to deal with this new relationship.

Our agency has worked with only some success to re-tool staff to relinquish their control skills and hone new listening and negotiating skills. It is difficult for them to capture the same vision some of us are developing. They have a right to be cautious as they wonder about this dignity of risk stuff when it happens on their shift. We wonder too how to best go about the business of assessing quality of life in such a way that it satisfies all of the stakeholders.

Simultaneously we struggle with the reality that our age of enlightenment is not shared by the majority of our communities. Inclusion because "it feels good" is not a convincing argument to families, some of our peers, the average taxpayer and many legislators.

Despite the fact that we are uncomfortable with our current status, and we really don't know all that many how to's we have to find ways to articulate the new age to our boards, our many consumers, our staff and our legislators.

And how about those dilemmas . . .

I don't know. . . Given the example of the young women I cited, what's best for her, for us? Legally we don't think we're responsible for her adolescent behavior. Do we throw our hands up and say if she continues on her current track we can't continue to support her? Do we solicit some level of legal protection for her, e.g. a very limited guardian status to limit her negligence of her financial well being? Shall we assume her other life style risk taking models that of the larger society?

And what about the concern of my board member.

I don't know?

We don't have all the skills! Can we really admit that?

We don't have nearly all the answers. We never in fact have!

The question remains, in our litigious society, will this count?

As we wrestle with the ethical pendulum over each individual, where will the social/legal judgment of our day fall?