A plan is not an outcome

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Michael W. Smull

Person centered planning is our label for learning how people want to live, to learn what is important to them in everyday life and to discover how they might want to live in the future. But, a plan is not an outcome. The only reason to do the planning is to help people move toward the life that they want, and person centered planning is only the first part of the process. Whether anyone can *get* the life described is also determined by their access to resources and the *rules* for using those resources.

When you put these two things together, planning for your future and control over resources, you have self-determination. Not too many years ago this was not an issue, most of the groups pursuing self-determination were individual agencies that believed in helping people with disabilities chart their own destinies. They gathered circles of caring people around each person to discover what they might want and used their resources to help people move toward the life that was described. Now some of the public agencies that fund and manage services are mandating person centered planning. They are requiring that everyone get a person centered plan. Whether this will result in people moving toward the lives that they want will depend in part on the quality of the planning but also on the control that people will have over the resources.

Those who are the best at both the planning and helping people have control over their resources recognize that it is as much a journey as it is a destination. It is about helping people find and maintain a balance in their lives. It is a journey because what people want changes over time (sometimes quickly and often slowly). Everyone has to try things to see what they like and what they like changes as they grow and mature. It is about helping people find a balance because real life is complicated. Most of us want mutually exclusive things (e.g. to be thin and eat all the fattening food we want). Most of us need to take into consideration the desires and preferences of other important people in our lives. Many of us have more that we want than we can afford. Resources are finite, so we have to decide how to prioritize what we want. Good plans are a snapshot that takes of this into account (implicitly or explicitly) at a moment in time. They reflect the current balance that someone wants and give direction for the future.

Good person centered planning requires that you be able to learn what is important to each person, separate what is important to the person from what is important to others, and communicate what you have learned in a way that others understand. Implementing plans is also about supporting a journey. In trendy business terms, it reflects using a learning wheel. We begin by listening and trying to understand what we hear. We record what we learn in a plan. As we act on what we have learned, we see how it works. And then begin again by listening and understanding.

Those who fund and regulate need to change the current reality. For most people with disabilities, who receive services, the present reality is a world of programs. Most of the current resources are fully committed to buy capacity, to buy *slots*. There are people living in group homes and going to segregated day services who have told us that they hate their roommate and are bored during the day. There are high school students attending educational programs they find meaningless because they do not prepare them for the future that they desire for themselves. Where people want change, planning without real action simply creates cynicism for everyone. One of the traps that this creates for planning is that what is available now shapes what is asked for.

In trying to not be limited by what exists we have learned that the kinds of questions that you ask and the order in which you ask them, make a difference in the outcome. Ask about what is important before asking where it could happen. Learn what is important in everyday life and then look at all the different ways that it could happen. Look at what is happening in the rest of the world. We now have enough *best practice*, enough *pilots*, that what people have in mind is likely to already exist. It may not be next door, it may have been developed on the other side of the US, or in the UK or in Canada, but it is likely to exist. Only after people have explored what is possible should they look at what is available now. Where what someone wants is not offered the next question is how do we develop it here? Knowing that it has been done elsewhere gives people the sense that it can be done and someone to learn from.

Clearly this is easier to do with people who are just coming into the community system, people who are leaving their family homes or are leaving institutions. When we plan with those people who are already receiving services, we are facing a number of new challenges. One of these is that people are not used to looking outside of their current ways of doing things. Plans that started with what was wrong with someone were typically part of a professional ritual where *good paper* counted more than good lives. These plans were written with those who spent the least amount of time with the person having the greatest input. They were read only by those who wrote them (and those who inspect) and were not used in everyday life. This part of professional culture continues and interferes with implementing person centered plans. To change the culture, we have been recommending that those who manage, or visit ask some simple questions after the person centered plans are written. Ask those being supported and those providing the day to day supports: How is the plan working? What have we learned? What have we tried? What else could we try? What else do we need to learn? Ask these questions often and in as many ways as makes sense. Write the answers on the person centered plans. Where this is done, those who provide the support see what they learned incorporated in the plans. They see that what they do and how they do it changes as we all learn. Those who are supported and those who provide the supports feel respected, and part of a partnership. The plan becomes a living document that is changed as our understanding deepens and as the person changes.

If we want to change the system, we need to look for incremental change as well as revolutionary change. At any moment, we can create best practice for a few people if we put in enough effort and resources. However, if the many are not to be left behind, we need to move our entire system incrementally toward best practice. One way to do this is to think of the changes as happening in phases. Start by looking for every opportunity for best practice and seize each one. Then think about how to start incremental change. For many it begins with simple person centered plans where we ask what is important to people in everyday life, compare that with how they are living now, and change what can be changed now. Change what can be changed without having to make major changes in structure or practice.

Making the easy changes is a good way to start, but an unacceptable place to stop. If people with disabilities are to get the lives that they want, change has to continue. Planners, managers, and those who support have to look at what people want and compare that with their capacities to deliver what is being asked for. Where there is a deficit in capacity, they need to look at what needs to change. Does the deficit in capacity reflect a deficit in skills, knowledge, or competencies? Does the development of new capacity require changes in policy, practice, or structure? Is the deficit a reflection of problems in how we think or in the unwritten rules for how we act, is there a problem with organizational culture? Again, this is most easily seen as a learning wheel where we are looking at what individuals want and using that to change the system.

Those who mandate the planning will need to make changes in funding, practices, and structures if plans are to reflect what people want and be implemented. They need to invest in the new vision of quality. They will need to build structures that are rooted in values of respect, trust, and partnership. They will have to change a provider agency culture that sees the funding that people receive as the agency's money and uses the language of ownership about people with disabilities. And they need to do this with a minimum of wreckage.

Those who get the support need to be able to say that I am moving, and I am taking my money with me. However, those who are left behind need to be able to continue to live as they wish. The change literature makes it clear that there is no change without loss, but we can make change without wreckage. We need to make sure that those who provide the supports are offered the technical assistance to find the win-win solutions. Most will need help to learn the new skills and make the changes in practice and culture needed to move from a relatively static system of supports to one that has the flexibility needed to support people in their evolving visions of how they want to live.