

Choice, Common Sense, and Responsibility: The System's Obligations to Recipients

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I'm going to speak, primarily, as a person who has used mental health services on and off for the last thirty years and, secondarily, as a bureaucrat. I want to pick up on two themes that Clarence Sundram raised in his opening remarks. One of them is common sense and the other one is responsibility.

All too often common sense has not been a part of the discussion about choice for people with psychiatric diagnoses. The discussion has often been based on myths and stereotypes, unquestioned assumptions and mistaken judgements about what those of us with diagnoses are capable of doing.

Those of us who feel that choice is a right—not a privilege to be afforded for good behavior—make a mistake when we let people who would like to slow down the move toward choice frame the issues around hypothetical examples or extreme situations that

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might happen once every ten years. Because for most of us who have received services, or who have been in hospitals and institutions and community residences and day programs, the truth is that most of the interference with choice actually occurs in much more mundane, routine noncrisis kinds of matters. Things like when we eat,

when we're allowed to use the telephone, who we can associate with, and what we do with our time. And, while those issues don't have the "glamour" of the high-risk situations we hear about, I really believe that that's where most of us have felt the most intruded upon and where the lack of choice has really been a burden to us over the years. So if we deal in a common-sense way with choice in day-to-day situations, and we see that often staff don't *want* us to exercise

choice, we have to wonder, how much of it is for staff's convenience? And, how often is it framed in those words that I think most of us have come to dread: "for your own good," or "in your own best interest"? And, how do professionals *know* what *our* best interests are? As Michael Kennedy pointed out earlier, *we* know that on a daily basis, in a gut way, that professionals who deal with dozens of clients don't.

Michael made a very good point when he noted that if those of us who receive services appear to lack good judgment at times, we really need to examine how much of that is due to the negative effects of learned helplessness and institutionalization, and how much of it may be due to a temporary or long-term extreme mental or emotional state.

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There hasn't really been much research in that area, but most of us who have been in the system know that after a long time of other people making your choices for you, making you dependent, and not allowing you to make choices, your decision-making skills atrophy. And then staff say we're not competent to make choices—it's almost a matter of blaming the victim. The system has created groups of people who have had their volition taken away from them, who haven't been able to exercise their choices and who, therefore, may have forgotten how to do it. And all of a sudden the system turns around to them and says "Okay, we've decided you're empowered, now go make choices." The system needs to take responsibility for how it has disempowered people, and help them get the supports they need to relearn those skills.

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People in the consumer/survivor/expatient movement often say that the mental health system treats us like children. But, frankly, I think that's an overgenerous assessment. If you think about good parenting, parents want children to grow up to become independent, to be able to make their own decisions. For most of us, the system hasn't done that. It has, in fact, not given us the opportunity to develop those skills or to keep practicing them if we already knew them, but instead has often taken that right away from us and,

therefore, not prepared us the way a parent would prepare a child to go out in the world and be an adult.

This brings me to the theme of responsibility. I'd like to talk about the responsibility of staff and the responsibility of the mental health system. I think

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the system needs to seriously consider its responsibility in creating feelings of dependency and learned helplessness that interfere with people's abilities to make choices. The system not only has a responsibility *not* to continue to do that to new generations of people, but also to help and sup-

port the people who have been victims of that learned helplessness.

Many of us who have used the system are more concerned about avoiding the negative effects of this system than we are in splitting hairs about what kind of services we want. One thing that we *do* want is protection and safety while we're in the system. It's ironic that a mental health system which has created institutional conditions that are often unsafe also sets itself up as the expert on what's a safe choice for recipients.

The Commission on Quality of Care recently released some studies on the effects of the use of restraint and seclusion—and one of the very troubling statistics in the report is that over a period of about ten years, over one hundred people have died in restraint and/or seclusion. If the mental health system paid as much attention to protection and safety in those kinds of circumstances as it does when it decides where we are allowed to live and if we are allowed to get a haircut, things would be a little more balanced.

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Both professionals and recipients are trapped in a system that gives professionals too much responsibility and requires them to

be accountable for too much. Professionals are often as unhappy about that situation as we are. A lot of times professionals don't know what to do, they can't guarantee success, yet they feel that society has placed them in a position where that's required of them.

Mental health professionals have a responsibility to examine how the situation was created and what their own responsibility in creating it was. How might we all pull ourselves out of this dilemma? I know that many professionals feel very burdened by this.

I had a discussion the other day at a conference with a psychiatrist. We were talking about my expectations the first time I voluntarily went to a psychiatric emergency room. He asked, "What did I expect to happen?" I said, "Well, I guess I naively expected somebody to do something or say something that would make me feel like I didn't need to kill myself." And he sort of recoiled from that and said, "It's not fair to expect that of us." He said, "It's not my responsibility to save your life." And I said, "Well your system has set up the expectation that that's where I go if I'm in that state. So, if you're not capable of doing that, your profession needs to rethink what you can offer me and what you can't offer me." He was very open to the idea that it's time to sit down and do that. In fact, he said it scares him to death when

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someone comes to him and says, "I want to kill myself," because he doesn't know what to do. And he would like to get away from that burden as much as I would like to get away from the burden of having someone lock me up if I say those words.

Finally, I want to talk about the idea that Ed Knight, who is the director of the Recipient Empowerment Project, calls the "healing power of choice." It is his contention that choice isn't just an add-on. That, in fact, if you talk to people who have recovered—whether we're talking about recovery from trauma, recovery from an extreme mental or emotional state, or recovery from learned helplessness and institutionalization—that people who have recovered are people who have made choices on their own. Choice is an integral part of the healing process. It's not just something that we can tack on to treatment when we feel it's convenient. If choice isn't available, then healing cannot occur.

Thank you.