



Pathways to Adulthood:

Person-Centered Planning & Personal Networks

(a 2-part series)

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Part 2. Personal Networks

There's nothing like the panic we parents feel as our children approach graduation from public school. We all wonder if our children are prepared to succeed in post-secondary education or a job, live independently, and have friends; we wonder what supports for assistance and safety are available. These concerns led me to gather a group together to do person-centered planning for my son Will when he was 20. I also became a person-centered planning facilitator and have had the wonderful experience of facilitating a variety of groups for planning an individual's future. But as I gained experience with PCPs, I began to worry about how these plans would be carried out. Most families feel overwhelmed when facing transition and may lack the resources to carry out a plan. So I began to think about how to extend the PCP group to become an on-going support.

Then it struck me that personal networks would provide the structure for this on-going support. The idea of personal networks comes from a parent organization in Vancouver called PLAN (Planned Lifetime Advocacy Network, at www.plan.ca). Their book, *A Good Life*, describes parental fears for children with disabilities and then presents a tool for supporting a person at risk of isolation. Here are words from *A Good Life*:

"A Personal Network is a team of people who have come together for one single purpose: to befriend, support, and advocate for the person with the disability. It's their job to worry, to oversee, and to plan in advance, to anticipate, to 'be on top of.' A healthy Personal Network is one where all members of the network are in touch with each other. They coordinate their support. They assign responsibility among themselves."

"A Personal Network is a group of men and women who voluntarily commit to support a person who is at risk of being isolated and vulnerable by reason of their disability. Each person of the network has a relationship with the focus person and with every other member of the network. Through their relationship they offer support, advocacy, monitoring and companionship."

"The best guarantee of a safe and secure future for a person with a disability is the number of caring, committed friends, family members, acquaintances and supporters actively involved in his or her life."

Will's PCP group turned into a network that still meets now, 10 years later. The group has met many times just to have fun: we eat a pot luck, drink some wine, talk and catch up on our lives. Will is always present and seems to enjoy each person: he falls over one's feet, spills another's wine, draws another around the house by the hand, or sits close beside another. We always update the group about Will's activities and well-being, and they have all gotten to know each other and Will.

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But gradually, as the group has matured, the members have become more aware of their responsibility as a personal network for Will, the work of building a web of support for the day when we parents are less active or no longer available. So they have begun to learn more about Will's needs and assets and to see distinct roles for themselves. One member knows best about Will's daily care, medical needs and communication - that area will be her specialty. Another has a financial background and is best suited to watch over Will's resources. The parent of another child with disabilities is part of the group and knows how to manage the CLASS program. Finally Will's brother, who has been active in the network from the beginning, has stated that with the network's support, he is willing to be Will's guardian. You can imagine how excited and reassured we parents feel about this development.

Another TXP2P parent, Denise Sonleitner, has started a network for her son Maverick and has told me:

"We started a person-centered plan group for Maverick in elementary school. PCP's are a great tool, but I had bigger concerns looming about Maverick's future, when his dad and I could no longer care for him. People wanted to help in some way, but none of us knew how. When I heard about personal networks, I decided to give it a try. The best thing to result from having a network is feeling hopeful about Maverick's future. Creating a community of people who come together for one purpose (i.e. Maverick) and are over time becoming closer, more cohesive, and more vested in Maverick's future."

Getting Started

When parents hear about networks, they are intrigued by the concept but always ask: Who can I ask? How do I ask? Why would anyone join?

One way to answer "Who to ask?" is by looking at the people in your life. Think of friends or relatives who've said, "Let me know how I can help." It never seems to go beyond this offer, but at least the comment does show interest and willingness. Being a network member will provide those who have offered a way to help in a safe, open environment, where it's okay to ask questions and possible to organize the how to's. Think of people you know who are young and uncommitted or older and just retired, people with a bit more time and effort available to spend on a "cause," maybe even people who are searching for a network for themselves. Or maybe another parent—I'll be on your network if you'll be on mine! Here's a list to spark ideas:

- Family friends, relatives, siblings
- Your child's friends, peers at school
- Church members, neighbors
- People in a club, interest group
- People at work
- Retirees
- Other parents
- People who work with your child or have worked with your child in the past

The question "How do I ask?" might be answered by looking at it as a request like for any other volunteer opportunity. When I asked my sister-in-law, who has served on many community boards, to

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join, she wanted to know how much time it would take. That led me to write an invitation explaining the concept of a network, what time commitment it involved, and how each person might contribute.

“Why would anyone join?” brings up the fear, what if a person I ask says No! *A Good Life* tells us to never take it personally if we are turned down. Just remind yourself that the person you asked may be too busy right now to commit. Another way to look at this question is by describing the network as something that will be positive for all participants, instead of asking people for help because we feel needy and overwhelmed. Taking a page from *A Good Life*, learn to describe your child in positive terms: instead of saying Will needs help eating, dressing and in all life areas, I explain what people will learn from being with Will about non-verbal communication, living in the moment, humor, and unconditional love.

I have observed that networks expand the energy, resources, ideas, and community connections available from one or two parents to a whole range of people. A network can give back to a family the hope that often leaks away through years of feeling isolated, losing services, hearing about the deficits of your child; the network gives a family the sense that there really are people out there who care, who will share time and effort, who are ready to learn and assist.

A network might be 3 people for someone who doesn't like crowds or 50 for someone who loves a party. It might be a group focused on just one issue, set up for a limited amount of time; for example, a network could be set up solely to help a person find a job or transition to life after graduation or buy a house, then disburse until another time. It might be focused on social opportunity; a shared on-line calendar would be the perfect tool to schedule outings for several in the network to accompany the focus person to the movies, meals out, or days in the park. A network might appear spontaneous to the focus person who doesn't want anyone to plan his or her social life. A network looks different for every focus person.

What can you do now, at whatever your child's age, to promote the possibility of creating a network someday?

- Start to share your life with others.
- Encourage your child's interests and hobbies, which can become a link to a group.
- Encourage your child's social skills.
- Learn to describe your child in terms of his or her gifts and talents.
- Talk to people about your child's gifts.
- Start to share your vision of your child's future with people who are important in your child's life.
- Quit thinking you have to do it all yourself!
- Let go of being the total parent, the perfect parent!
- Become the learner.
- Make time to develop your own relationships.
- Open up your child's schedule and your own to make time for friendship.
- Let go of the necessity of being present at every social occasion. Maybe someone else can provide the supports that you usually provide for your child.

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- Have faith in your child.
- Have faith in your community.
- Look for new communities to replace the ones that have let you down.
- Find ways to become optimistic about the future.

What if you are interested in starting a network for your child right away? Here are a few suggestions:

Order the PLAN book *A Good Life* and read it. Try www.amazon.com or other used book dealers or go to the PLAN website, <http://store.planinstitute.ca/> and click on Courses and Products. *A Good Life* is at the bottom of the page.

Get in touch with me at TxP2P, rosemary.alexander@txp2p.org, or 866-896-6001 or local to Austin, 458-8600 and I will talk to you by phone or meet if possible to talk about how to get started.

Stay tuned to the TxP2P Pathways to Adulthood Program for future developments regarding networks.

Go to The Arc of Texas website (www.thearcoftexas.org) and click on Microboard Collaboration at the bottom of the home page. A Microboard is a personal network that has been incorporated as a non-profit. Someone from The Arc will facilitate a PATH planning session to start the group and Arc personnel will guide you through the process of forming a Microboard.

Encouragement to change your perspective

Our lives as parents of children with disabilities are often spent defending, fighting, advocating, searching, worrying, learning, pushing and pulling; we become strong and tough, informed and able. And yet a time arrives when we must say, enough. I found that as my son Will grew up, I began to see him as okay the way he is. Of course, I continue to seek ways for him to learn and grow, but I have begun to think of him as a person in his own right, with gifts, talents, quirks, a strong personality, almost a finished product, beyond my control! I am ready to turn to others, to share my child, to let my child go into the world, to see what others have to offer him and what he has to offer others. And that's where Will's network comes in - it provides a safe way to make that transition. We can begin to imagine a life for him that is safe and enriched but in which we, his parents, are not the main force in his life, where others are available to him for love, fun, care and concern. Starting to think about networks can be the first step toward that new life.

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