



Providing support and information for families of children with disabilities, chronic illness and other special health care needs

## Pathways to Adulthood: Person-Centered Planning & **Personal Networks**

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When my son Will was 20 years old, I panicked! It really hit hard that he only had 2 years left in school and then he'd be "out on the street," with nowhere to be each day and none of the services and opportunities of public school programs. At that point, I called in the troops to do person-centered planning.

Person-centered planning (PCP) is a process that brings together a group of concerned friends and family to explore opportunities with the focus person. Developed in the late 70's to early 90's in Canada, the US and the UK, the term "person-centered" emphasizes that plans are based on the focus person's dreams and goals, as opposed to "service-centered," which promotes the convenience and needs of service agencies and providers.

You can start this process for your child at any age, but this planning process is often used as a person approaches adulthood...so that's why I grabbed the idea for Will at age 20. We were lucky that our school district had staff trained to facilitate PCP, so I requested a meeting. We had it in our home--I thought home was best for planning a life after school supports were gone -- and we invited school staff, care providers, Will's brother, and a family friend who had known Will for years.

I was scared that we'd throw a party and no one would come—but they did come! We had a light supper and a meeting led by 2 facilitators. They brought large tablet paper and markers and a list of questions to ask the group, so we got started planning what Will's life would look like after graduation.

In most PCP meetings, the facilitator first addresses questions to the focus person and then opens it up to the group, but because Will does not use words to express himself, we all spoke for him. We put ourselves in his shoes, and judging from his behavior and responses in various situations, imagined what he would say. We talked about where he spends his time and with whom, what he likes and dislikes, what he's really good at, what he fears (and some parental fears came out at that point) and what his dreams and goals are. Then we chose one goal and created a list of steps to accomplish that goal, including who would do what by when.

The first goal we chose to work on for Will was to have a day full of things he wanted to do routinely after graduation. We talked about jobs and what his school job coach (present at the meeting) was pursuing to develop work for him; recreation and social opportunities; transportation; and people to assist him through his day. We divided up the tasks and set a date for a follow-up meeting.

I soon became a PCP facilitator myself and have facilitated many plans for people of various ages over the last 10 years; I've had the pleasure of seeing how this process can work in a variety of circumstances. One thing I've observed is that you never know what the focus person will say, things that sometimes really surprise parents! "I want to lose 20 pounds." "I want a girlfriend/boyfriend." "I want to be a jet pilot." "I want to move out." "I want to live with my parents forever." "I want to not be bullied at school anymore." "I want a driver's license." The trick is for the facilitator to take whatever is said and use it as an opening door to the future.

Want to be a jet pilot? I would ask, "What do you like about the idea?" The answer might be: I like airports, I want to wear a uniform, I like to tell people what to do! Now you have the first step along a career path! Want to not be bullied at school anymore? The steps generated by the group might be: let's build a small group of school supporters and friends, talk to the principal and staff, assure the person that it's a good thing to report being bullied, and work on the skills to know when and how to report bullying. Now you have the first steps for working on social groups and safety. Want to lose 20 pounds? The facilitator might ask for input from the group on how they have lost weight, then plan for the focus person to join a gym or find an exercise buddy. Want a driver's license? That wish starts exploring what it takes to get a license and what alternatives are available when someone doesn't have a license—a door opens to discuss transportation.

The process is positive and exploratory; it gives the focus person a chance to practice self-determination; it provides the group with a direction to proceed in looking at options for the person's future. The process often leads to a discussion of the fundamental questions, where will this person work, play and live in the future? And then how will this person be safe and supported?

Another thing I have learned through my PCP experience is that any process that focuses on the future is useful—it doesn't have to be Person-Centered Planning. The fundamental idea is to initiate a discussion with a small group of people who know the focus person, can brain-storm with him or her to generate ideas for carrying out a goal, and can give a little time to support them, even if it's just for a few months.

You are probably asking, great, but how do I get started? Where can I find a facilitator? First see if someone in your public school special ed department or your Regional Education Service Center might be up on PCP training or some other planning tool for transition. If not, try other sources: PATH is a similar process and The Arc of Texas has facilitators trained to lead a PATH (<a href="http://www.thearcoftexas.org">http://www.thearcoftexas.org</a> then look for the Texas Microboard Collaboration through the Arc). There are several excellent websites that could help you get started:

http://www.pacer.org/tatra/resources/personal.asp

http://www.ncset.org/publications/viewdesc.asp?id=1431

http://www.capacitythinking.org.uk/PersonCtrPlShort.pdf

Using one of these guides, perhaps you and another parent could trade off facilitating a planning process for each other.

Finally, I have learned another truth about PCP, a hard truth: most families need a supporting group to carry out a plan. I have seen far too many lovely plans end up on a shelf, with no action and no outcomes. Families often are too overwhelmed with day-to-day parenting to have the energy and

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resources for working on the steps that a group might generate. Not only do we need PCP facilitators, we also need personal networks to help carry out a plan. And that is another great topic. (Tune into the next TxP2P newsletter for more on networks!)

Now Will is 29. We have worked hard over these years to help Will carry out his goals, but we had to have goals in the first place to inspire and activate us. I recommend finding a way to begin envisioning a positive future for your child and to share that vision with a group who can multiply your energy, ideas, community connections and resources to carry out your child's goals. I'm happy to report that the little group who sat down together for supper and talk when Will was 20 are still meeting; the group honors that person-centered plan as a guide to what Will likes and dislikes, what his gifts are and what he wants to do with his life. It's a process that continues.