step two

nurturing friendship

We spend our free time with friends. We can relax with them and allow our masks to fall. It is all right to be ourselves and we can do what we like, we are not constrained by rules.

But friendship also implies commitment. A true friend feels responsible for his friends, during bad times as well as good, in success and failure, humiliation and sorrow.

JEAN VANIER

george's story

A web of support for Rick

"I'VE SEEN A LOT OF PROGRAMS come and go. Many of them are baloney—no matter how thin you slice it! At one of these senior parent meetings, this young woman came around and started talking about circles—circles of friends. Well, I have to admit I thought it was one of those baloney stories. How could this possibly work?

"It was too theoretical. It looked good on paper but it would never work.

"But they turned the tables on me. They said they wanted a guinea pig for one of those circle things. I guess they figured if they could convince me they could convince anyone. Several of the other parents were prepared to take the risk. So I took a chance. Remembering what my wife had asked I said to myself, 'What have I got to lose?'

"Now, at the time Rick knew only a couple of people. He had a very narrow social life. He bowled once a week. And he attended a program at the community centre. That was it. He wasn't working or in any kind of a day program although he used to work at Campbell Industries."

When George came home to talk to Rick about the circle, he got a chilly reception. In fact, Rick was downright cold to the idea. Rick was emphatic. "Do what you want. Just don't include me!" said Rick.

Not a great start.

George explains Rick's disinterest simply. "Rick had been to many services over the years and attended lots of classes and nothing ever changed for him. I guess I really couldn't blame him. I felt the same way."

Despite his own ambivalence, George persevered. To this day he doesn't really know why. Perhaps it was the memory of his wife's insistence to do more. Perhaps it was his apprehension about the future—he was ready to try anything. Perhaps it was because other parents were also trying it.

George had other anxieties. He and his wife had never discussed their concerns about Rick's future with any of their relatives. It was a private matter. It was their responsibility and theirs alone. Would they be interested? Wouldn't they be too busy? Did they even like Rick?

George didn't know it at the time but this is the hardest part for most families—asking family and friends for help.

"It was the most awkward part of it," he admits. "You feel so exposed. You're brought up to take care of your own. Asking for help was just not in our vocabulary."

Finally he hit upon a solution. PLAN had developed a short questionnaire mapping the relationships in the life of a person with a disability.

continued on page 42

step two

Nurturing friendship

here is probably no one who can ever look after your relative with the same persistence, interest, and determination as you do. That's a fact. However, unless you've tapped into the fountain of youth, you won't be around forever. That's a fact, too. So what's the next best thing? The best guarantee of a safe and secure future for a person with a disability is the number of caring and committed friends, family members, acquaintances, and supporters actively involved in their life. It's as simple as that.

Friends make gifts and gifts make friends.

The real strength of these caring relationships comes not just in their connection to the person with a disability but in their connections with each other. Imagine a spider's web. The strands extend from the centre of the web to the edge. Imagine if there was nothing else holding them together. They would flap in the wind. Their functional value would be minimal. They need to be linked with each other in order to form the web. Otherwise spiders would starve! The strength of the web comes when all components are interconnected.

It's the same for our family members. The focus of support for people with disabilities must be placed both on their individual

Worksheet 4 – The Web of Friendship



On pages 55 and 57, we've provided a sample web and a web for you to work with. To fill out your own web, follow the instructions on page 56.

The web will help you examine the current relationships in your relative's life and to explore ways of strengthening the network of support.

george's story

continued from page 40

George found the questions quite thoughtprovoking. He decided to mail the questionnaire out to his relatives to test their interest.

Some of them came to the first meeting, as did a neighbour and a former staff person of Rick's.

"Anyway, so there we were, all of us sitting around the room talking about Rick. There were eight of us at the first meeting. Rick was in the other room, but his name kept coming up. I guess he was straining to listen. Pretty soon he was standing at the entrance to the living room. Before you knew it he was sitting down with the rest of us and joining in the conversation. That was a turning point for Rick and me. Neither of us could believe that people were actually interested in him that way.

"After the circle formed, Rick went through a change. He had always been very quiet—a bit of a loner. Either keeping to himself or doing things just with me. He was never one to initiate a conversation, never one to pick up the phone. Soon he found there were people he could talk to. And they would phone him. And they'd go for coffee or something. And he was phoning them!

"You know it all adds up. Rick gets all kinds of help now, beyond our wildest imagination. In fact, I couldn't have imagined any of this five years ago."

For George that has been the greatest benefit of the circle. He can sit back and watch a web of support being spun for Rick before his eyes. It's almost like watching a movie about the future from the comfort of your easy chair. George is confident that Rick's network isn't going to evaporate. He knows it doesn't depend solely on his input anymore. It will carry on without him. There is no idea more ancient than a circle of friends. And there is nothing more predictable than the discovery by such a circle that the one in need is somehow helping the others. relationships and the relationships among the members of the personal network. These interconnections create the web of support that begins to approximate the thoroughness with which families care for each other. PLAN's specialty is facilitating these caring relationships for people with disabilities. We call them Personal Networks.

A Personal Network is a team. People who come together for three basic purposes: the safety, health, and well-being of your relative, the person at the centre of the network. A healthy Personal Network is one where all members are in touch with each other, coordinating their involvement, and staying on top of things. They are united by bonds of friendship, love, and trust. This is the sum of everything you embody but won't be able to provide forever.

The role of friendship in our lives

The oldest literature from all cultural traditions attests to the importance of friendship. Themes about our interconnectedness are but one indication that we are, above all else, social beings. Friendship is a necessity for all of us, as important and essential to life as food and drink.

Aristotle, a Greek philosopher and major influence on Western thought, put it succinctly: "For without friends no one would choose to live, though he had all other goods." Perhaps it's because friendship is so fundamental to our existence that we take it for granted... or we aren't conscious of its importance until it is brought to our attention.

Lucien Bouchard—a former Canadian political leader commented on his recovery from a life-threatening illness that underscores this point. Aside from the centrality of his wife and children to his thoughts, he observed that much of his time during recuperation was spent counting the blessings of friendship. In particular, he recalled those friendships that had lapsed or had been fractured and his determination to repair them.

When asked to boil our life down to its basics, most of us would agree that we are interdependent not independent beings. The impact of this recognition is far greater than our contemporary society

What the research says

- · People with supportive social ties are less likely to become ill.
- Social contact helps us to heal more quickly.
- Social supports affect the sense of control we have over our well-being and improve our ability to stick with healthy behaviour patterns.

appreciates or acknowledges. Understanding this interdependence is critical to our health, our quality of life, our sense of belonging, our peace of mind, and our security. And, therefore, it is also fundamental to the future security of our family members with disabilities.

If you love someone, put their name in a circle, instead of a heart, because hearts can break, but circles go on forever. The foundation of this future security is not the size of the estate you leave or whether you have a Will. Yes, these are important factors in building a successful future plan. But they are not enough. We agree with Emily Dickinson who wrote, "my friends are my estate." What provides texture and vitality and makes all living worthwhile are caring relationships and friends.

Friendships—ranging from acquaintances to intimate relationships—are formed by choice. They are freely given, based on mutual interests. Friendships are not one-sided. They are reciprocal, a two-way exchange. They are not paid visitors. They are not volunteers. They are not one-to-one workers.

Good friends support us through good times and bad, when we are on our best behaviour, and when we are not. We don't change ourselves to be with friends. Our gifts and our frailties are accepted as part of who we are. Our friends are not expected to fix us. They are just there. Friendships are naturally enjoyable.

When we are truly loved and valued, we gain a sense of belonging. When we feel like we belong, we change for the better. Our confidence improves as does our self-esteem, our sense of well-being, and our quality of life. Life takes on new meaning. At PLAN, we have consistently witnessed this transformation.

Caring Relationships: a source of support

Think of our own lives. When someone close to us dies, we are not left alone. We still have supportive friends and family. We want this same I would just like to have someone call and ask me out for a coffee. That doesn't happen to me. JAMES, A LIFETIME MEMBER OF PLN caring, secure environment for our family member with a disability when we die. This means formalizing the existing relationships of our relative into a Personal Network or creating a new Personal Network around them. It is the only answer to the question, "Who will replace you when you are gone?" Personal Networks can become the next best thing. Personal Networks can become your eyes and ears, arms and legs. Nothing offers peace of mind better than that.

The good feelings that arise from our connectedness to others are an obvious benefit of friendship. However, these good feelings are just the beginning in evaluating the benefits of caring relationships. Investing in an extended network of friends and family for our relative provides both short-term and long-term returns.

When it is time to monitor and advocate, our relatives with disabilities will benefit from the presence of friends and supporters. Individuals who lack supportive ties are vulnerable to a wide variety of negative consequences. If not surrounded by people who have a vested interest in their well-being, our relatives may be at risk for abuse, neglect, and exploitation. Further, the needs of our relatives can be ignored by a busy, overworked service system unless friends are present.

Success in school and on the job is directly correlated with the size and health of our social networks. Social networks are also a determinant of health. There is now a mass of evidence to indicate that social ties may be one of the critical factors distinguishing those who

Reciprocity

Personal Network members often describe how meaningful their relationship is with the person at the centre of the network. They talk about getting as much as they give. This is called reciprocity.

A few years back, we commissioned a study to document the experiences of Personal Network members. The results were impressive and confirmed our belief: people with disabilities make a real difference in the lives of Network Members. We also confirmed that the relationships between people with disabilities and Network Members were mutual. In the context of relationships, our family members are contributors. remain healthy from those who fall ill. Did you know that the health risks of being isolated are as detrimental as cigarette smoking? Clearly, friendships are necessary for good health.

The power and potential of Personal Networks have far exceeded our expectations. Over the past 20 years, we have seen members of PLAN's Personal Networks:

- monitor the formal programs and services that our relatives receive
- become effective advocates
- · serve as executors and trustees or as advisors
- act as supportive decision-makers (see step 4)
- · respond promptly and effectively to crisis
- solve problems and handle the unexpected
- carry out the wishes of parents.

Stages of a personal network

PLAN hires a Community Connector, who works an average of two to six hours per month, to create and nurture its networks. Vickie Cammack, Founding Director of PLAN Institute for Caring Citizenship, CEO of Tyze, and a co-author of this book, developed this program. She advises that Community Connectors should "do as much as necessary and as little as possible."

Personal Networks take time, sometimes as long as one to two years before they have legs, as Vickie describes it. Or until the network members develop a close and caring relationship with each other and with the person at the centre.

Personal Networks go through three stages:

STAGE ONE: EXPLORATION This is the time for the individual, family, and the Community Connector to get to know each other; it's the time to focus on interests, passions, and possibilities for meeting others. At the end of this period, the Community Connector will provide a set of objectives, a time line of activities, and a list of potential network members.

Maria has shown me how to appreciate the little things in life. My faith in humanity has grown.

THOMAS, A PERSONAL NETWORK MEMBER **STAGE TWO: DEVELOPMENT** This is the time when all the leads and possibilities are followed up, contacts are made, and invitations extended. The goal in this stage is to recruit network members and to introduce them to each other. Practical strategies are developed.

STAGE THREE: MAINTENANCE By this time caring relationships have formed and networks meet regularly. The network settles in for the long run. As new interests emerge—and they often do—new connections are made. The network gets stronger and becomes more dynamic.

The art of making friends

Did you know that over 50 per cent of the first attempts pre-schoolers make to join in a group with other children are rejected? They must keep trying before being accepted by their peers.

In other words, the first step in meeting another person is a learned skill that comes with practice. This is a skill that most of us take for granted and which developed more or less naturally for most of us. A psychologist, Dr. Michael Guralnick, has observed that children with disabilities often do not experience this trial and error process. He suggests that there are three skills which very young children develop while playing with each other:

- 1. They learn how to initiate contact with peers;
- 2. They learn how to maintain play. These are the skills we learn to keep the interaction or relationship going;
- 3. They learn conflict resolution. Inevitably in any caring relationship, we have to learn to negotiate, to share, and to compromise.

Qualities of Community Connectors

PLAN's talented Community Connectors share similar characteristics. They:

- recognize and nurture the capacities and gifts of everyone
- pay attention to detail
- are great event planners

- are creative, pragmatic, and reflective
- know their community and use their connections.

Friends. by sharing time with us, are saying that we are worth the gift of time. I am excited to be a Community Connector because I can be a part of creating this opportunity in someone else's life. JOSHUA, A COMMUNITY CONNECTOR

Friendships rarely develop by chance. We cultivate them as carefully as we nurture a job or a family, a talent or a hobby. Some of us may think that friendships happen naturally and that, if they don't occur, there is nothing we can do about it. Not true. There appears to be a certain skill set associated with initiating and developing our acquaintances and friendships.

The ability to make friends may have to be relearned for some people. As a result of an accident or injury, their friends may have drifted away and their social circle changed dramatically. They may have had limited opportunity for socializing as a result of institutional living. They may be surrounded by staff that don't recognize the importance of friendship or don't know how to facilitate it. They may have tried to make friends, were rebuffed, and then became discouraged from trying again. They may lack or have lost confidence. They may believe that no one would want to be their friend.

Because friendships do not always develop naturally for some of our family members with disabilities, it is often necessary to approach the development of caring relationships in a focused and strategic manner. PLAN hires a Community Connector to assist with developing and maintaining our Personal Networks.

What we've learned about personal networks

- They take time, about two years on average, to become a smoothly functioning team.
- It's important to focus on people's interests, passions, and what they *can* do. There are enough people focusing on what they *can't* do.
- Connections among and between network members are as important as their relationship to the person at the centre.
- There are more people interested in developing a caring relationship with your relative than you may think!

Significant contributions

Personal Network members make significant contributions because they:

- · see the gifts and abilities of our relatives
- · validate our relatives by letting them know they are valued
- help our relatives develop their talents
- create opportunities for our relatives to make contributions.

How caring relationships challenge families

While many families recognize the importance of caring relationships in their relative's life, they often feel some ambivalence when it comes to actively seeking opportunities for these relationships to form. From our experience, there are three challenges that families face: asking, opening, and believing.

I let go and trusted. We moved fast and wild. I had no idea what it looked like, nor did I care. The dancer inside me was out. BONNIE SHERR KLEIN ASKING To ask is to make ourselves vulnerable. There is always the possibility of refusal. Yet reaching out and asking is integral to developing and deepening our relationships. Friendships often form because we ask others to participate in a shared activity. We invite acquaintances over for tea to get to know them better. We ask neighbours to help us with building a fence. We ask friends to give us a hand with setting up for a party. Each of these casual invitations presents an opportunity for the relationship to grow into a caring one.

This process is not as easy when it comes to reaching out on behalf of our family members. We grew up with the unwritten expectation not to complain and to take care of things ourselves. We are fiercely and justifiably proud of our self-sufficiency.

We may feel that extending even a casual invitation is risky. We worry that others will feel obliged—or worse—that they might be saying yes because they feel sorry for us or for our relative. This worry speaks to how deeply many of us have been hurt by negative cultural stereotypes about disability. It makes us forget the gifts our relative has to offer. It makes us forget that others may indeed care.

What a network means to James

All my life I've been alone because I had no friends and no place to go. When my mom told me about having a network, I had a few questions... Would these people be my friends? Would they like to talk about music and photography? My mom said the network would be what I wanted it to be. So I thought about it and this is what I would want from my network:

- friends who want to spend time with me
- being with musicians that share my love of music
- people who will help me with my music and photography projects
- not having to spend so much time with my parents
- finding a relationship with a companion
- no more being lonely or bored.
- getting out of the house and spending time in the community

We need to remind ourselves of the beauty and richness our family member has added to our lives and to the lives of those around them. We constantly hear stories from ordinary people attesting to how their relationship with our sons and daughters has brought meaning to their life. These are often people who wanted to reach out but did not know how. Each invitation we offer is an opportunity for others to extend their community and to broaden their relationships.

No disability precludes relationships. VICKIE CAMMACK **OPENING** In order for others to come into our lives, there needs to be a place for them. It is impossible to meet people or deepen a friendship if we have no time to spend with them. This is an issue for many people with disabilities. Virtually all areas of their lives may be programmed. From an outsider's perspective, there is no apparent need for a friend. Our relative may be too scheduled for friends and acquaintances to spend time with them. We may need to give up a program or change schedules to create the space that would allow for others to engage with our relative.

On a more subtle level, some of our own actions might inhibit the involvement of others. Over the years we may have become used to doing many things for our family member. The presence of others changes our routines too. The involvement of somebody new might

Reaching out: a portrait of social network facilitation in Canada

This is a portrait of facilitated social network development across Canada. Author Nancy Rother describes the seven critical elements of resilient social networks, explores challenges, and offers practical tips. For more, please visit www.planinstitute.ca.

> be threatening. Shouldn't we be doing it ourselves? That's good, old fashioned guilt talking. We can do it better. What if they do it better? What will they think of us? That's letting fear do the talking for us. As we feel ourselves losing some control, we may resist or undermine the contributions of others. We need to ask ourselves honestly and courageously what we are willing to let go of in order to make room for others to become active and involved in the lives of our relatives.

When you really think about it, this process of letting go is our lifetime task. It is why you are reading this book. Friendships provide a catalyst to accomplish this task. Our family members grow richer from having experiences outside of their immediate family. Their friends can inspire and encourage them to participate and contribute to society.

BELIEVING Of the three challenges, this may be the greatest. We worry that the distinctive traits or history of our relatives may make them unloveable—to everyone, that is, but us. We remember the absence of invitations to birthday parties or sleepovers. We notice—yet again—someone staring in the supermarket or we receive a look of pity from a passer-by. We feel hurt by these things and we ache for our relative. Our overwhelming desire is to protect, and we cannot find it in ourselves to truly believe there is a caring community of people available to befriend our relative. This lack of belief affects our ability to be open to others, and to trust in their integrity.

After 20 years of nurturing Personal Networks at PLAN Canada and in dozens of locations around the world—we can assure you, no disability can prevent a caring relationship from forming. No previous experience, no characteristic, no behaviour, not anything. And we don't

The heart keeps looking for itself. It knows and does not know where it belongs. JAN ZWICKY just believe this, we know it. The proof is in the hundreds of friendships that have developed within our Personal Networks.

In spite of the negative view of an uncaring society profiled regularly in the media, people do reach out to each other. PLAN's experience bears this out. People are genuinely hospitable and eager to become part of our relative's life. Often they just need to be asked.

Our challenge as parents and families is to not let our fears dominate the opportunities for friendship.

Relationships and contribution

Relationships play an important role in enabling our sons and daughters to contribute their gifts. From the comfort of supportive friends, family, and Personal Network members, people with disabilities can find opportunities to work, volunteer, create, inspire, care, serve, and contribute.

Our family members make contributions in two ways:

CONTRIBUTIONS OF DOING These are the action-oriented contributions we are most familiar with such as volunteering and working.

CONTRIBUTIONS OF BEING These are contributions made by the majesty of our relative's presence. Being present is an important way for our family members to make their contribution. The exchange is fellowship and communion. Our relatives offer grace, caring, attentiveness, wonder, acceptance, silence, receptivity, compassion, inspiration, pleasure, gratitude, loyalty, and friendship. These gifts—often overlooked in our society—are critical to society's well-being. In fact, they are a necessary antidote to "too much doing."

Identifying the gifts and contributions of our relatives can lead to meaningful relationships. See Worksheet 5 on page 58.

For more on the relationship between contribution and citizenship, see the Philia dialogue discussion on page 180.

That's what friends are for

There is something about being human that makes us yearn for the company of others, to be with and to be touched by our family and

friends. Isolation and loneliness are devastating by-products of having a disability. We believe that these by-products are disabilities in and of themselves.

Loneliness can weigh even heavier when a person with a disability is served by a large, impersonal service delivery system which has little time or resources to focus on friendships. The only way to truly diminish this loneliness is by paying attention to caring relationships. Even though this may be challenging for both our family member and for us, it is critical for their future security and well-being.

The key to creating these connections is first, our willingness to *let* them happen and second, our effort to *make* them happen. All the riches of the world will not compensate for the security of being cared about. That's what families do. That's what friends are for.



Tyze is an online service that works to create and maintain Personal Networks and is based on the proven PLAN network facilitation model.

Tyze is about the person at the centre of the network and the connections among the network members. It's a place to celebrate contributions and achievements; it's a way to stay connected to friends and loved ones. Please visit www.tyze.com.

Enough talk: the belonging initiative

There has been a lot of talk over the years about the importance of friendship for people with disabilities. Unfortunately there hasn't been a lot of action, until now that is.

A group of Canadian organizations has banded together to do something about ending isolation and loneliness. Members include L'Arche Canada, the Canadian Down Syndrome Society, Canadian Abilities Foundation, Independent Living Canada, Inclusion Press, Developmental Disability Resource Centre, Laidlaw Foundation and, of course, PLAN and the PLAN Institute. For more information, please visit www.nurturingbelonging.ca.

Nick's network

With support from his friends, family, and caregivers, as well as his Tyze network, Nick goes to concerts, reads IT magazines, and even has a blog called The Hockey Ambassador. When he found out that some retired NHL players were going to be visiting his home town, he invited them over for a beer and used the Web to special order some Molson Canadian for the occasion. Nick has a vibrant life studying Information and Communication Technologies. Despite being largely bed-ridden with chronic pain, he lives an extraordinarily rich life.

With support, Nick is able to study at the university. His team of friends and caregivers know when his assignments are due and are available to help him write reports and tests. He relies on his caregivers—some of whom only work once in a while—to book transportation to and from concerts, record NHL games, and bring him to hospital appointments.

It's a lot to remember, and a lot to coordinate. And that's where Tyze comes in.

Nick's parents, friends, and caregivers have come to rely on his Tyze network as a critical part of how they manage his care. Nick's parents—along with his live-in caregiver and other agency coordinators and professional caregivers—login to Tyze on a regular basis to see what medications and side effects they need to be aware of, what transportation might be required that week, and what personal projects Nick has on the go. Donna, Nick's Mum, tells us that they need to run a "faultless system that allows staff to coordinate everything in Nick's life" which is a considerable task, given how busy he is.

Before they started using Tyze, there was a white board in Nick's room with information for

the current day as well as the four days prior, but the caregivers just didn't read it. Donna still had to verbally communicate all the critical elements of Nick's day and medical needs to each new caregiver as he or she arrived, and she worried that things would fall through the cracks.

With Tyze, communication is now ongoing and Nick's caregivers have access to the information they need, whenever they need it. Tyze commands their attention in a way that the white board did not, in part because they are young and they understand computer communication, but also because the information is timely and relevant. Every time an entry is made regarding Nick's care and schedule, his caregivers receive an email message. Each caregiver knows that they have to start their shift by logging into Nick's Tyze network to stay current.

Some of the caregivers access Nick's Tyze site using their iPhones, so that they can send and receive messages while they're on-thego. Passwords, medication information, social activities and doctor's appointments are all stored within Nick's private, Tyze network so that his team of caregivers can share information and stories, and deliver the best possible care.

Nick is a sports fan, technology enthusiast and indomitable spirit with high hopes for his future. He's curious about the world, and fearless when it comes to using technology. With the support and involvement of his friends, family and caregivers, Tyze is playing a significant role in helping him to achieve his dreams. It provides seamless communication for all the people who have Nick's care as their common objective. ■



Sample web



To download a copy of all worksheets, visit www.plantoronto.ca and click on Safe and Secure worksheets.

Worksheet 4

The Web of Friendship

The sample web has already been filled out. To fill out your own web:

- 1. Write your relative's name in the centre circle.
- 2. The inner circle represents the area in their life that is filled with people they trust, feel comfortable with, and confide in. They can be friends or family. However, exclude anyone in a paid position. The people in this circle will have a reciprocal relationship with your relative, based on friendship and respect.
- 3. The remainder of the web represents the rest of the people who are involved in your relative's life. Write their names down, using the distance from the centre to represent how close their relationship is.
- 4. If you wish, the dotted lines can be used to indicate the different areas in your relative's life. For example, family in the top section, friends on the left, school and work in the other quadrants. This will help you to visually demonstrate the interrelationships in your relative's life.
- 5. When you have completed this picture, think about how you can strengthen the web, by joining up the people in your relative's life. In a different coloured pen, draw in all the potential connections.

Your family member's web



Worksheet 5

Contribution

The following questions may help you identify the various ways your family member makes or could make a contribution.

We suggest you answer these questions and then share with your family member and others who know them well.

What contribution does your relative make to your family?

What are the three activities they love the most?

What are their passions?

What gives them the greatest joy and pleasure?

Who are their heroes?

What famous public personality (singer, actor, athlete) do they like?

What are their gifts of doing?

What are their gifts of being?

What would they like to learn?

What could they teach others?

What have you learned from them?

What positive attributes do others like about them?

What is the greatest accomplishment of their life so far?

What job or volunteer position would best suit their interests and personality?