

After the Plan

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Introduction. Learning how people want to live and then doing nothing with the information is a form of abuse. A good plan not only clarifies what each individual wants but creates the perception that those who participated in the planning will do something about it. Planning should only occur where there is a commitment to implement. The challenge in implementation is where to start. The disparity between how people want to live and how they are living often creates a feeling of being overwhelmed, of not knowing where or how to start. The following is an effort to assist those who are engaged in this struggle and to reduce implementation to its essential elements. The process is outlined in the flow chart that is shown as **figure 1**.

Learning how people want to live. The process of implementation of a person centered plan begins with learning how people want to live through a structured process of asking and listening. Honest planning is never finished. People continue to grow and change. As what is important to them changes and as our understanding continues to deepen, the plans should change. Plans are a snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow. They need to be written down so that we have a benchmark of how people want to live. Honest plans also reflect how each individual wants to live, not how we think they should live. Plans should reflect the typically modest wishes and desires of the person and not represent fantasy of the "good life" from the person doing the planning. Person centered planning can be learned by reading and practicing but it is easier (and safer for people with disabilities) to learn from others who have been trained.

Continuously considering issues of health and safety. Doing person centered planning does not relieve us of the obligation to address issues of health and safety. People who are unusually vulnerable need to have safeguards and people with medical needs must have adequate health care. The challenge is to consider these issues within the context of how the person wants to live. In the flow chart this is shown as occurring after the comparison between how people want to live and

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how they are living. Its presence near the top of the process is in part symbolic. In careful implementation, issues of health and safety are not considered only once, they are continuously considered. The challenge in implementation is to enhance safety and ensure health without compromising those things that are important to the person. Once there is an understanding of how the person wants to live, any compromises in what is important to the person are made consciously, after efforts have been made to think of how the person can have what is important and still be safe and healthy.

Comparing how the person wants to live with how the person is living.

Comparing how people want to live with how they are living is a form of discrepancy analysis. The result creates the agenda for action. Knowing what is important to a person (and knowing how important it is) is followed by looking at how the person is living now and determining to what degree each of these things is present or absent. Careful consideration of the difference between what people want and what they have shows what parts of their lives make sense and what parts do not.

Giving credit for those things that are being done that do make sense (and continuing to do them). It is important to not only highlight the need for change but to highlight those things that are being done well. There is an unfortunate tendency to wallow in blame and guilt when the discrepancies are seen between what is important to the people and how we have been supporting them. A sense of urgency is needed but guilt is not helpful. Rhonda's story illustrates these issues. How Rhonda was being supported Monday through Friday reflected a deep caring and understanding of how she wanted to live. Although she does not use words to talk, staff who loved her were listening to her behavior and honoring her positive rituals and choices. As a person centered plan was developed with Rhonda, it became clear that the weekend staff did not know her as well and were not listening. The reaction of the people who supported Rhonda during the week was dismay and determination. They were pleased at how much they knew and dismayed at how it was not being used help Rhonda on the weekends. Talking about what was going well validated the efforts of the direct care staff who loved Rhonda and were listening to her. Looking at the discrepancy reframed what had

been seen as her "behavior problems" on weekends into a problem with the support she was being given. It gave a sense of direction.

Changes that can be made within current structures and resources. Rhonda's life also provides an example of how needed changes can occur within current structure and resources. Planning with Rhonda made it clear that she must be supported by people who are calm, soft spoken and not "in her face". She must be supported by people who understand how she communicates with her behavior, who listen to what she is saying. Some of the people supporting her on the weekends were not calm or soft spoken and tended to "get in her face". They were the wrong people to support Rhonda. They were not "bad" people, it was a bad match. With some rearranging of where people worked Rhonda began to have weekend support that made sense to her. The staff who know Rhonda also developed a "cheat sheet" that told how to interpret what Rhonda was saying with her behavior. For example, everyone who supports Rhonda now knows she tells you when she wants to get up in the morning by being on her stomach, propped up on her elbows. Her "problem behavior" is gone and someone who was labeled "nonverbal" is now described as "outspoken".

Those that require changes in current structures and/or resources. Some of the issue's in Harry's life illustrate how some changes can be made immediately while others will take time and require changes in structure. Harry will not eat with people that he dislikes and shares his house with a roommate whom he strongly dislikes. He does like eating in his room, by himself. Using typical "group home thinking" staff used to say: "We eat family style and we all eat together." As staff learned about choice they were willing to support Harry eating in his room-except that it would not be "fair" to another roommate. Harry had another roommate who liked to store food in his room. Staff felt that they could not want to let Harry do something that another person in the house could not do. They did not feel that fellow who "hoarded" food could be allowed to eat in his room because it would create a health issues as perishable food aged. In trying to honor choice, staff were saying that Harry did not have to eat with everyone, but there were no in-home alternatives. Harry could, and often does, eat with friends and relatives who live elsewhere but he was also simply not eating some nights.

When we did the planning with Harry, the fellow who stored food in his room had moved, so "fairness" was no longer an issue. (If that roommate had been present the argument would have been made that treating everyone the same in this circumstance is inherently unfair.) As the issues for Harry were reviewed, it was clear that supporting Harry in eating in his room made sense. Harry left the planning meeting with a "dining" table for his room (that had been stored in the basement) and was going home to have supper in his room. The staff who support Harry had committed to find a way for Harry to only live with people that he chose (and liked). However, helping Harry move requires that the agency figure out the finances involved in closing the group home. While this will take time, in the interim Harry will be happier and will eat regularly.

Harry's story also brings up an issue of health. Since Harry has no unusual medical issues skipping an occasional meal is not a problem. The concern is that he would skip enough meals to unbalance his nutrition and/or to cause him to lose too much weight. Harry does not have enough money to eat out all the time and he does not eat with his friends every night. He was skipping enough meals to have a noticeable weight loss (although not enough to raise immediate health concerns). Neither depression nor an eating disorder seemed to be needed to explain his not eating at home. Hating one of his roommates and having no alternative appeared to be sufficient explanation. Eating in his room is the temporary solution. He still eats out as he can afford it and he eats with friends and relatives as often as he is invited.

A life that makes sense to the individual. The desired outcome is a life that makes sense to the individual. How each person wants to live should be congruent with how they are living. This does not mean that everyone gets everything that they want. Some things are beyond our power to provide, some things take time, and some things cost more than we can afford. A woman I met in Chicago told me that the only living situation acceptable to her was to live with her mother. Unfortunately, her mother made it clear that regardless of the supports offered she was not prepared for her daughter to return home. To help this woman achieve a life that makes sense we have to help her deal with the loss of her home with her mother and to develop other relationships.

Many of those things that are important to people take time to achieve. For people living in group settings, the changes that are possible will not work for everyone. If you hate one of your roommates, not having to eat in the same room helps. However, it does not address the underlying issue that you should be able to pick who you live with. Because sites are funded rather than people, because having one or two people move may leave a deficit that cannot be covered, helping people leave group settings takes time. Moving to a new place requires that we not only know how people want to live but how we can pay for it. Where group homes are being closed, disposing of the building may require significant effort. Helping people leave group homes can be done and should be done, but it does take time.

Many people say that they want to live by themselves. This is the request that most often challenges the disability system. The easiest way to control costs is to share them. By requiring that people share housing and staff, costs are reduced. Where people live by themselves this economy is absent. If everyone wanted to live by themselves the disability system would never be able to bear the cost. However, if only a small percent want to live by themselves at any one time it should be affordable. Many people want to try living by themselves, but only a few people like it as a permanent way of life. Further, many people have been forced to share their lives with their roommates and need to experience what just sharing space is like. (When you share lives you do everything together, when you share space you sleep in the same house and otherwise select what you do together.)

Home ownership is another example of something that appears too costly. The disability system has made it possible for agencies to own thousands of houses but sees home ownership for individuals as too expensive. It does take time, knowledge, and commitment but people across the United States and Canada are finding ways to buy their own homes. It is only too costly when it is seen as something which should be solely financed by the disability system.

Home ownership is also an example of a dream. Whenever a dream for the future is expressed there are a few questions that should be asked. The first question to ask is whose dream is this? Most people need to have a life before they begin to have dreams of things like owning **their own** home. Check and see if it is really their dream or is it the dream that the facilitator thought they should have. If it is their dream, does it really need to happen tomorrow or is it something to work toward?

Simple dreams like living only with people that I like, only being supported by people that I trust, or having privacy in the bathroom, should be achieved quickly. Expensive dreams, extraordinary dreams, which are the person's and not the product of a guided fantasy, become something that the person should be supported in working toward.

Remember to keep listening. Whenever people are empowered a dynamic situation is created. The process of listening and then acting on what has been heard is an ongoing cycle. What people want today will be different from what they want tomorrow. The process is lifelong and interactive. The only thing worse than never listening is only listening once. The process should continuously loop back, comparing how people are living with how they want to live. Where there are differences a plan needs to be developed to help the individual to continue the pursuit of happiness.

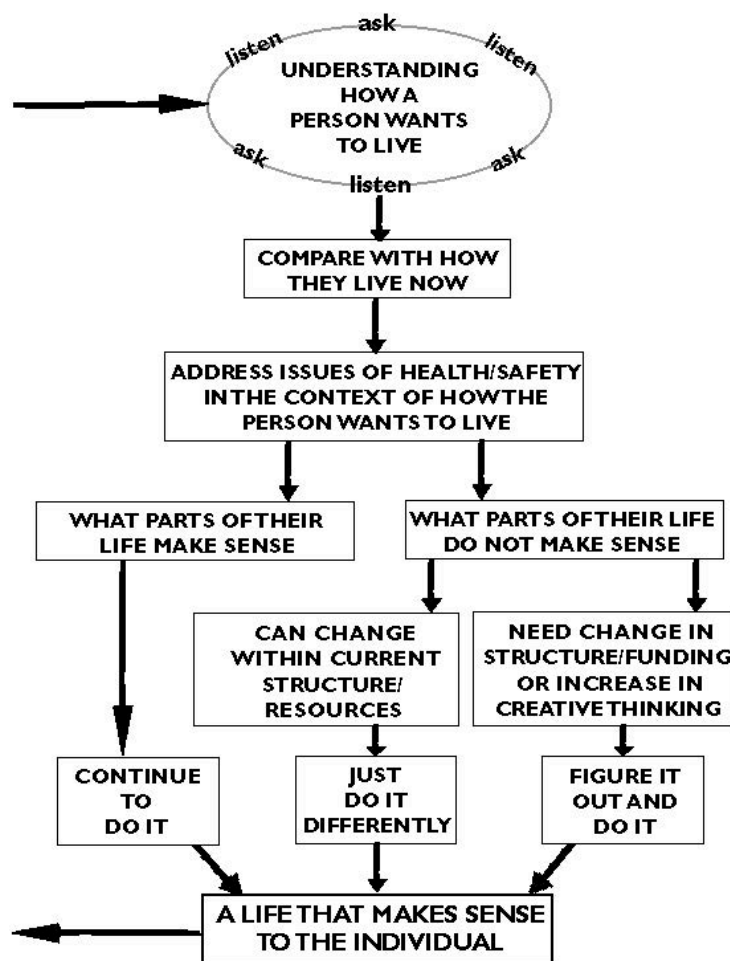


Figure 1