

Person centered planning and perversion prevention

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Changing our actions as well as our words

Person centered planning, in all of its forms, is moving from something done by a few enthusiasts to an activity that is being widely adopted and adapted. As it leaves the caring hands of the pioneers there are concerns for how it will be used. Our experience suggests that abuses generally arise from a lack of understanding on the part of those conducting the planning. The change from a program to a support model has been described as a paradigm shift. As a paradigm shift we are changing the "filters" through which we sort information. It changes the relative importance that we give to different pieces of information. What an individual cannot do is seen as less important than discovering the life-style that individual might like to live. Professionals who have learned to change their words but have not changed how they "filter" the information are not uncommon. It is easier to change the way we talk than the way we act. Most of the misuse of person centered planning results from using program model practices while using support model language.

Seeking and achieving understanding

Person centered planning is a technology. Properly applied it results in understanding the lifestyle desired by the person and how it may be achieved. Unlike many technologies, person centered planning is value-laden. While each of the person centered planning technologies has a different focus and a different process all of them are rooted in a profound respect for the individual and an expectation that the individual will be included in her or his community. All of the techniques assume that those who are facilitating the planning will spend sufficient time to discover the core values of the individual and to insure that these values are accounted for in the plan. When these techniques are treated as just another process, without regard to their explicit and implicit values, they are perverted.

Not discovering the core values

A good plan develops a vision of the future. The vision that should arise from a person centered plan is the individual's vision, not the vision of the professionals or the system. Describing someone else's vision of their future requires that we understand the individuals and their core values. Understanding an individual is never complete, people continuously change while they remain complex. The understanding that we do achieve arises from what is shared. We share stories from our past, dreams of our future, and the experiences of the present.

Understanding is a process that occurs over time. In the artificial process of person centered planning we substitute interviews and discussions for the time that we have not spent with the individual. We need to recognize the limitations of these substitutes. A person centered plan is a way to begin the process of understanding. It begins with

listening to the words and behavior of the individual and continues with listening to those who know and care about the individual. The end of the person centered plan should be the beginning of a lifelong effort of understanding the changing desires and needs of individuals.

The most common misuse of the person centered planning process is to confuse soliciting the superficial expression of choice with discovering the core values of the individual. The core values of the individual are relatively stable over time. They tell us who the individual is and the characteristics of the settings where the individual would like to live and work. If you know the core values you will understand how much privacy the individual requires. You will know where to begin in supporting the individual in the community. You will discover that there is no substitute for taking the time needed to understand the individual. The people most vulnerable to this abuse are those who wish to leave an institution. People who desperately wish to leave an institution will supply any answer in order to leave. Because they cannot leave without being selected they will agree to any conditions necessary to be selected. The professionals who have conducted the interviews will say that they have elicited the choices of the individual. In reality the professionals have distorted the process and abused their power. They have carried on a form of negotiation where they have all of the power and the individual who is desperate to leave has none. They have not spent the time necessary to discover the core values of the individual. They do not know what is essential in the life of the individual. They know what they have available and obtain the coerced consent of the individual to accept it.

The presence of significant disabilities should reinforce the need to understand the person. However, the profound power of the current model of services allows professionals to assign people to places to live (and who to live with) according to their disability labels. For individuals who do not speak for themselves this becomes even more tempting. Reliance on labels denies the individuality of the people we support. The more severe the disability an individual has, the more time will be needed to understand the individual. Unfortunately, the more severe the disability the more likely professionals will rely on the labels alone.

Implementation with understanding

Understanding another person is a process and a skill. Participation in the planning activities initiates the process and builds skills. Where those who are developing the supports have not had the opportunity to participate in the planning process, they must have other opportunities to develop understanding. They need to: spend the time needed to get to know the individual; talk to those who know and care about the individual; and make the effort to understand what is behind the words in the plan. The more skilled you are, the less time is needed to achieve a basic level of understanding, but there are clear minimums.

All people are complex, regardless of the presence or absence of a disability. All people show different facets of themselves in different settings and with different people. Understanding requires that more than one facet be seen. Further, we cannot claim to

understand someone if we do not know their core values. Discovering core values requires a picture of the person across settings. By definition, core values are stable across settings although they may be manifested differently in each setting.

Understanding deepens over time

Given the complexity of people, our understanding should continue to deepen indefinitely over time. Our initial efforts should be seen as a beginning, not an end. Sharing experiences with those we support is the best way to deepen our understanding. Sharing portions of our lives also develops the relationships upon which mutual commitment and interdependence are based. Careful implementation of a plan that honors choice is the first part of the process. The understanding that arises from sharing life experiences is the necessary next part of the process.

Understanding is a process that is focused on a moving target. People change over time. People who have lived in impoverished environments may need a period of frequent change. They need to learn what their desired life-style is by trying a variety of settings. We need to keep listening to their words and behaviors while these individuals test the perception of who they are against the reality of their life experiences. This requires that we support change that occurs at the pace requested by the individual rather than the pace dictated by our review cycle.

Once people are empowered to seek their desired life-styles they will continue to want changes to maintain their evolving perception of a reasonable quality of life. Carol Beatty of Alternative Living, Inc. (ALI) tells how 70 of the 74 people that ALI supports wanted significant changes in a one year period. These were not changes that the agency could not afford, they were the reasonable changes that any group of people might want over the course of a year. Some people wanted to change who they lived with. Some people wanted to change where they lived. Many people wanted to change how they spent their time. These changes did not occur according to an agency review schedule. People's lives changed according to their own schedule. The staff of ALI see supporting these changes as a challenge but they also see it as central to their mission.