

Consumer-Directed Person-Centered Planning

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Brief on Person-Directed Individualized Planning (OHSU/CSD)

Person-Directed Individualized Planning

Efforts across the nation are working toward infusing the principles of self-determination into the supports and services for individuals with disabilities. This brief looks at the education and support needed for people to take charge of one of the many critical pieces of this journey, their individualized planning process.

Evidence shows that the use of "person-directed" approaches has resulted in changed lives for many individuals with diverse disabilities and their families, who report fewer unmet needs, more community connections, more satisfying living situations and support relationships, and enhanced employment opportunities (Beatty, Richmond, Tepper, & DeJong, 1998; Benjamin, Matthias, Franke, Mills, Hasenfeld, Matras, Park, Stoddard, & Kraus, 1998; Conroy, Fullerton, Brown and Garrow, 2002; Conroy & Yuskauskas, 1996; Foster, Brown, Carlson, Phillips, & Schore, 2001; Foster, Brown, Phillips, Schore, & Carlson, 2003; Richmond, Beatty, Tepper, & DeJong, 1997; Sowers, McLean & Owens, 2002).

The four principles of self-determination - **freedom** to determine and direct one's life; **authority** over key decisions, including how to best spend targeted support funds; **support** to reach personal goals; and **responsibility** for contributing to one's community and using public money wisely - have found fertile ground as state systems redefine their strategies to assist the maximum numbers of individuals in the most beneficial and cost-effective way (Nerney and Shumway, 1996). All four principles can find individualized expression in one of the very first activities a customer experiences when receiving services.

Every state has their own variation of a planning process, however each plan must be in place as the individual's "plan of care" or "plan of service" in order to receive Medicaid funds. Many states are using person-centered planning approaches to develop this plan with the individual, utilizing the family, circle of support members and professionals to actually manage the meeting. For most individuals, this plan development phase can be enriched by providing them with increased authority and responsibility. The table below details traditional steps taken to arrive at a final plan of care, and 'person-directed' steps that could be incorporated to increase the individual's control and responsibility with the process. As with all supports, this process should be tailored to each individual but within each step, the individual, no matter the level of their disability, can be encouraged and supported to actively participate in and direct their planning process.

Service coordinators, brokers and other supporters need to be exposed and trained in the various person-centered and person-directed planning approaches that are available so they can inform the customer of their options and share their professional judgment about the processes that they believe would bring the best results, given that person's particular circumstances.

As with any planning process, we must remember that the goal is not simply to have a great plan, but also to put great effort into the actions taken to see that each goal on that plan materializes - to turn dreams and visions into reality. As John O'Brien, one of founding fathers of Person-centered planning wrote: "To put it simply, I do not see person-centered planning as the cause of change. I see it as a way to improve the odds that purposeful change will happen."

Directing their planning process, or even small elements of the process, can be the first steps that an individual makes in taking charge of his or her life and supports. It can be the first stage of understanding by customers that support is there not only to assist them in reaching their goals, but also to assist them to direct the process by which those goals are developed. For many individuals with disabilities, this process of "customer-direction" will take practice, patience and trust that service providers are truly committed to this infusion of self-determination principles.

Traditional and Person-Directed Planning Approaches

Traditional Approach

Organizing and carrying out the planning meeting

1. Decide with key stakeholders the best approach to gathering information for this particular individual.
2. Ask for ideas of who to invite, where to have it and when. The details are taken care of by the professional or whoever volunteers.
3. Everyone shows up at the meeting, the process is explained and usually the broker or facilitator run the meeting, making sure to include the individual as much as possible.
4. The notes are typed and mailed by a service provider to all present.

Traditional Approach

Developing the plan of support and individualized budget

5. Service coordinator or Broker uses PCP, notes and research to write draft plan and possible budget.
6. Plan and budget are discussed at meeting and changed as needed and approved.
7. Final approval process completed.
8. Process repeated annually

Person-Directed Approach

Organizing and carrying out the planning meeting.

1. Share examples of various planning approaches with the individual and trusted others using videos, written materials and final plans. The individual then decides which planning process they would like to use.
2. Present to the individual a list of activities that need to be done in order for the process to occur, with a column indicating the types of support they would need to complete that task and by who and when.
3. Present the individual with list of questions that they should be thinking about before the meeting.

4. Determine if support is needed and if so, who will support the person to accomplish setting up the meeting, to think about the questions and write down ideas.
5. Determine with the individual how they would like to begin the meeting to indicate to all present that they are in charge.
6. Meeting occurs with the individual directing as much of the process as possible. Support is provided, as prearranged with the individual.
7. Confirm with the person after the meeting is written up that all the information that they wanted is present and accurate.
8. The individual decides how to distribute the meeting notes.

Traditional Approach

Developing the plan of support and individualized budget

9. Using a graphic image of the allocated funds, assist the person to prioritize the supports and services s/he needs. If necessary and possible, have a few different options to present. Include natural supports that can be developed and talk about how the individual can give back to the community for those supports.
10. Whenever possible, have the individual present to his or her circle ideas for his or her final plan.
11. Final approval process completed.
12. Individual participates in plan activities, including those to increase his or her understanding of different living, employment and support options. Follow-up planning meetings are organized any time the individual clarifies his or her preferred goals and supports.

Strategies and examples of 'person-directed' steps:

1. Many individuals and family members are only familiar with professionals leading meetings and they may want to take the most direct and least 'hassle' method to obtain the much sought after supports and services that the person needs. Being able to share success stories right from the beginning is a way to introduce the principles of self-determination as they relate to the planning process. Using videotapes of successful PCP meetings or small informal talk sessions with the person and a trusted other are tools for educating everyone about the various approaches. Giving examples of how different individuals were supported to direct their meetings and how this resulted in very individualized and positive plans, is well worth the extra half hour it may take. Explain at this point, that this is the first step in giving the individual the freedom and choice to define their own life plan; that you will be asking the individual to decide on the type of meeting they would like and explain that whatever help they would need to get the meeting organized will be provided. Depending on the communication skills of the individual, have the appropriate tools available to ask for their opinion about which planning process they would like to direct. If the person is non-verbal, have a picture cue with both written descriptions and drawings of what the various meetings might look like (e.g., large

group with food, easel and flip chart in a living room; a coffee shop with the person, the broker and one family member; the broker's office with the person and three relatives). Ask the individual to point to the one that they'd like. If necessary, ask the person when they are alone without family members and ask why they like that process. In explaining their choice later to reluctant family members, being able to add the 'why' will go a long way towards getting their support. It should be stated at this point that even this step might be too overwhelming for the individual or family members to believe it is doable or valuable. If that is the case, proceed with the most person-centered approach and try again the next time a meeting needs to occur. Over time, as they have positive experiences, individuals and family members usually become increasingly comfortable and interested in having control in the process.

2. The list of planning items will vary depending on the type of meeting the person wants, but most will include the location, the date, the time, the people to attend, food or drinks, facilitator or recorder and interpreter. By separating all these items out, it is more likely that some items can be identified that the individual can indeed decide upon, thereby arriving at the first stages of 'directing' their own meeting.

Planning Areas to Cover

Item - Support - Who/When

Location - Offer ideas; assist to reserve space - Parent, broker, friend
Schedule with person

Date - What works best - for the individual and then family?

Time - What time of day is the individual most likely to be engaged and be able to have all the people they want to attend?

People to attend - Who does the person want to come? Share ideas of who might be beneficial to attend; ask who loves them and supports them. Supports might include, helping the individual to make phone calls, set up appointments or send invitations, or it might be you sending the invitations. - Family might need to give ideas and they may want to invite others. This is fine, but get permission from the individual.

Food or drinks - Can the person make cookies or be supported to go to the store and purchase the snacks? - Parent, broker, friend
Schedule with person

Facilitator/recorder - Describe personalities of several facilitators; support the person to meet and choose one, if desired - Broker

Interpreter - Do they know someone who has interpreted for them or family members before? Support might be accessing list and assisting person to make the call or actually calling yourself. - Parent, broker, friend
Schedule with person.

Other information - Do they want a note taker if there is no group recorder?

3. Have available a series of materials, worksheets or videos that will allow the person to think about the topics which will be discussed at the planning meeting. This can be very basic as not to overwhelm the person. There are many formats already available: "Dream cards", "listen to me", etc. A simple large print version of topic headings such as "What I want to do", "Where I want to live", "Friends I'd like to make", etc., can be enough to allow the person to develop ideas that may be hard to think of right on the spot at the meeting.

4. Find out if the person needs support to do this and to record their thoughts. If at all possible, assist them to ask someone who knows them to help.

5. Depending on the abilities of the individual, ideas for presenting themselves as 'running' the meeting could be: asking others to introduce themselves; using a bell or gavel to start the

meeting; arranging seating so the person is at the head or centrally place. If the person is non verbal and has a limited range of motion, suggest a 'welcome to my meeting' card prepared in advance and assist the person to hand them out to everyone to start the meeting.

6. Meet with the person before the meeting to go over the agenda and to figure out creative ways they can introduce the next subject, ask other people for their feedback and opinions, and be able to communicate "yes" and "no" to ideas (e.g., holding up different colored cards, etc.) Always include the individual in introducing the next topic or when asking questions by saying, "John and I talked about this earlier and he would like to know your thoughts on..." Avoid speaking for the person (e.g. "Susan wants ...").

7. Either directly after the meeting if a recorder was there, or right after the notes have been typed up, review the intention of the meeting, the information generated by the pre-meeting "list of questions" and the ideas recorded during the meeting. Make sure the individual is able to say, "Yes, this is what I want my life to look like." By asking this question before you send it out to the entire group, you are giving the person the authority and responsibility of approving the notes and the freedom to change or develop other ideas around their plan.

8. Assist the person to think how he or she wants to share the notes. Does she want to mail them out, hand deliver them, have you send them, personalize them with her signature stamp or choose the color paper? Each small step that can occur in giving choices and making decisions is preparing the individual to direct more and more aspects of his or her life.

9. Allowing the person to visually or tactically understand how the decisions they are making effect how their life will look, is another step in deepening their understanding of the freedom to develop a personal life plan and their responsibility for carrying out chosen activities and using public money wisely. Being able to contrast the proposed plan with their current situation (i.e. nursing home dollars vs. community living costs; family members doing and paying for everything vs. employment; school pays for ½ their day, parents support the rest vs. semi-independent living; etc.) is a way to demonstrate how they now have the authority to decide on how their money is spent and who supports them. This entire process demonstrates to both the individual and his family that they will receive the support they need to actively participate in as much of the process and their lives as possible.

10. This can be as simple as the person handing out the written materials and being the first to sign the document, or as detailed as the individual going over each line item with the appropriate support from the service coordinator or broker.

Customer education is crucial when assisting someone with a disability to take charge of his or her life, to whatever degree is possible. We must look at the smallest as well as the largest tasks that are involved in planning and carrying out the person's life and support plan, and figure out ways to support customers in participating as fully as they desire.

Questions To Be Thinking About Before The Planning Meeting

1. Am I happy where I live? (If yes) What makes it a good place to live? Is there anything that could make it better? (If no) Where would you rather live? Describe your ideal living

arrangement?

2. What do I do during my day? What are the parts I love the best? What would I like to add? Are there parts of my day I dislike?
3. Is there anything I'd like to talk about as far as school or work? Any new opportunities I'd like to try out for education or employment?
4. Do I have enough social activities in my life? Do I have as many friends as I'd like to have? Do I have enough money to pay for all the activities I'd like to do? Do I have the transportation I need to get places?
5. What kind of support do I need to live the kind of life I want? Do I receive all the support I need? Are there supports I get that I don't need or want? What type of person makes the best support person for me?
6. How is my health? Is there anything I want to talk about as far as my health or my safety?
7. Are there other topics I want to talk about in this meeting?

Suggested resources:

1. John O'Brien and Connie Lyle O'Brien - Responsive Systems Associates, (through a subcontract with the Center on Human Policy) <http://soeweb.syr.edu/thechp/rsapub.htm>
2. Michael Smull - Essential Lifestyle Planning <http://www.allenshea.com>
3. Jack Pierpoint, Inclusion Press, Inclusion Network, Marsha Forest Centre <http://www.inclusion.com>
4. The Boggs Center - Richard Blumberg <http://rwjms.umdnj.edu/boggscenter>
5. Communities of Power, Michigan <http://www.copower.org/pas/index.htm>

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