



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

HOW TO BUILD A PERSONAL NETWORK

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INTRODUCTION:

This is a how-to manual for establishing a personal support network for a loved one with a disability. It is designed for anyone who has learned a little bit about networks and is interested in setting one up for their son or daughter. It is designed to help parents develop the personal network themselves. If you have never heard about personal networks and want to learn more about starting a network for your child, go to the Texas Parent to Parent website at www.txp2p.org. Also, for additional information you can contact a TxP2P network specialist in Austin at 512-458-8600 or toll free at 866-896-6001.

The goal of this how-to manual is to provide step-by-step instructions on how to start a personal network. Because the hardest thing for many families is “just getting started,” we have provided tools and sample agendas for the invitational meeting and the first two network meetings. We also provide suggestions for how to conduct subsequent network meetings. Finally, we discuss network sustainability. This manual has the following segments:

- A. WHAT IS A NETWORK AND WHY START ONE?
- B. GETTING STARTED: INVITATIONAL MEETING
- C. FIRST NETWORK MEETING
- D. SECOND NETWORK MEETING
- E. SUBSEQUENT MEETINGS AND NETWORK SUSTAINABILITY

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A. WHAT IS A NETWORK AND WHY START ONE?

There's nothing like the panic we parents feel as we try to envision our child's future. How are we going to make sure that our child with a disability has a good life (friends, community, fun, employment, education etc.) both now and after we die? Who is going to make sure that the plans we have arranged for our child are implemented and functioning well after we are dead and gone? Who is going to monitor the services, both public and private, our child is relying on? How are we going to make sure our child is not lonely, isolated, neglected or abused? How are we going to give caring friends and family an opportunity to have a fulfilling relationship with our child? How am I, a person with a disability, going to achieve these goals for myself? The first answer to each of these questions is, "Not alone." Because many families never get past the questions, families are often isolated and "stuck." Sadly, children with disabilities often grow into isolated adults. A wealth of resources of friends, family, and community members is untapped.

Personal networks provide a structure of on-going support for a person with a disability, during the course of that person's life and even after the parents are dead or unable to care for them. The idea of personal networks comes from a parent organization in Vancouver called PLAN (Planned Lifetime Advocacy Network). PLAN has developed a model for establishing person networks, which is published in their book, *A Good Life*. This model is thriving throughout Canada and many families worldwide are developing networks for their children using the PLAN model. 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."

"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."

For more information about PLAN, visit their website at www.plan.ca. To order *A Good Life*, go to <https://plan-31.myshopify.com>.

Personal 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.

We have both developed personal networks for our children and agree that personal networks are the best hope we have found to work for quality of life for a person with disabilities, even after parents are dead. Rather than panic, personal networks give us and other parents room to feel peace of mind as we envision our child's future.

Sounds great, right?! So how do I begin a personal network for my child? The first step is to get started!!!

B. GETTING STARTED: IDENTIFY POTENTIAL MEMBERS AND HOST AN INVITATIONAL MEETING

When parents hear about networks, they are intrigued by the concept but always ask, How do I get started? The strength of a network is in its members, so you start by inviting members to join. Here are the steps to start a network. We'll call the focus person "Helen Smith."

1. Decide Who to Invite.

One way to answer "who can I 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 to help an opportunity to collaborate with other members of the network in developing concrete strategies to support your child and family. 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	Church members	Neighbors
Club members	People at work	Retirees
Other parents	Lawyers	Case managers
Teachers	Bankers	Former teachers
Therapists	Caregivers	Anyone who has offered help

2. Invitational Meeting

The invitational meeting is an informal opportunity to explain what a network is to potential network members. Here are the steps to holding an invitational meeting:

- a. Schedule a day, time and place for the invitation meeting.
- b. Send out an invitation to possible members. Here's a sample invitation.

Introduction to Personal Networks

and

Invitation to Join a Personal Network for Helen

Wednesday, March 15, 2012

7:00 to 9:00 p.m.

Smith Family Home, 123 Community Street

The Smith family is going to organize a personal network of support for Helen. Because you have a close connection with Helen and her family, we invite you to join us to learn more about personal networks and think about whether you might like to be a part of this network for Helen.

Snacks will be provided. RSVP, please to 498-234-5678 or johnsmith@gmail.com

- c. Host the invitation meeting. Here's a sample agenda.

INVITATION TO JOIN HELEN'S NETWORK

MEETING AGENDA

May 6, 2012, 11:30-1:00

1. Welcome and Introductions. How do you know Helen?
 2. What is a personal network?
 3. Why are we starting a personal network? *describe the network as something that will be positive for all participants, instead of asking people for help because we feel needy and overwhelmed. Learn to describe your child in positive terms: instead of saying Helen needs help eating, dressing and in all life areas, explain what people will learn from being with Helen about non-verbal communication, living in the moment, humor, and unconditional love.*
 4. What are the expectations of network members? Review Handout--*Who Are Network Members?* (see next page).
 5. What comes next? *Let attendees know you will follow up with them in a week about whether they would like to join the network. Also let them know you will hold the first official network meeting in 4-6 weeks.*
 6. Conclude meeting.
- d. Send a follow-up email thanking everyone for coming and ask them if they want to join the network. *This may bring up the fear, what if a person I ask says No! Try not to take it personally if you are turned down. Just remind yourself that the person you asked may be too busy right now to commit. You can still appreciate their presence in your lives and know that you'll continue to care about one another in other ways.*

Tips

- Just do it!
- Don't wait until you think you know what you're doing. You'll learn by getting started
- A network might be 3 people for someone who doesn't like crowds or 50 for someone who loves a party.

Who Are Network Members?

(Hand out at Invitational Meeting)

Network members, including Helen, are a group of people of all ages with a variety of interests, abilities, areas of expertise, talents and connections. Each person who participates is valued for his or her unique contribution.

Here are some expectations for Network members:

- Care about Helen and her family.
- Get to know each other in the network.
- Have time to meet for 2 hours 3-4 times per year and more often when the need arises.
- Be willing to take an assigned role at meetings and outside of meetings, such as researching an option or monitoring a service.
- Attend special occasions such as Helen's birthday.
- Work with group to replace yourself if you have to quit.
- Maintain the network and monitor supports for Helen (see below).

Here are some of the different characteristics or talents needed in the network:

- energy, compassion and commitment
- knowledge of disabilities and disability issues, services, resources
- connections to the nonprofit world, businesses, recreation, etc.
- organizational skills
- financial skills
- decision-making skills (weighing and analyzing choices)
- involvement in Helen's day-to-day care, care providers who want to be network members.

Here are some of the tasks the Network might perform:

1. Maintain the network
 - decide on the time and place for meetings and frequency of meetings
 - assign roles as needed such as a meeting facilitator, scribe, meeting organizer, agenda coordinator

- decide on the group structure, such as 2 tiers: a core group and a larger group for consultation and specific areas of expertise
 - recruit new members as needed
 - keep network sustainable
2. Review Person-Centered Plan and decide if it needs revisions or additions
 3. Consider how to meet Helen's needs now and in the future in these areas:
 - Financial
 - Medical
 - Daily care
 - Fun and useful daily activities
 - Guardianship
 - Companionship
 - Fitness and nutrition
 - Where Helen will live
 - Who will take care of her
 - What she'll do with her time

It will take a team to get Helen through life. We invite people into her life for a commitment, whether for the short, middle or long term. This group will meet on a regular basis to plan, focus on different aspects of Helen's life, and work to ensure Helen's quality of life, for now and the future.

C. FIRST NETWORK MEETING:

Okay, so you had your invitation meeting and people have let you know if they want to join the network. Now it's time for the first meeting! Here's what you do:

1. Within 4-6 weeks after invitational meeting, schedule a day, time and place for the first network meeting. You may have to juggle a few dates so everyone can attend.
2. Have the meeting. Make it a potluck, so everyone is contributing—remember, the goal is to not do it all yourself!

Here's a sample agenda you can follow. (*comments in italics.*)

NETWORK MEETING AGENDA

June 15, 2012, 11:30-1:00

Facilitator: Stephanie

1. Introductions-What's New with Group Members?! *Yes, the focus person is the reason for the network, but developing closeness among network members and getting to know each other well makes for a more cohesive network.*
2. Check in with Helen—*most people would not be comfortable with being the focus of a meeting. Just want to remind her about why you're meeting today, and see if she has any comments or rules.*
3. Develop the network organization
 - name it—*a name will help members identify with the network*
 - list and assign roles to run the group (facilitator, scribe, meeting organizer, agenda coordinator). *Parents are encourage to let other members fill these roles*
 - group communication tool: *Email? Website? Facebook?*
 - Talk about goals for the group—*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 opportunities; a shared on-line calendar would be the perfect tool to schedule outings for several in the network to accompany Helen to the movies, meals out, or days in the park. It could be focused on the course of the focus person's lifetime!*
 - discuss when to meet, how often, where to meet—*I recommend 3-4 times a year, but at least two.*
4. Provide brief overview of Helen's supports. *Parents will probably need to do this. Time to tell group brief explanation of the services Helen receives (e.g. waivers, school, health care, therapies, equipment, person-centered plan, etc.) Some focus people won't want this discussed. You can also prepare an informational notebook of supports. Network members will likely have no idea what these supports are—educate them.*
5. Activity Calendar—*This is the time to let network know what's on Helen's calendar between now and the next network meeting (e.g. special events such as birthdays and sports events, case manager meetings, ARD's, doctor appointments). You may want to invite network members to attend.*
6. Next Meeting—*some find it helpful to get the next meeting on their calendar*
7. Adjourn—*end meetings on time*

Tips

- Always have Helen present at meetings. Find ways to include her.
- Have fun! Get to know one another!
- Encourage friendship among group members.
- Determine what size you think the group should be; if you need new members, ask current members to help find likely prospects.
- Over time, parents can practice “stepping back” from all the responsibility and let others take responsibility for the network.
- Keep on meeting even when you're not sure what your purpose is.
- Don't get discouraged. Remember that establishing the network may take several years.

D. SECOND NETWORK MEETING

NETWORK MEETING AGENDA

October 6, 2012, 11:30-1:00

Facilitator: Stephanie

1. Introductions-What's New with Group Members?!
2. Check in with Helen
3. Network organization business
 - communication tool: how's it working
 - any questions
 - Review notes from last meeting
4. Provide overview of Helen's supports. *This overview will go into more detail than you went into at the first network meeting. Consider spreading this overview out over several network meetings. Eventually, you'll be providing "updates of supports"*
5. Activity Calendar
6. Next Meeting
7. Adjourn

E. SUBSEQUENT MEETINGS AND NETWORK SUSTAINABILITY

Subsequent Meetings— As the network continues to meet, members will come up with ideas of what meetings will look like and what topics will be covered. Here are some ideas you may want to explore in your own network:

1. Future Topics

- Vision Statement: Share family's hopes for Helen's future
- Update regularly on Helen's services
- Develop (or Update) Person-Centered Plan
- Invite Helen's support systems to speak at a network meeting about what they do (e.g. case managers, therapists, trustees, attendants)

2. Developing Member Involvement

- Let network members take lead on agenda items
- Parents can step back and let network members take on roles
- Create "support committees" who follow certain portions of Helen's supports (e.g. education, equipment, attendants, etc.) and report at each meeting
- Discuss what it's like to serve on a personal network. What do group members see as their roles in Helen's life? What are barriers? Fears?
- Have members take turns between meetings reading a chapter from [A Good Life](#) or any other good book on networks, and present on it at next meeting.
- Members can share stories about time they have spent with Helen since last meeting
- If members decide to leave the network, encourage them to work with the group to replace themselves

Network Development and Sustainability

Developing a healthy, sustainable network can take several years. Developing a network is always a work in progress. The key is to make sure the network gets together at least 2-3 times a year, even if it's only to share a potluck and catch up on what's going on in the focus person's life. Even if that's all the group does for a while, this is successful network development. You may want to assign one or two network members whose responsibility is to make sure that these meetings occur 2-3 times per year. Don't give up or get discouraged.

Here are our observations about the development of our children's networks:

Will's network has been together for over ten years. 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.

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.

Maverick's network has been together for over three years. The best thing to result from having a network is feeling hopeful about Maverick's future. We have created a community of people who came together for one purpose (i.e. Maverick) and are, over time, becoming closer to each other, more cohesive, and more vested in Maverick future.

Conclusion: We hope that this manual will help you get started with developing a personal network for your child. Texas Parent to Parent encourages and supports the development of networks and we are available to answer your questions about this valuable process.