

Belonging to One Another: Building Personal Support Networks

This resource is meant to inspire. It is meant to stimulate your heart and your head in considerations of how to support friendships and social connections for people with developmental disabilities. Supporting relationships is both a set of beliefs and a number of practical strategies that can lead to positive outcomes for our family members, those we support and those we have yet to meet and welcome into our communities. This may be the most important topic we need to talk about to build strong communities that welcome all citizens and fulfill our longing to be together.

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Why are we talking about Personal Support Networks?

British Columbia has much to be proud of in our support system for people with developmental disabilities. In 1996, through the concerted advocacy of the community living movement, and in partnership with the provincial government, BC was among the first provinces in Canada to successfully close its major institutions.

Community living has been the active commitment of local agencies, families and individuals for over 50 years. Despite the changes and progress that has been made with and for individuals, a good life in welcoming communities with friends and valued identities, still remains very limited for many people. Many individuals with developmental disabilities still rely on people paid to be in their lives and struggle with loneliness and isolation. While services are often needed to help support living in community, what is also essential to life are friendships and an authentic sense of belonging. The social ties of kinship, friendship, and participation as well as the psychological ties of attachment, identity and a sense of belonging to a place or a group, are vital human desires. Without them we may have lives that are rich in physical comforts, but impoverished in terms of our hearts.

We believe that to build fulfilling lives in community for people we support and care about, we must deepen and sustain our commitment to building personal support networks and social connections. There are champions active in our communities promoting and supporting this work and these ideas. The opportunities to assist abound. This resource is about reminding us of the importance and necessity of these essential needs and offering ideas about how to develop a focussed relationship lens that supports this work and broadens the scope of considerations regarding individuals with developmental disabilities and their lives. This resource is about inviting your active participation.

Personal Supports are Safeguards

CLBC has been involved in supporting conversations about safeguards. Everyone needs safeguards in their lives – things that they and others do on purpose to reduce vulnerability. Safeguards can be very personal and individual, or community-wide.

CLBC recognizes that formal safeguards are important to ensure the safety and well being of individuals with developmental disabilities. These formal safeguards include things like: monitoring, writing personal plans, health supports, accreditation, and reviews of service providers. We know though, that formal safeguards aren't enough. We still need to think about the informal safeguards that enhance and enrich our lives, our sense of connectedness, and keep us safe. Friendships, community connections, lives in community beyond the service system are essential to both living a good life and enhancing our sense of self worth.

This resource talks about ways in which informal safeguards, like personal supports and community connections, can be nurtured. Having people in your life that care about you is one of the most important ways to feel safe and valued. Having friends to talk to, places to go for fun and the opportunity to be involved in your community, not only adds to the satisfaction you feel about your life, but also helps build protection and provides support for us when we feel vulnerable.



Social supports also enhance our health and wellness, both physically and emotionally. Living our lives without the benefit of friends and social connections is now well known to negatively affect both our bodies and our hearts.

"A sense of belonging," writes Dr. Kenneth Pelletier of the Stanford Centre for Research and Disease Prevention, "appears to be a basic human need – as basic as food and shelter. In fact, social support may be one of the critical elements distinguishing those who remain healthy from those who become ill."

The Reality of Loneliness in our Communities

Although this resource has been written specifically about people with developmental disabilities, it is important to reflect on how deep and pervasive the experience of loneliness is for many people. Loneliness doesn't discriminate based on age, income, gender or race. There are many people who live in our communities who struggle with isolation, being friendless and the vulnerability that comes with that. For people with disabilities, we know that the potential for limited friendships, loss of family, and social isolation is greater. Some of this is because of our elaborate systems of support which have successfully served people's physical needs, but not typically supported their heart connections.

How has this happened?

The move into community and the creation of a service support system has been heralded as a key success of closing institutions. Services have been designed, with the best of intentions, to look after housing, employment, daily activities and health support. The system that has been built is complex, organized, and hard to penetrate from the outside, which makes ordinary connections with other members of community harder for people who use our systems.

While it cannot be denied that the relationships that are formed between paid staff members and people with developmental disabilities are often significant, long-term connections, it is also true that they may constitute the extent of the scope of relationships for those using services. When a staff member leaves, as can and does happen, the ties are hard to sustain. Having a larger circle of acquaintances, friends and connections helps to bridge changes and transitions for all of us.

We advocate that actively working to build personal support networks is not only about cultivating more choices for relationships, but also about compensating for the professional nature of services. If we use the metaphor of a tree, each friend, each support you have, is one root. If you've only got one root, and a big wind comes, it's far likelier that you'll topple over than if you have a number of roots spread over a larger area. We've learned that the greater the network of social connections, the greater the potential to withstand the predictable shifts and changes that will occur in our lives.

Families have sadly sometimes lost contact with their family member over time. Others have reduced their involvement in their family member's life and feel displaced or irrelevant because of the scope and authority of the service structure in place.

In the case of people who have remained living at home with family members, sometimes the stress of care needs, extra demands and supports required, can result in the entire family becoming isolated and vulnerable. While this isn't always the case, the history and unique needs and situations of families can be factors in how relationships have or have not been built.

The service system provides a multitude of necessary, formal supports that help to ensure people's safety and well-being in the community; however, these supports sometimes have the unintended outcome of supplanting, rather than augmenting natural supports that the rest of us take for granted in our own lives. Families, neighbours, community members who might want to be more involved, often shy away because of a perceived lack of opportunity for engaging with the supported individual, or worse, a perception that they aren't needed. Nurturing voluntary, reciprocal relationships in community requires us to step back, to create a space for others to enter in. The challenge before us is to honour the ways in which our formal supports are working, while also recognizing the ways in which those supports may in fact be inhibiting relationships.



"We need to belong intimately to a few people who are permanent elements in our lives. A life without people, without people who belong to us, people who will be there for us, people who need us and who we need in return, may be very rich in other things, but in human terms, it is no life at all. All the complicated structures we create, are built on sand. Only our relationships to other people endure."

Rabbi Harold Kushner

Key Beliefs that promote Personal Support Networking

This resource has been written with a distinct perspective and set of beliefs.

We believe:

- Everyone is ready for relationships; we don't need a program, or a *pre-friendship* course.
- Friendships and social connections are a right and fulfill a deep human need and longing for connection.
- This isn't about disability; this is about humanness and that has nothing to do with how we get around, how we communicate or how we've been labelled. The labels we give people usually prevent us from truly knowing them.
- Community is a powerful source of solutions, ideas, and answers and generally should be our *first* resort.
- Systems have their benefits but they also have their limitations. All our good intentions may in fact be the problem!
- Money is not the primary resource needed to fulfill a desire for friendships and social connections.
- People with developmental disabilities have gifts, abilities, capacities and are important citizens of our communities.
- Risk and rejection are part of making connections in the world. It is typical for all of us to have these experiences and there is dignity in taking these risks.
- Experiences, opportunities, and relationships are all connected to each other. The more experiences and opportunities a person has, the greater likelihood they will have relationships.
- The ability to form a friendship or social connection has nothing to do with a person's intellectual abilities, economic contribution or education. Forming a connection is a result of ease and comfort growing between people, that builds over time into a relationship.
- Sometimes we will know things are going to work; sometimes we won't. What is important is to continue to explore opportunities and keep trying.
- Supporting relationship building and social connections does not come with a precise guide, roadmap, or rule book. We have to trust the process.
- There is a stark difference between being "IN" community and truly "OF" community. Living in community has not always meant having a full life.
- People with developmental disabilities are motivated to participate and deeply desire friendships and social connections.
- Relationships are as unique as the individuals participating in them. A person's vision of social connections and personal supports may be very different from what we assume it to be. The process must be guided by the individual you are supporting. Their goals, ideas and gifts are the heart of the work.

"To be vulnerable is not to be in jeopardy. To be vulnerable and isolated is the matrix of disaster."

William Gaylin, M.D.

An Invitation...

This resource is meant to inspire you to think both with your heart and your head because we've learned that supporting friendships and social connections for people with developmental disabilities involves a combination of these centres of knowledge. Supporting relationships is not a formulaic, linear process; it will test your comfort zones, and **definitely doesn't come** with a step-by-step instruction manual. It does, however, involve thinking deeply about someone you care about, considering their existing and potential connections, inviting their active participation, and the participation of those who also care about them, and setting off on the journey of transformation together.

Supporting relationships is a revolutionary act; both a set of ideals as well as a number of concrete practices that lead to different and positive outcomes for people with developmental disabilities. This process offers an invitation to think about your own relationships, call on your friends and acquaintances, and rethink your role and commitment to the people you care about. Thinking about relationships should feel very personal because it is! Building relationships and social connections should be the soul of our work.

Supporting Personal Connections in BC

Thinking about and promoting personal supports and community connections is not new to our province or to our country. British Columbia has a rich history of several inspired initiatives which have intentionally worked to support the creation of personal connections for people with developmental disabilities. Through the leadership of the BC Association for Community Living in particular, several projects have been pioneers in this work.

From 1985 to 1990, the Rights Now! project worked in three communities in BC, fostering self advocacy and community building. The inspiration from the Rights Now! project was continued, under the mentorship of John McKnight, in the communities of Powell River and Prince George, supporting community building projects in each. These successes led to the work of the Building Bridges project which again blended self advocacy and community building with personal support networking. The success and innovation of these initiatives has been recognized across Canada and internationally.

Building on this legacy, and in support of their vision of *"good lives in welcoming communities"*, CLBC, as part of its commitment to informal safeguards, provided funding in 2007 to initiate four demonstration projects in BC. Organizations in Langley, Mission, Grand Forks and Vancouver were chosen from among several applicants. Lessons from those personal support networking demonstration projects are featured in this resource, along with ideas gathered from others.

Rethinking our Roles

In the guiding beliefs which shape this resource, we noted that we believe that there is a stark difference between being “IN” community and truly “OF” community. We can live in a home, in a neighbourhood, ride the bus and shop in local stores without feeling true community membership.

Being part of a community seems like such a “natural” thing. Yet, as the experience of those involved in supporting this work can attest, supporting people who are isolated into community does not just happen “naturally”. There are aspects of this work that challenge us to rethink our roles and our commitments to the people we care about. Building connections is intentional, strategic and purpose driven.

Is there a difference between Inclusion and Belonging?

Inclusion is a word that has become part of the lexicon of the community living movement. It has represented hope for a world that includes everyone, regardless of ability or disability. The vision of an inclusive society has acted as a north star, guiding our work over the years.

There is however a distinction worth noting when thinking about inclusion versus belonging. Consider the difference between when you’ve felt you were included in something or someplace versus when you felt you truly belonged somewhere. The difference is subtle but important and speaks to the essence of sustaining relationships and the reciprocity inherent in a valued connection. Our connections support our sense of belonging and offer us ways to be included in various aspects of community, be they work, social and recreational environments, school, faith communities, clubs or associations.

Inclusion was where we began. Belonging is what we need to strive for as it offers the joy and celebration of lives embedded in a rich circle of relationships that honour us as whole beings.



Qualities of Personal Support Networkers

In almost every initiative which has worked to promote friendships and personal connections, the work was championed by key people who made this their focus. Projects took different approaches, sometimes recruiting, sometimes utilizing existing team members, sometimes reframing job descriptions and roles. The focus, regardless of the model used, involved intentionally building bridges between people with developmental disabilities and community.

We have begun to notice the key characteristics of those who are successful in this work and realizing the vision of community connections and personal supports. The title or position held was never as critical as holding the vision for this work and believing in the potential for success. Typically successful networkers:

- Begin from an **asset perspective**, identifying gifts, capacities, interests and aspects of people that will encourage relationship building.
- Believe in community and actively work to build connections.
- Take direction from people with developmental disabilities and are excellent listeners and observers.
- Are willing to be curious, ask, and keep trying.
- Have strong networks of friendships and social connections themselves from which to draw upon and understand.
- Believe in the capacity of individuals with developmental disabilities to form and sustain friendships and are capable of building relationships of trust with those they serve and support.
- See and seek connections between people and their gifts and abilities linking dreams and strengths with possibilities.
- Start small, take time, see opportunities, and find creative solutions to challenges.
- Do not feel compelled to 'fix' or change those they support.
- Endeavour to work themselves out of a job... over and over again.
- Are innovative, work outside of a formal, systems approach, and frequently keep irregular hours.
- Do not define themselves by a particular job description or title.
- Adapt, change and redefine responses as circumstances, situations and needs change.
- Remain committed to the goal, present to possibilities and responsive to ideas other than their own.
- Are natural "hosts" and networkers – they feel excitement and display exuberance for this work.
- Have a deep appreciation for how isolation has occurred in the lives of people with developmental disabilities and their families and are passionate about the value of friendships and social connections to heal the wounds of loneliness.

"Loneliness is the most significant disability of our time."

David Pitonyak

Exploring Personal Networks for People with Developmental Disabilities

Although we've already said that this kind of activity does not offer a clear, linear process, we have learned that it always begins with a deep curiosity about the person who you are supporting. The role of the networker or bridge builder is pivotal to seeing the possibilities and potential for relationships and assisting the individual to explore them.

Celebrating gifts and abilities

Relationships are formed through shared experiences, interests, abilities and opportunities. Seeing possibilities involves exploring and articulating these same aspects of the person you are supporting.

Asset inventories are very specifically focused on the positive aspects of a person, on their capacities and what they can offer others. These can include things like a sense of humour, having a talent for listening, and being open and welcoming to new people or experiences. The typical experience of people with developmental disabilities has been to receive labels which are negative, alienating and intimidating. As a result, people become known more often by their limitations than by their capacities.

A **personal asset inventory** is about promoting the person and their gifts, abilities, and contributions, and is specifically and intentionally focused on the following areas:

- Things the person is good at
- Activities they enjoy or would like to try
- Experiences that have been successful in the past
- Qualities that attract others to them
- Hobbies, sports, and recreational pursuits
- Stories from friends and family that help build a portrait of the individual
- Participation in faith communities, clubs or other community groups
- Preferences and other individual characteristics: e.g. Do they enjoy small or large groups, noisy or quiet activities, day or night time events?
- Neighbours who have demonstrated interest and support to the individual
- Friends from the past who the individual may have lost contact with
- Jobs and volunteer roles which they have participated in
- Family connections both near and far

Ideally, a personal inventory stays as a *work in progress*, always being added to and involving the participation of many people who know and care about the individual. Contributors can be family, co-workers, friends, present and former staff, acquaintances and neighbours. It is absolutely essential that the person you are supporting be involved and contributes to generating the asset inventory.

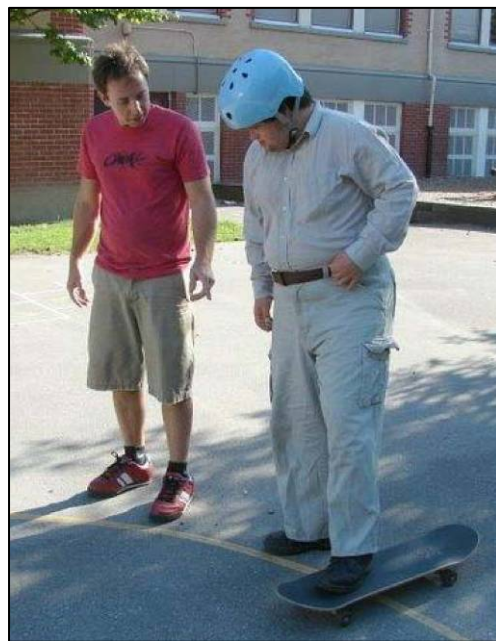
The personal support networker or bridge builder ideally leads the conversations that build this inventory and in doing so, also creates and builds excitement about the possibilities that can emerge. The conversations should be written down and photographs should be used to enhance the portrait you are creating. Pictures of the individual being supported can also ensure that they understand and recognize the people and places that are being recorded. Photos can also be used to support choice making by an individual when considering activities, people or events to participate in.

The process of capturing ideas both in written and picture form is important to the process for a couple of reasons. First of all, it honours the importance of the work and records the ideas, dreams and opportunities so they can be recalled. Secondly, the focus is placed very directly on outcomes for the individual. Finally, the emphasis on assets, capacities, opportunities and abilities is a way of celebrating the person and inspiring the next steps forward.

The possibilities are endless and the potential for creativity is immense in this process. Some things that have worked for others have been documenting friends in a special book, photographs of people and activities, address books using graphic recordings and photo albums that offer a pictorial map of a neighbourhood.

This process **will** and **should** take some time. Personal support networkers typically find that these conversations must be supported carefully both with individuals with developmental disabilities and their families who may have been let down in the past by professionals and service providers whose grand plans never materialized. Often families have participated in many, many meetings where promises have been made but never kept. This can lead to scepticism and natural reluctance to be disappointed again. As one organization learned, their key commitment became to *do no harm*.

For many individuals with developmental disabilities, their families and even staff, experiences with the service system have often created confusion about the nature of relationships. Staff members, who surround individuals, are naturally important to them. Their involvement can be misunderstood as a deeper relationship than it may be. Often individuals with developmental disabilities have had limited experience participating in relationships and making social connections and are therefore, uncomfortable or shy and need support to develop confidence and social skills. Families, sensing the scope of the service system's influence, may have retreated from regular involvement. The personal asset planning process offers an invitation into the circle and helps define a focus on the individual's social connections and relationships that honours care and concern and demystifies roles.



On the next page is an example of an Asset Inventory for a person (name fictional) to assist the reader in seeing how an asset inventory might look including a visual representation.

Asset Inventory: Buddy Jones

Life Purpose: Buddy's purpose is to live a healthy life; physically, mentally and emotionally, supported by the people he cares about and who care about him.

Passions:

- music of all types
- being around, and interacting with friends and family
- haunted houses and horror films
- all types of animals
- yoga and meditation
- his volunteer position working for "world peace now"
- working, with friends (or new friends)

Unique Strengths: Buddy's unique strength is his talented and funny impersonations of cartoon characters, superheroes and music divas! He's a star at a local Karaoke spot. He's great at introducing himself in all kinds of situations, interacting socially, and figuring out ways to utilise his creative impulses. He can be silly when the situation calls for it. He cares deeply about his friends and a really nice thing about Buddy is that he knows talking to new people is easier for him than for most people, so he's a careful, natural facilitator, always introducing people to each other and helping them find common ground. He has no sense of "disability" and will assume a person, whatever their abilities, should be included and will ensure they are.

Values: Buddy values honesty, diversity, respect, joyfulness, patience, honour, kindness, and forgiveness.

Beliefs: Buddy believes that all people should be treated equally, regardless of their ability, colour, gender, and orientation. He likes to say "violence causes silence" and believes we should treat people with care and kindness to bring out the best in them. Buddy also believes that people should be treated with respect, integrity, and loyalty so that we all can achieve greater happiness.



The Work of Networking

While personal support networkers rarely have formal titles or recognizable job descriptions, they do not act randomly in doing this work. The work of helping support friendships and social connections does not tend to have dramatic results, and it can be hard to discern how or if efforts are making a difference. Networking takes place in community, and the process of connecting can appear to others as unmanaged and unaccountable time. Support for networkers is essential to sustaining the belief in the value of this kind of role.

A consistent recommendation from networkers is to keep notebooks, address books, and diaries of their interactions. In one community, they developed specific tools for documenting their process which supported keeping everyone aware and up-to-date so that no one and nothing was forgotten.

Their ideas include:

- Maintaining up-to-date weekly schedules for each person they were supporting, indicating who accompanies the person on various activities, who they come in contact with during the activity and strategies for support these informal relationships.
- Noticing the key relationships that are important and successful for the individual they are supporting.
- Creating and maintaining up-to-date contact lists and address books.
- Journals, scrapbooks and photo albums for keeping track of family and friends.
- Ways for individuals to offer their contact information to initiate a second connection. These included business cards with their name, phone number and email address.

Another valuable suggestion is to routinely carry a camera with you and photograph connections, places, people and activities to use to build scrapbooks, augment address books and develop the asset inventory for both the individual and community. The adage *"a picture is worth a thousand words"* is particularly apt for individuals who may not communicate using typical methods or who do not read and write fluently. Photographs allow choices to be identified, honour and confirm preferences and participation, and encourage individuality while celebrating the person's past, present and future possibilities for friendships and social connections.

What is most essential is beginning with an idea that feels manageable and doable and following through on it. Starting with small steps leads to greater confidence, experience and more ideas about how to support networking and social connections. A critical component of sustaining enthusiasm is sustaining the conversation about this vision and activity in the various arenas where you gather. These can include staff meetings, personal planning sessions, informal gatherings, training opportunities and celebrations. Conversations are key to generating ideas.

Engaging Community

We have discussed the importance of beginning with an **asset inventory** to support deeper knowledge of the individual with developmental disabilities. The same principles of asset based assessment apply to explorations of community.

Building a **community inventory** involves looking at the community with different eyes, as a series of opportunities and potential relationships. Building an inventory of community options is often best created by walking through the neighbourhoods and charting the resources that are available. These include things like:

- Recreation centres
- Stores
- Businesses
- Banks
- Churches and other faith communities
- Schools, including colleges and universities
- Parks
- Cultural resources like theatres, art galleries and libraries
- Child care centres
- Bars or clubs
- Community services like hospitals, police and fire halls
- Clubs and associations
- Resources that welcome volunteers like SPCA, food banks, and thrift stores
- Local hangouts like coffee shops, restaurants, and other places 'regulars' gather

These kinds of assets, while often obvious, are rarely deliberately recorded to create a map of the opportunities that exist. The resources and places identified should be literally drawn to help visualize the scope of opportunities and to support the involvement and access of people with low literacy. Using photographs can again enhance the quality of the community map you create, help remind people of places they are comfortable going to or interested in visiting, and build excitement for the process.

The community asset inventory should be specifically enhanced with the key preferences of the individual with developmental disabilities you are supporting so that it represents their personal perspective and connections while you are building more.

In addition to the "bricks and mortar" places you identify, it is also important to inventory what associational connections are available to explore. These include clubs of various kinds, service organizations and not-for-profit organizations such as the SPCA. The process of searching for and finding these gems in your community will be interesting and support the exploration of interests, abilities and experiences for the individual you are supporting.

It is also important to pay attention to the community calendar of events. Small towns are historically quite rich in community events which offer opportunities for social connections. Neighbourhoods in larger cities also host events. Learning about when these occur and making sure they are on the calendar is an important way to support new experiences and new relationships.

Explore volunteer opportunities in your asset mapping as well. Community events offer many opportunities to volunteer as do local not-for-profit organizations. Including these in the asset inventory will extend your creative thinking with respect to potential friendships and social connections.

Seeing Opportunities

Crafting both personal and community asset inventories provides some of the essential foundational information to begin to identify possibilities and opportunities the individual wishes to pursue. The momentum that can be generated by the conversations about personal interests and capacities and community options, naturally lends itself to collaborative brainstorming and planning.

Gathering together the key people invested and supportive of the individual becomes the circle in which planning and dreaming can occur, and from where action can be taken. Considering both the person and their community, begin to identify a selection of activities, places and people to focus on. Ensure that planning honours the comfort level and willingness of the person you are supporting.

An easy, but often overlooked way to see opportunities, is to become a "regular" in your neighbourhood or community. Becoming visible involves doing things at the same time and same place in order to build potential connections. This can involve an introduction to the clerk at the corner store where you regularly buy your newspaper, the cashier at Safeway who works on Wednesday afternoons when you shop, or the other neighbours who go out walking in the evening at the same time as you. The point is to become familiar and to see and seize these potential connections. The two stories that follow provide examples:

A Generous Heart

"With Greg's artistic flavour, we look at this as an opportunity for him to meet new people. This provided Greg the incentive he needed to get out and meet people. He still wanted to collect boxes and staff helped Greg identify places in the community he could go to ask for them. Over the next several months, Greg found one store in particular that he liked to visit to pick up boxes and get to know some of the employees there. Two employees in particular seemed to connect with Greg. Both Erin and Melissa got to know Greg by name and over time got to chatting with him each time. We tried to get Greg to go at similar times each week so that the employees could come to expect him. But we discovered he does not like having a set schedule and prefers spontaneous visits. As Greg got to know Erin and Melissa more, he no longer wanted to visit them just to get boxes to decoupage, but to give them his decorated boxes as gifts. Pictures of Greg and the two employees were taken and Greg gave them a copy to hang on their walls at the stores. Although at this time Greg's connection to Erin and Melissa is casual, the Work n' Play store has become a place Greg feels a sense of belonging and both employees always have a smile (and a few boxes) waiting for Greg when he visits."



As this story illustrates, the connections for Greg were initiated around his artistic abilities and gift of generosity. Through the gentle exchange of his art and the shopkeeper's unneeded boxes, Greg has become a visible member of his community.

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Garage Sales and Community Connecting

"A garage sale at the house was organized during the summer (thanks to generous donations from family members and staff). It turned out to be a wonderful opportunity for Peter and his friends to interact with their neighbours, do some negotiating, and have fun together. They even had a small bake sale and offered complimentary cold drinks. It was festive, inviting and very 'neighbourly,' and has greatly improved the connection between all the neighbours – they now stop and chat or wave as they are passing by. Our focus during the yard sale was not on selling everything, but on meeting everyone. Investing in a little lemonade went a long ways towards this objective."

This story illustrates the informal ways in which neighbours can come together to build community.

Other Ways of Supporting Connections

Building relationships and engaging community requires many supporters. Cultivating connections is critical to sustaining this work. Some strategies that have helped to build networks of support include:

- Invite others to assist with the work. Call people, talk about what you are doing. Invite their participations and ask for their ideas and contacts.
- Become part of the associational life of a community. Become active, visible and make contributions as a way of learning about community and inviting reciprocity.
- Identify other groups who are engaged in this work and who value these ideas. Immigrants, new students on campus, social groups, and community building groups all have similar concerns and speak the same language and will be glad to find new colleagues.
- Follow up with contacts; relationships take time and energy.
- Find allies who will champion networking with you.



This is Hard Work and Heart Work: Challenges

Although supporting friendships and social connections is rarely challenged as a valued need for individuals with developmental disabilities, we know that we still have much work to do to meet this need. Some of the struggle emerges from fear about how best to initiate this work. Some challenges are a result of more subtle negative attitudes about the value or potential of this ideal for individuals. Addressing these challenges is essential or the vision and enthusiasm will flounder.

Some typical challenges include:

“This sounds so hard”

Stepping outside of traditional roles and job descriptions isn't for everybody. Choosing people for this work carefully is essential. The work can be lonely, is not routine and may occur outside of the standard pattern of shifts and schedules. But, supporting social connections can also be fun and is optimistic. It is about being in community and trying new things.

It is important to talk about discomfort, and whether or not this work is the right fit for someone. Talking about capacity and providing support to build confidence are essential but so is finding someone committed to the personal support networking role.

“This isn't my job”

The service system that surrounds individuals with developmental disabilities often creates limitations and isolation for them. It is equally limiting for those who work in it who may wish to step outside their prescribed role and tasks but aren't sure they have permission to do so. The service system is risk averse and built on protecting people. The world of relationships can be messy and seem risky. It is important to remember however, that dignity is expressed in the risks and rewards of living one's life in community.

“But I'm their friend”

The nature of support in our services is often about providing the most intimate of care to the individuals we serve. This level of contact can be confusing for those we serve who become used to only people paid to be in their lives around them. The nature of service can create a sense of proprietorship on the part of staff that become protective and connected to folks. The reality is however, that very few of these relationships extend to the level of real friendship. The truth is that we are friendly, and we care, but we seldom move to an authentic level of friendship with those we are in paid relationships with. It is necessary to create safe spaces for conversations about roles and expectations, in order to think through our futures together as staff and person supported, in a critical way.

“The person is too disabled”

The idea that disability is a defining quality which renders people unable to participate in relationships is a product of both the organization of services and the labels assigned to people which measure and isolate them. Further, this view of disability is connected to a deeper belief and comfort with a world divided into disabled and able bodied; into comfort with separateness and the limitations created by divisions. Being differently able does not preclude capacity for relationship. Actively practicing self-reflection to discover deeply held beliefs about difference and diversity is essential to succeed in this work and promote this vision.

The demonstration projects found, as did initiatives that preceded them, that all persons, no matter their degree of disability, can engage in growing and meaningful relationships. Self advocacy is about asserting your needs and wants and having your supporters listen and act with and for you. The more assertively people demanded a focus on relationships in their lives, the more likely they were to have these connections.

“Are personal support networks really just a way of reducing services?”

While it is our belief that money is not the primary resource needed to fulfill a desire for friendships and social connections, it is important to honour the anxiety and fear that this work can engender if it is perceived to be a way of reducing access to required services. Entangling conversations about money and services and the desire for a richer network of friends and social connections can occur however. They are separate issues and should not be confused or linked. The desire for relationships extends beyond our basic needs being met. It is about the heart’s survival.

“It’s lonely work. I cannot tell if I’m making a difference”

As mentioned earlier, a common lesson emerging from personal support networkers was the need to create intentional and regular support for those working in community building and social connecting. Various methods have been recommended including:

- Keeping journals
- Training events that inspire creativity and community building skills
- Regular meetings to discuss successes, strategies and challenges
- Coaching and mentoring
- Gathering resources to provide for inspiration, ideas and reflection
- Broadening the knowledge and understanding of everyone in the organization, circle or your family about what this work is. Maintaining open communication and celebrating accomplishments as well as acknowledging challenges have proven vital
- Host celebrations with people and groups. Notice the small steps and achievements along the way. Honour the work and the commitment

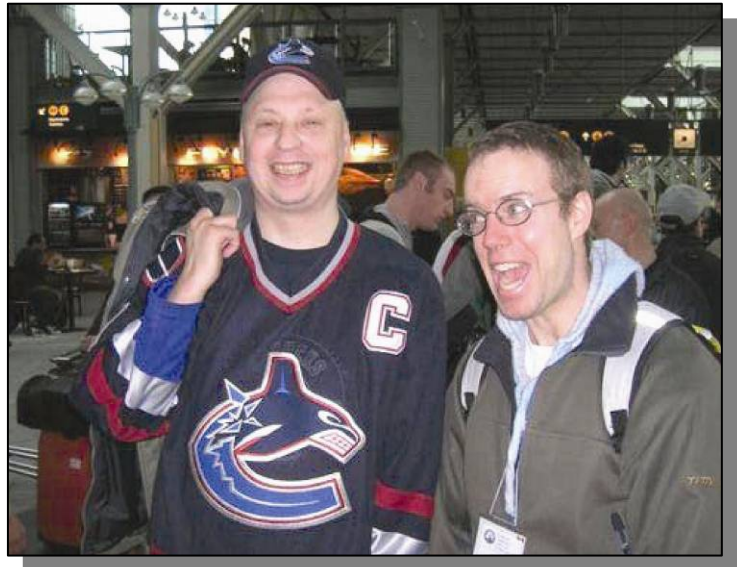
Support was found to be a critical element of sustaining this work and renewing the energy of those engaged in it. These ideas also serve to help define successes and help identify the changes and shifts in an individual’s life. These changes can include shifts like increases in social opportunities, more friends calling or dropping by, increases in community activities, and more contacts with neighbours and family. Knowing where you are going is enhanced by knowing where you started from.

Sustaining and Supporting this Work: Lessons from BC and elsewhere

In the various projects that have been initiated here in BC and elsewhere, certain themes are returned to again and again from those who engage in this work.

They include:

- The more we practice the art of hospitality, of asking, the greater confidence we develop to continue to take risks and explore opportunities.
- Knowing people intimately supports the process of cultivating belonging with them.
- This work takes time, takes courage and involves shedding historic service roles and learning about people across a variety of contexts and experiences.
- This work is guided by values, principles and the heart.
- Involves showing up in community over and over again to truly find membership.
- Requires that we suspend our judgements and expectations about what a person's network should look like or who their friends should be.
- Networks offer solace to families, and promise an end to isolation and offer practical social and moral support. Over time, families often feel a greater sense of security about the future as they experience the caring commitment of trusted others.
- There is no "right way"; there are only the ideas, experiences, successes and disappointments of the journey you've designed with the person and their supporters.
- Friendships exist along a continuum with many types, levels of intimacy and expressions. Friendships can be maintained via e-mail, phone and through letters, as well as in person.
- Relationships and social connections are not typically formed around extraordinary capabilities and attributes. Rather, they are celebrations of the magnificence of the ordinary, the everyday ebb and flow of just being.



What Can You Do?

If you believe, as we do, in the power, potential and necessity of personal supports, social connections, and relationships then you are ready to begin and participate in supporting this work. It could be as simple and as profound as opening yourself up to a relationship with someone. It could be that you begin talking about this at a staff meeting, with a family member or the individuals you serve.

Think in terms of taking one small step to supporting the ideas in this resource book. Define one thing you might do, within the next few days, that could make a difference. For example, buy an address book, call around and ask for a meeting about this topic, check out some of the resources listed below and bring it to someone who can help you champion this cause.

What is important is that the conversations begin.



Some Links to People and Resources who are thinking about Personal Support Networks

www.planinstitute.ca - Planned Lifetime Advocacy Network (PLAN) *Weaving the Ties That Bind*, an online training course for facilitating Social Support Network.

www.margaretwheatley.com - Dr. Meg Wheatley describes simple processes that can bring us together.

www.neighboursproject.org - An organization in Chicago working on reconnecting neighbours with tips on connecting.

www.101friends.ca - Created by Spectrum Society to support thinking about networking.

<http://syr.educ/rsapub.htm> - The work of John and Connie Lyle O'Brien who have been thinking and writing about this work for many years.

www.inclusion.com - Resources on community building and person-centred planning.

www.dimagine.com - David Pitonyak's site with a focus on relationships.

www.sesp.northwestern.edu/abcd - Asset Based Community Development, the work of John McKnight and colleagues.

www.johnlord.net - Offers information and links to John Lord's work, including how to purchase his new publication *Pathways to Inclusion: Building a New Story with People and Communities*.

www.communitylivingontario.ca - New publication called *Kirby's Lane: A well travelled path*, written by Charlotte Dingwall, that offers a collection of stories that deepens our conversations about relationships, services and community.



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