

## Person centered planning, should we do it with everyone?

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Over the past five years person centered planning has undergone a transformation. It has gone from something mysterious that only a few dedicated and skilled people did to something where nearly everyone says "I have been doing person centered planning for years". Person centered planning and person centered services have become trendy. It has become a litmus test for being politically correct. Any activity where people are asked what they like or want is seen as person centered. Further, states, regions, and counties are beginning to require (or to consider requiring) person centered planning for everyone receiving services or entering services.

From my travels (and from the materials that get sent to me) I have learned that many of the alleged person centered plans and person centered services are not person centered at all. Plans are being written where what is important to those who provide services is written as if it were important to the person receiving services, that abuse the "voice" of the person (e.g. "I must be restrained"). People whose only real dream is to get out of the institution they live in have plans that say that it is their dream to live by themselves in a house in suburbia. People are asked questions where they do not have the life experiences necessary to give an informed answer. Questions are asked that have the answer built in. Equally troubling are the honest plans that are not implemented. Over and over again I hear of people who tell us things such as desperately wanting a new roommates who never get one. Much of what is being done represents no real change in practice. It is business as usual masquerading as being person centered.

### **Person centered planning is a means not an end**

A person centered plan is a means and not an end. The life that the person wants is the outcome, not the plan that describes it. Person centered planning is a process of learning how a person wants to live and then describing what needs to be done to help the person move toward that life. It is a description of where the person wants their life to go and what needs to be done (and what needs to be maintained) to get there. Good plans are rooted in what is important to the person while taking into account all of the other factors that impact on the person's life - the effects of the disability, the views of those who care about (and know) the person, and the opportunities as well as the limitations presented by the need for public funding.

A person centered plan reflects a process:

That is respectful of the person with the disability, the family, and those who support the individual;

Where the time and effort necessary is spent to be sure that the "voice" of the

person with the disability is heard, regardless of the severity and nature of the disability; and

Where there is a focus on learning what is important to the person in how he or she wants to live, what is important to those who love the person, and any issues of health and safety (from the perspective of the person).

The resulting plan is a written description of what is important to the person, how any issues of health or safety must be addressed, and what needs to happen to support the person in their desired life. The plan cannot be separated from the process. A compromised process produces a compromised plan.

Beyond these common elements there is considerable variation. Some of the better known formal processes include: personal futures planning; PATH; essential lifestyle planning; individual service design; 24 hour planning; and whole life planning. Additionally there are a host of processes that have been developed locally. These local processes are often unnamed and usually are a blend of the better known processes. However, the label of the process is not an indicator of the utility or integrity of the plan. When done well, what unites all of these efforts is a commitment to learning what is important to people and a commitment to implementing what was learned. They all require partnerships between: the person; those who know the person; those who develop the plan; and those who implement the plan.

### **What has been learned**

Where careful planning and implementation have been done we have learned that:

When we listen with skill and respect, we can learn what is important to each person regardless of severity of disability;

Planning is a continuous effort, what people want tomorrow is different from what they want today;

Growth and learning occur naturally when people have the opportunities that they want, opportunities that make sense in the context of what is important to them;

Providing structure inside those opportunities helps people with severe disabilities access and learn more from those opportunities;

Most of the behaviors that we have labeled as non-compliance, as challenging, or as problem behaviors, go away when what is important to people is present;

Regardless of severity of disability, people are able to take positive control over their lives as we learn to listen and trust develops; and

Building community, a network of self-sustaining reciprocal relationships, occurs but it usually takes years not months.

We have also learned that while what is most important to people is modest, implementation is affordable only if we change the way we do business. Unless we begin to fund people rather than capacity, individuals rather than houses, we cannot afford to implement plans where people are asking to change who they live with or what they do. We have learned that it is our own structures that are the barriers and that many of the reports of high costs reflect the rigidity of our responses.

#### **Person centered planning is also a promise**

Shifting a system cannot be done by fiat and it cannot be done overnight. It requires the development of capacity, changing the structures that define where the system is going and what it should pay attention to, and it requires political courage and political capital. Some of the ingredients needed to change the system are:

Training in person centered thinking for all of the people involved in planning and implementation;

Requiring that those who do the plans demonstrate competency in person centered planning and that some of their plans be periodically reviewed;

Training for those who license and inspect and requiring that they be able to determine that plans meet criteria and that the plans are being implemented;

Changing the rules for services and requirements for funding so that they support person centered planning and implementation;

Support (training and technical assistance) for agencies that want to change their practices and structures;

Helping people with disabilities and their families build community before they are desperate, while families have the energy and resources to form a partnership; and

Leaders who understand what real person centered planning is, the changes needed for their implementation, and a willingness to build support while defending the changes from those who feel threatened.

At its core, developing and implementing person centered plans is about shifting power and control. It is about sharing control with the people supported and their families. To many people this is an opportunity to be embraced but to others it represents a serious loss of power. Person centered planning should be done with everyone only where there is the willingness to make the investments and changes necessary. However, those who lead must also sustain the change in the face of resistance and attacks. Those who wish to initiate the change need to develop the strategies necessary to sustain the change. In learning what is important to people we make an implicit promise to act on what we have learned. We should not make the promise unless we believe we can keep it.

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