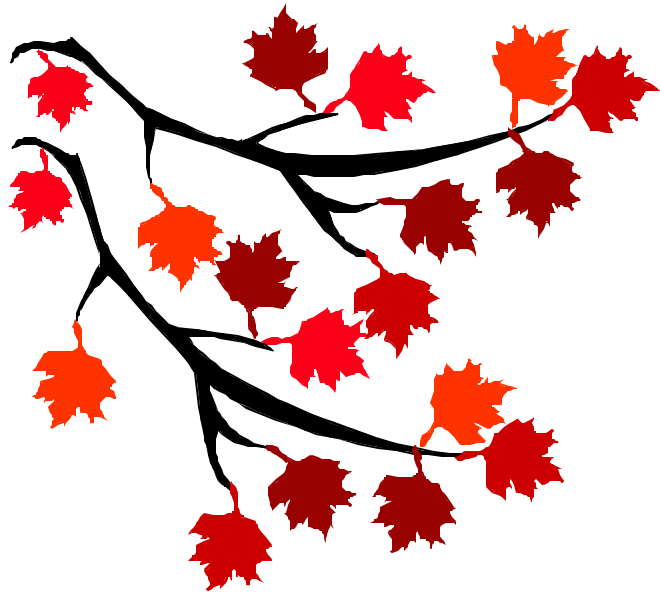

The Importance of Belonging

David Pitonyak



*To be rooted is perhaps the most
important and least recognized need of
the human soul.*

Simone Weil

i m a g i n e

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Pitonyak, D. (2002). *Toolbox for Change: Reclaiming Purpose, Joy, and Commitment in the Helping Profession*. Blacksburg, VA: Imagine.

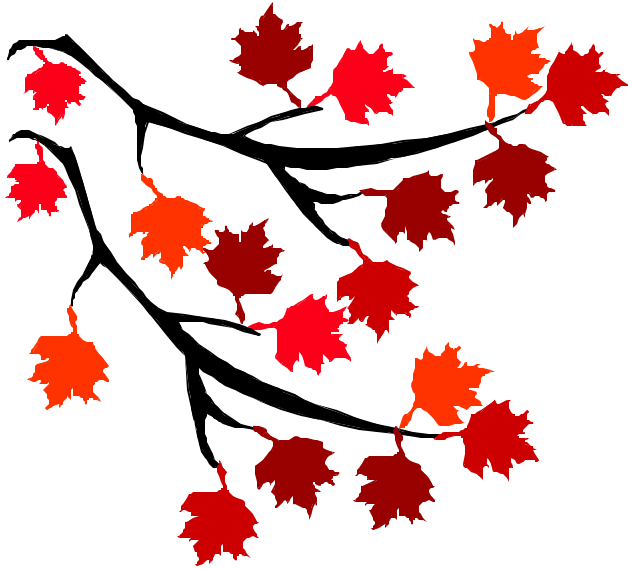
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Printing Suggestions

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We are all longing to go home to some place we have never been — a place, half-remembered, and half-envisioned we can only catch glimpses of from time to time. Community.

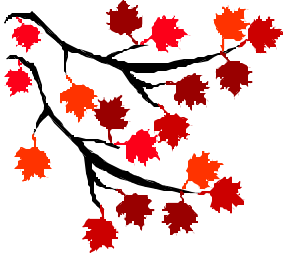
Somewhere, there are people to whom we can speak without having the words catch in our throats.

Somewhere a circle of hands will open to receive us, eyes will light up as we enter, voices will celebrate with us whenever we come into our own power.

Community means strength that joins our strength to do the work that needs to be done. Arms to hold us when we falter. A circle of healing. A circle of friends.

Someplace where we can be free.

- Starhawk



Introduction

Many people who experience disabilities live lives of extreme loneliness and isolation. Many depend almost exclusively on their families for companionship. Some have lost their connections to family, relying on people who are paid to be with them for their social support. Although paid staff can be friendly and supportive, they frequently change jobs or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone.

Bob Perske describes how a person whose life is devoid of meaningful relationships might feel:

"We have only begun to sense the tragic wounds that so many [persons with developmental disabilities] may feel when it dawns on them that the only people relating with them -- outside of relatives -- are paid to do so. If you or I came to such a sad realization about ourselves, it would rip at our souls to even talk about it. Chances are some of us

would cover it up with one noisy, awkward bluff after another. And chances are, some professionals seeing us act this way, would say we had "maladaptive behavior." Think about what it would feel like to have even one person come to us without pay, develop a reliable, long-term relationship with us because he or she wanted to... literally accept us as we are. Then think of the unspeakable feelings we might possess if -- when others were "talking down" to us and "putting us in our place" -- that kind person could be counted on to defend us and stick up for us as well! Most of us do have persons like that in our lives. But will the day come when [people with disabilities] have them too?" (1)

In my view, most people served by the human services industry are profoundly lonely. Loneliness is the central reason why so many are unhappy and distraught. It is not because our instructional strategies are ill-informed or because our planning processes are inadequate. It is not because our medications are in-potent or because staff are untrained. Their suffering results from isolation. As Willard Gaylin has written, "To be vulnerable is not to be in jeopardy. To be vulnerable and isolated is the matrix of disaster (2)."

The Wrong Questions

For years, the human services profession has been pre-occupied with three questions (3):

What's wrong with you?
How do we fix you?
What do we do with you if we can't fix you?

The central function of our human services system, in my view, should be to help people who experience disabilities to develop and maintain "enduring, freely chosen relationships" (4).

Why?

The Importance of Belonging (5)

"A sense of belonging," writes Dr. Kenneth Pelletier of the Stanford Center 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." (6)

In their 1996 book, *Mind/Body Health: The Effects of Attitudes, Emotions and Relationships*, researchers Brent Hafen, Keith Karren, Kathryn Frandsen, and N. Lee Smith describe the results of a nine-year study of 7,000 people living in Alameda County, California. "The people with many

Loneliness is the only real disability

I thought, for the longest time, that I had made this quote up on my own, and then someone said they heard it from Judith Snow first. I asked Judith if she had coined the phrase and she said, "I wish I had." Years later, someone in Georgia told me that Beth Mount had said it first so I wrote to Beth to see if they were right. She wrote back, "Use it and don't worry about making it mine--so much of what we all say and do has been borrowed from our network...don't worry about crediting me with that which we all know, the power of relationships to heal and make whole. " Looks to me like Beth deserves the nod.

social contacts – a spouse, a close-knit family, a network of friends, church, or other group affiliations – lived longer and had better health. People who were socially isolated had poorer health and died earlier. In fact, those who had few ties with other people died at rates two to five times higher than those with good social ties.” (7)

Hafren, Karren, Frandsen, & Smith write that “social support is the degree to which a person’s basic social needs are met through interaction with other people. It’s the resources – both tangible and intangible – that other people provide. It’s a person’s perception that he or she can count on other people for help with a problem or for help in a time of crisis.” (8)

Although the reasons why social support leads to better health are not entirely understood (one theory is that belonging improves immune function), the implications are profound for people who experience our services. It may be that a great deal of what we see as pathology (e.g., poor health, mental health issues, problem behaviors, etc.), is, in fact, a symptom of loneliness.

Sidney Cobb, president of the Society of Psychosomatic Medicine, argues that the data supporting a link between

loneliness and illness is overwhelming – that “social support can indeed protect people in crisis from what he calls a ‘wide variety’ of diseases. Adequate social support, Cobb says, has been proven to protect against conditions from ‘low birth weight to death, through tuberculosis to depression, alcoholism, and other psychiatric illness. Furthermore, social support can reduce the amount of medication required, accelerate recovery, and facilitate compliance with prescribed regimens.” People who are suffering from a break down in social support are also more prone to cancer, hypertension, and heart disease (9).

It’s true — you can die from a broken heart.

Better Questions

The field is now moving toward a much more promising set of questions than *What’s wrong with you? How do we fix you? And What do we do with you if we can’t fix you?* Processes such as person-centered planning pose a deeper more illuminating set of questions (10):

What are your capacities and gifts and what supports do you need to express them?

What works well for you and what does not?

What are your visions and dreams of a brighter future and who

will help you to move toward that future?

In addition to these questions, I like those posed by Mary Romer. Mary's questions strike me as fundamental to anyone's success (11):

Are enough people engaged in the person's life?

Are there people who are imbued with the belief and hope for a brighter, better future for the person?

If not, how might such people be found or how might that sense of hope be instilled in those committed to walking with the person?

Ask, "Am I lonely?"

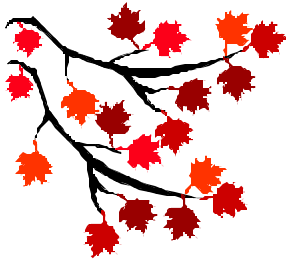
Loneliness affects all kinds of people. Tall and short, rich and poor, black, white, yellow, Republican, Democrat, Catholic, Jew — you name it, loneliness knows no bounds. There are broken hearts everywhere.

The awareness that many people who experience disabilities may be lonely necessitates an awareness that the people who are supposed to help may be lonely too. In order to support the development of relationships for other people, we must examine our own sense of connectedness. Ask yourself, How do I stay in contact with my family? How do my visits home feel? Who are my friends? Who is my partner? Do I see them often

enough? What do I contribute to these relationships? What do I know about relationships and how can I use this knowledge to support the person?

It is also important to examine your relationships with the person's supporters. How well do you know them? How often do you provide them with positive feedback about their contributions? How often do you ask them what they need? And how often do you listen?

You can also ask these and other questions of the general culture surrounding the person. Do people know each other? How often do they support each other? Does anyone listen to what the people who know the person best have to say? If you are involved in the service delivery system, you can ask "Does the organization treat staff in a valued way?" Do staff feel that their superiors are personally concerned with their well-being and that their needs will be attended to? If it is a family home, you might consider the supports available to the entire family? Are the relationships supportive or contentious? It almost goes without saying that an organization of supported and involved caregivers is key if the goal of the organization is to support "belonging." To paraphrase Jean Clark, "A person's needs are best met by people whose needs are met."



Wake up to the people right next to you.

I BELIEVE THAT ONE OF THE MOST fundamental reasons why professionals have lost touch with the importance of relationships in the lives of the people they serve is that they have lost touch with the importance of relationships in their own lives.

A solid resource for understanding why relationships are important and how they are formed can be found by examining our own relationships. We are brothers and sisters, sons and daughters, nieces and nephews, Moms and Dads, lovers and partners, etc. We already know a great deal about *how* to be connected.

Things You Can Do

- ◆ Go home right now and hug your sweetheart like you used to (when her/his hands were too hot to touch). Make a regular date with your partner to spend time with each other (alone). It doesn't have to be complicated. Get Chinese takeout and rent a movie together.

- ◆ Spend time playing with your children. Put aside your worries and To Do lists. Make joy a goal.
- ◆ Go visit your Mom and Dad. Share with them stories of good things they did for you when you were a little boy or little girl. Look through old photographs. Tell stories.
- ◆ Contact your siblings. Make a plan to get together somewhere fun to "reconnect."
- ◆ Call a friend you have lost touch with over the years. You both need to hear from one another.

IT IS ALSO TRUE that people offering support as professionals often do not know each other. Consider how well you know your fellow workers. Do you know how it is that they have come to this work?

It is often the case that we do not know each other in any meaningful sense. And, having failed to know one another deeply, we then try to come together and solve complex human problems. It makes no sense.

Things You Can Do

- ◆ Find regular time to pause and reflect with your fellow employees.
- ◆ Explore questions such as these, adapted from Margaret Wheatley's (2002) *Turning to*

one another.

*How did I come to this work?
Do I feel that my vocation is truly right for me?
What is my faith in the future?
What do I believe about others?
What am I willing to notice in my world?
When have I experienced good listening?
Am I willing to reclaim time to think?
What is the relationship I want with the earth?
What is my unique contribution to the whole?
When have I experienced working for the common good?
When have I experienced the sacred?*

Make Friends With Yourself

Finally, consider making friends with yourself. Many of us have become our own worst enemy. We are taking on the needs of others and forgetting our own needs, running ourselves down again and again for what we have not done rather than what we have done.

Ask yourself, "Do I treat myself as well as I would treat a guest in my house?" The answer, sadly, for many of us, is "No." We are far more generous with others than we are with our own selves.

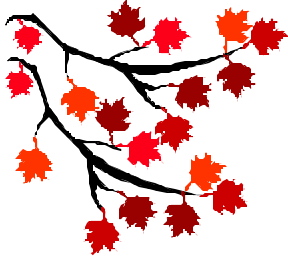
In North America (and I suspect elsewhere), we are obsessed with self-improvement strategies —

things to help us *be* better. I like what the Buddhist nun, Pema Chodron says. She says that "every act of self-improvement is an act of aggression towards the self." The basic idea of self-improvement, after all, is that once you improve, then you will be lovable.

For many of us, the practice of running ourselves down is like an overly-developed muscle. We do it so easily, we don't realize we have done it. Running ourselves down has become a way of life. The encouragement, in such cases, is to "lighten up." Instead of trying to change your habit of "self-injury," just notice it. Be curious about it without trying to change it into anything at all. Invite it in for tea.

Things You Can Do

- ◆ Make a list of those things that bring you joy, those things you never seem to have time for anymore. Grant yourself permission to enjoy yourself. Lighten up. The suffering of others will be waiting for you when you return
- ◆ Read Pema Chodron's *The Wisdom of No Escape And The Path of Loving Kindness*. A most practical book for people in the helping profession.



Learn about person-centered planning

In the book, *A Little Book About Person-Centered Planning*, Connie Lyle O'Brien, John O'Brien, and Beth Mount describe the powerful differences between traditional approaches and person-centered planning. Unlike traditional approaches to planning, which ask questions like, "What's wrong with you?" and "How can we *fix* you?", person-centered planning focuses on questions like "What are your capacities and gifts and what supports do you need to express them?" and "What works well for you and what does not?" and "What are your visions and dreams of a brighter future and who will help you move toward that future?"

Describing the roots of person-centered planning Lyle O'Brien, O'Brien, and Mount write (1998):

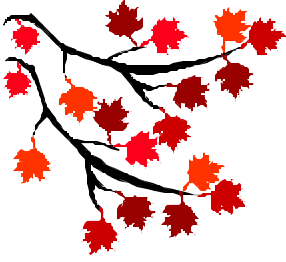
"Person-centered planning did not ignore disability, it simply shifted the emphasis to a search for capacity in the person, among the person's friends and family, in the

community, and among service workers. A person's difficulties were not relevant to the process until how the person wanted to live was clear. Then it was necessary to imagine, and take steps to implement, creative answers to this key question, "What particular assistance do you need because of your specific limitations (not labels) in order to pursue the life that we have envisioned together."

For additional information:

- ☺ Visit my web site: www.dimagine.com
- ☺ Click on "Links and Other Resources"
- ☺ There you will find links to web sites and information about a variety of topics, including:

- Advocacy
- Assistive Technology
- Books Worth a Look
- Communication Rights
- Emergency Preparedness
- Employment
- Family Support
- History of Disability
- Housing
- Inclusion
- International Support and Resources
- Medicine, Health and Well-Being
- Microboards
- Music
- Person-Centered Planning
- Policy Links
- Post Traumatic Stress Disorder
- Relationships
- Self-Determination
- Spirituality
- State-by-State Resources
- Storytelling
- Videos



Promote the “medicine” of inclusion

In my workshops about positive approaches, I often begin by asking participants to describe the kinds of behaviors that they find most troubling from the people they support (*). I make a list of the behaviors of concern on large pieces of paper. Some of the behaviors are serious, others are not so serious. For example, a list might include:

hitting other people, rectal digging, breaking windows, lying, running away, eye poking, nose picking, fantasizing about Demi Moore, saying the same thing over and over again, sleeping during the day, depression, peeing on the lawn furniture, screaming, stealing food from the refrigerator, and jumping into traffic.

In my workshops about organizational development,

Toolbox for Change, I often begin the day by asking managers to describe the kinds of employee behaviors that they find most troubling in the workplace. Again, I make a list of the behaviors on large pieces of paper. Examples of the kinds of behaviors people list as problematic in the workplace:

talking behind people’s backs, spreading rumors, failure to perform job duties, depression, jealousy, acting ruthlessly to get ahead, stealing, lying, refusal to accept responsibility for mistakes, complaining after a meeting is over, acting bossy, acting self-important, denial, and spending too much time at the water cooler.

After I have asked people to make a list of the behaviors they find most troubling in an individual they serve or a fellow human services worker, I ask them to think about a time in their lives in which they felt “included,” “welcome,” “a part of.” To assist them in the process, I ask them to remember a family reunion they attended, or a party held in their honor. Most people can remember a time when they were included in something big or honored for their very presence. I ask, “What did it *feel* like to be included?” Typical responses

I am thankful to Jennifer York from the University of Minnesota for teaching me this exercise in 1991 at a supported employment conference in Ellensburg, Washington.

include:

happy, satisfied, warm, popular, powerful, confident, special, secure, needed, loved, rooted, important, content, fulfilled, joyful, pleasant, embraced, involved, welcome, valued, loved, supported, comfortable, like I can be myself, I don't have to impress anyone, accepted, not being judged, part of, admired, etc.

Next, I ask people to remember a time in which they felt “excluded,” “left out,” “not welcome.” It is amazing how quickly people are ready to describe their *feelings* of rejection. Examples of the kinds of responses I hear:

dejected, unimportant, aggressive, depressed, alienated, awkward, mean, angry, alone, empty, suicidal, insecure, sad, suspicious, not motivated, suspected, invisible, rejected, frustrated, lonely, attitude, resentful, in a lot of pain, ignored, trying, worthless, spiteful, inferior, politically incorrect, hateful, paranoid, ostracized, blackballed, like I should disappear, like I have faded into the background, criticized, laughed at, conspicuous, like I want to get away, like I'm shrinking,

like I want to become someone else, etc.

When I ask the group to describe how a person might *act* if excluded, the participants invariably begin to create an updated version of the first list (the list of difficult behaviors). Examples of the kinds of responses I hear:

aggressive, angry, manic, insane, frantic, irrational, psychotic, indifferent, withdrawn, uncontrollable, "out," tearful, impatient, ineffective, unaffected, bitter, depressed, defensive, silly -- trying to get attention, confused, hostile, petty, sleepy, resentful, violent, pretentious, snotty, mistrustful, act out so that I repulse people so they wouldn't pursue a relationship with me, I would try to impress people, to brag, to boast about myself to try and boost my status, I might smoke or drink to look like a rebel so that I look cool, etc.

Often, even before I have had a chance to complete a list of ways that someone might act if excluded, a participant shouts out, “It’s the first list!”

For me, there are at least three important points to garner from the exercise:

1. Most (not all) difficult behaviors result from being excluded. It is not a person's disability that leads him or her to do things that others find objectionable. It is being on the outside of what is in.
2. Most of our consequence-based strategies reinforce the feelings listed under "what it feels like to be excluded." When people's behaviors get worse (and they often do), more, not less, is done to make the person feel excluded.
3. What's the medicine for someone who feels excluded? To be included, of course!

To conclude the exercise, I ask the participants to break into small groups. I ask them to develop a list of things they can do "the next day" to build "inclusive environments."

Why is this exercise important for people who want to help others to broaden and expand their relationships? First, the exercise helps people to understand that problem behaviors are often symptomatic of being left out. Once recognized, people become more motivated to help people broaden and expand their relationships. Second, many staff are afraid to help people get connected because they are afraid of how the person might behave "in the community." While this is an understandable feeling, it is important to understand that being

disconnected — being lonely — is the problem. And being connected — being included — is the medicine. Third, it helps staff to connect with their own broken



It isn't enough
for your heart to
break, because
everybody's
heart is broken
now.

- Allen Ginsberg

places, their own feelings of exclusion. It also helps them to connect with their personal need to be connected. Being included is the medicine they need too.

Part One

Make a list of the things you want the person to stop doing.

(Avoid jargon; describe the behavior with words my grandmother would understand).

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

Part Two

Ask, "What does it feel like to be included?"

The exercise described in this section was first described to me by Jennifer York. I am indebted to Jennifer for showing me a process that so eloquently makes the point that *not belonging* is a major cause of difficult behaviors.

Part Three

What does it feel like to be excluded?

Part Four

How might a person who has been excluded act. What might they do in response to their exclusion?

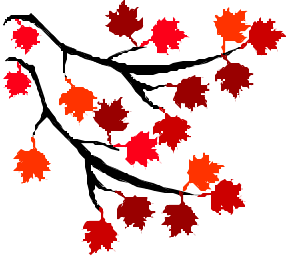
The exercise described in this section was first described to me by Jennifer York. I am indebted to Jennifer for showing me a process that so eloquently makes the point that *not belonging* is a major cause of difficult behaviors.

Part Five

Creating inclusive environments

Do you think the person might feel, from day to day, any feelings of exclusion? If so, pick 5 feelings from the inclusion list above. Beside each feeling, list 5 things you can do to help the person to experience each feeling

<i>When included, I/we <u>feel</u>:</i>	Five things I/we can do to help the person experience this feeling:
	1. 2. 3. 4. 5.
	1. 2. 3. 4. 5.
	1. 2. 3. 4. 5.
	1. 2. 3. 4. 5.
	1. 2. 3. 4. 5.
	Note: the proactive steps you will undertake to help the person feel included can be included as "prevention steps" in the person's support plan



Become the person's champion

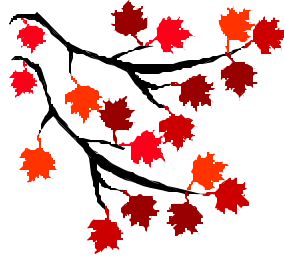
We all need someone who thinks we are special, someone who thinks we “hung the moon.” Often, how we think of ourselves is shaped by how others see us.

Many people who challenge us are seen only for their “limitations” or “problem behaviors.”

Helping a person to grow means that we must take responsibility for “seeing” the person's gifts and potential.

Become the person's champion. Make a commitment to help the person to find joy each day. Help others to see the person's strengths and gifts rather than limitations and shortcomings. Instead of being one more person who “works on” the person, be someone who “works with” the person. Speak about the person's struggles in a way that is respectful of those struggles. Let the person overhear you saying good things about him/her. If you can't be the person's champion, take responsibility for helping the person

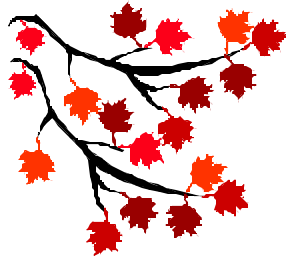
to find a champion. It's powerful medicine.



Remember that a crisis can be a great opportunity to form a meaningful relationship with someone.

A crisis can be an *opportunity* to teach a person the importance of relationships (12). The Outward Bound program is based on this idea. For example, counselors might take a group of “hardened” kids out into the wilderness. On the bus ride, the kids sit in the back, full of attitude and cool. The adults sit in the front of the bus, discussing logistics and responsibilities. When they arrive in the wilderness, the adults tell the kids that they are going to climb down a 100 foot rock face, and suddenly the kids who seemed full of attitude and cool change their

physical proximity to the adults (they get closer). They let everyone know that they are not so confident anymore. In essence, the adults have created a “crisis.” The goal of this crisis is to show the kids that the adults can be helpful. They can help them to overcome their fear of heights, help them to master new skills (e.g., using a harness, tying knots, repelling). And one by one, the kids step over the edge of the cliff and make their way safely to the bottom. Not surprisingly, once they unhitch themselves from their harnesses, they cop the same attitude they had at the outset. But something is different now. Through this crisis, the kids have learned that the adults will support them through during a crisis and help them to develop mastery over needed skills. Additionally, they now share a *story*.



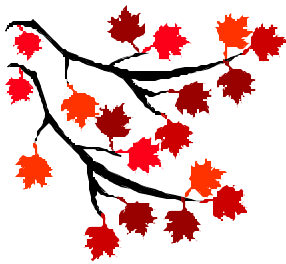
Keep your promises.

Many people who engage in difficult behaviors have too much experience with *broken* promises. Life has been full of tricksters -- people who say one thing and mean another. For example, Carl was told that he would be able to live in his own apartment if he improved his behavior. But the truth is much more complex. The funding streams which pay for the group home will not pay for an apartment. In the *real* world, Carl lives in the group setting because people are unwilling to deal with the “politics” the organization, funding streams and State regulations. In short, people don’t want to deal with the *real* problems, so they make Carl *the* problem.

Teach the person that your word is good by following through on your promises. Give the person a chance to learn that you are trustworthy, but don’t be surprised if the person is reluctant to trust you at first. It can take time for a heart that has been betrayed to

open up one more time.

And remember, in the real world there will be times when you can't keep your promise (for reasons beyond your control); life happens. But it will almost certainly be easier for the person to accept the change in plans if, on balance, you keep your promises.



Never underestimate the corrosive impact of our system on a person's capacity to develop and maintain relationships

An organization that actively supports the development of relationships for the people it serves does more than provide in-service training and workshops on the ins and outs of community building. It takes seriously the "architecture" of its services, supports, and decision-making. For

example, consider the contrasts between person-centered and system-centered approaches offered by David Korten on the next page.

Managers and policy makers must consider a variety of structural changes. I like those suggested by John O'Brien and Connie Lyle-O'Brien in their book *Members of Each Other: Building Community in Company With People With Developmental Disabilities*.

First, simple changes staff could embrace that "would create more room for relationships" and support community membership (13):

1. If they stopped acting as if they owned the people they serve and could arbitrarily terminate their contacts or disrupt their memberships.
2. If they modified schedules and tasks to accommodate people's relationships and memberships.
3. If they recognized and encouraged activities and contacts outside of their programs.
4. If they looked for the flexibility to assist with some of the ideas and plans that emerge from new relationships and memberships.

Second, policy makers "who want to be of genuine assistance, would follow these six directions" (14):

1. Increase the amount of personal assistance (attendant and family

A comparison of system-centered and person-centered approaches

System-Centered	Person-Centered
Production and efficiency are the most important outcomes.	Quality of life is the most important outcome.
Subordinates the needs of people to the maintenance of bureaucracy.	Subordinates needs of service system to the needs and interests of people.
People are seen as objects to be processed by the system.	People are critical actors with deep desires who shape their own future.
People's interests are often ignored, sometimes exploited.	Human growth and dignity in the process of change is critical.
Control for decisions is allocated to professionals who know best.	Control for decisions is placed in the hands of the people.
Complex regulations and procedures sustain professional interests.	Quality of support depends on good information and creativity.
Detachment is the preferred stance with people.	Workers develop personal relationships with people.
Workers rely on legal charters, formal authority, and control structures to motivate action.	Workers rely on family, neighborhood, church, and associations to provide social support and stability.
Resources are allocated to increase the holdings of services and the benefits of professionals.	Resources are invested in supports that help people be more effective at meeting needs for themselves.
Offers the promise of perfection at the expense of the diversity of the people and the workers.	Offers the richness of imperfection at the expense of order and control.

The above table is adapted from work by David Korten, as printed in Beth Mount et al.'s *Imperfect Change: Embracing the Tensions of Person-Centered Work*. Manchester: CT: Communitas Communications. For this publication and other fine Communitas publications, write: Communitas, Inc., P.O. Box 374, Manchester, CT 06040 (203-645-6976. Printed with permission.

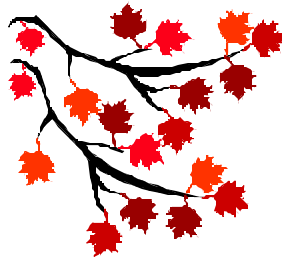
support) services available to people based on individual need by reallocating all funds that now support various forms of congregate long term care. Make personal assistance services more flexible by putting them under the direct control of the person who uses them, or, if the person is a child, under control of the child's family. Demedicalize personal assistance services.

2. Insure that people with severe disabilities have an adequate cash income and adequate health insurance. Eliminate benefits traps that prevent people who want to work from doing so. Eliminate stigmatizing practices.
3. Support individual or cooperative home ownership for adults with severe disabilities. Break programmatic links that tie people who need a particular type or amount of support to an agency owned building.
4. Offer a wide variety of supports for individual employment in good jobs of people's choice.
5. Insure that local schools fully include students with severe disabilities.
6. Invest in safe and accessible transportation.

Finally, a word about turn-over. Many people who experience our services have been traumatized by a fundamental break-down in their relationships that often has persisted for years. Our service

system's failure to help people find reliable paid-relationships is re-traumatizing people. It is incumbent upon professionals to find ways to help people to find personal assistants who not only provide a high quality of care but also stay.

My friend Al Vechionne of Vermont says that the goal of a support system should be to "lavishly recruit" and then, when the right person is found, to find ways to make the right person "feel guilty about the deal."



Hold the person's story in a way you would want your own story held

Who holds your story? My bet is that someone, somewhere, remembers you when you were knee high to a grasshopper. Someone remembers the day you lost your first tooth, or the day you swam to the raft in swimming lessons, your first date, your newborn. Someone probably knows about that hole in your heart or

that reason you fear change. I hope someone, somewhere, holds your story.

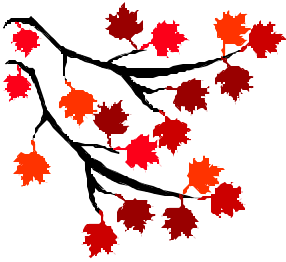
The problem for many people who experience our services is that no one holds their stories. We know them by their labels or brief social histories (e.g., “mother experienced complications in pregnancy...child was institutionalized at fourteen...home visits became less frequent in 1977...” etc.), but we know nothing, really, about their stories – where they came from, the names of their family members and long-lost friends. We know little of the events that shaped their lives, the achievements and disappointments that gave shape to their sense of self, where they feel connected and where they feel cut off. Thanks to processes such as person-centered planning, we are learning to ask different questions, questions that invite a story to be told. Instead of, “What’s wrong with you?” and “How do we fix you?” we’re learning to ask “Who are you?” and “What do you dream of?” and “How can we help you to move towards a desirable future?”

The rich details that make stories worth telling and retelling are emerging. But for most people served by our system, the preoccupation with deficits and limitations is still pronounced. We not only don’t know people’s stories. We don’t even notice that

their stories are missing

Things You Can Do

- ◆ A simple thing to do is to draw a horizontal line on a big piece of paper. On the left hand side of the line, write down the day and year the person was born. On the right hand side of the line, write today’s date. Now try to fill in this time line with as many major or significant events you can think of. What do you see? My bet is that there are gaps, spaces of time in which you know very little about the person. My bet is that most of what you know about the person falls in the recent past. A big part of the work, in my view, is to help people to reclaim their lost stories and to make sure those stories are told in a way that is respectful and meaningful.
- ◆ Sit down with the person, friends and family and look through old photographs. Photographs can dislodge forgotten memories and help people to remember important stories.
- ◆ Help the person to develop a written narration of his/her life. Use photographs to help tell the story and, if the person grants you permission, use the narration whenever new caregivers are hired.



Help the person to connect with people in the broader community who love the same things.

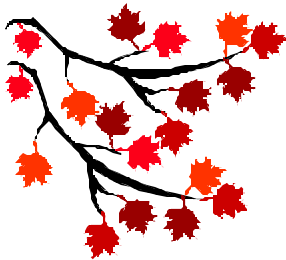
Many our friendships are forged because we share a common interest with another person. For example, my friend Rollin loves engines that roar. He has met many of his friends because he showed up, again and again, in places where people who love engines were gathering (e.g., stock car races, a truck repair shop, a dairy farm, a wood lot with a gas-powered wood splitter). Patty loves trains. She has made friends with the curator of a train museum in the city where she lives. She also loves coffee and she spends time in a nearby Starbuck's where people not only know her favorite coffee drink, they also know she takes longer than most customers to order and pay for her drink. They accommodate her need for

more time by telling her not to hurry. Dennis is a man who was once described as "obsessed with drinking cups." He now belongs to a cup-collectors group that meets regularly and holds international conferences.

Things You Can Do

- ◆ Make a list of the things a person loves with the person. Ask, "Who in the broader community loves the same things? With the person's OK, show up again and again. Make fun the goal (don't spoil a perfectly good time with an habilitation goal).
- ◆ Pay special attention to *who* goes with the person. First, the person should choose who he or she gets support from. The person providing support should ideally love the same activity. For example, Patty has more fun at Starbuck's when Clara, her support person, joins her. Clara is not bossy or over-bearing. And, better yet, she loves coffee the way Patty loves coffee (she cannot believe the organization is paying her to get a "buzz on" with Patty).
- ◆ It is sometimes difficult to know what a person likes to do because he or she has no formal means of communication. One place to start is to ask people who know the person best for ideas. If that fails (sometimes,

due to high turnover, no one in the person's life have any idea what he or she likes. A first step might be to invite the person to join you in doing things you love. Herb Lovett encouraged me to make "respectful guesses" when I was unsure. All I had to do was be willing to change if the person communicated to me that my guess was not working.



Help the person to make a contribution to the broader community.

Probably the least difference between a person who experiences disabilities and her non-disabled peers occurs on the day that she is born. But then, because we begin to systematically separate the child into increasing different experiences, he or she becomes more different with every passing day.

Whether it's early intervention services or special education or the adult service world, the person is increasingly cast in the role of the "needy" one. After years and years of being surrounded by people who ask, *What's wrong with you? How do we fix you?* and *What do we do with you if we can't fix you?* it should surprise no one that some people grow up "needy." I am not suggesting that the person is incapable of supporting the needs of other, capable of being needed. Nothing could be further from the truth. What I am arguing is that understanding and respecting the needs of others is learned through years of practice, practice many people who experience our service system never get.

Why is this important?

As John O'Brien once said, "It is dispiriting to always be the needy one." Our souls are deprived of the chance to make a difference to others.

One of the reasons why so many people who experience our services are so unhappy is that they are never welcome in places where their gifts are noticed or valued. When they show up in relationships, they often lack imagination about how to be a friend, or sister, or daughter, or fellow citizen. Sadly, many people have learned that the only way to be "seen" is to be needy. For this reason, many of their relationships

The importance of authentic presence

Many professionals *do* take the time to get to know the people they are supporting. But some do not. For them, 'professionalism' is a kind of armor against the uncertainties and insecurities of getting involved. When you get involved with someone, there is the risk that you will not know what to do, or that their behaviors will cause embarrassment or even be hurtful. But taking the time to get to know someone also offers the opportunity for great discoveries. I always find that I learn something important about myself when I work through my apprehension and make a commitment to know someone and let them affect me.

Here's what John Welwood says in his book, *Awakening the heart: East/West approaches to psychotherapy and the healing relationship*:

"...I have found that I most enjoy my work and am most helpful to others when I let them affect me. This does not mean that I should identify with their problems or get caught up in their neuroses. There are ways that clients try to draw the therapist into their world in a manipulative way which should, in fact, be resisted. Yet the therapist can still leave himself open to seeing what that pull or manipulation feels like, for this will provide essential clues to guide him in responding more helpfully to the person. What I am speaking of here is not losing my boundaries, but letting myself experience what the other person's reality feels like.

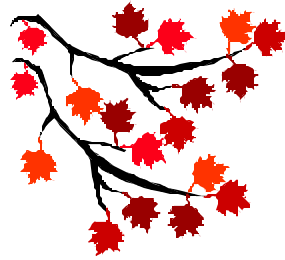
"If I can hear another person's words, not from a place of clinical distance, but as they touch me and resonate inside me, then I can bring a fully alive, human presence to bear on the other's experience, which is much more likely to create an environment in which healing can occur. Many other factors also determine the outcome of therapy, but without this kind of authentic presence on the part of the therapist, real change is unlikely to occur. Authentic presence is sparked in therapists when they let themselves be touched by the client, when they can really feel what it is like to be in the client's world so they can respond from a place of true empathy and compassion. (p. xi).

Welwood, J. (1985). *Awakening the heart: East/west approaches to psychotherapy and the healing relationship*. Boston: Shambhala.

fail because the relationship is a proverbial “one way street.”

Things You Can Do

- ◆ With the person, make a list of the most important people in his/her life. Describe each person’s relationship to the person (e.g., friend, sister, brother, mother, dad, etc.). Ask a group of people to join you both for a meeting (make it fun with lots of good deserts). Ask the group to help you think about what it takes to be a good friend, daughter, sister, brother, etc. With the person, choose ideas from the “what it takes” list that will help him/her to be a good _____ (fill in the blank). Develop a simple plan with the person to follow-through.
- ◆ Draw a circle one mile in radius around the person’s home. Dozens, perhaps hundreds, of people are probably doing things to build a stronger community each and every day. Help the person to show up in those places to help with those causes that he or she feels devotion towards. Show up again and again and help do what needs doing (in other words, don’t turn the person into the “project” help the person, if he or she needs your help, to work on the project.



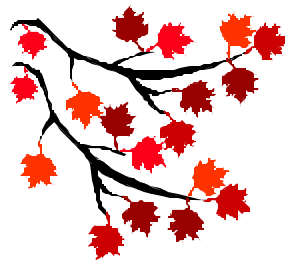
If the person continues to struggle, troubleshoot.

If the person continues to struggle with relationships, ask these questions from Linda J. Stengle’s book, *Laying Community Foundations for Your Child With A Disability* (1996):

1. Is the relationship between the person and the other person unbalanced?
2. Are there too few mutual interests?
3. Is this an activity that the person really wants to do, or is it something you want him/her to do?
4. Is the activity long enough to encourage the development of a relationship?
5. Is the other person afraid to get

- close to the person?
6. Is the other person too busy to take time to get to know the person?
 7. Are needed accommodations being made to allow the person to participate fully in the activity?
 8. Could your presence be interfering with the development of friendships?
 9. Do the same people tend to participate, or are there different people every time?
 10. Are there breaks, joint projects, or committees which allow people to talk with each other freely?
 11. Is the other person in the relationship mainly out of a sense of charity?
 12. Is there enough structure to the activity?
 13. Is the person projecting an attitude that is keeping others away?
 14. Do you think that something is preventing the other person from seeing and appreciating the person's good qualities?

Stengle, Linda J. (1996). *Laying community foundations for your child with a disability: How to establish relationships that will support your child after you are gone*. Bethesda, MD: Woodbine House.



A final note... When people are “relationship resistant”

Many people who experience our services have been traumatized at one point or another in their lives. Trauma can cause predictable changes in the way a person feels and experiences his/her surroundings. These changes can, in turn, result in the person becoming “relationship resistant.” The good news is that people can heal from traumatic experiences and learn the value of relationships, but they need help to do so. I have described the effects of trauma and what survivors of trauma need in my handout, *Supporting A Person With Post-Traumatic Stress Disorder*. The handout is available at my web site: www.dimage.com. Click on “Articles and Publications.” Scroll down to the article and follow the on-screen instructions.



**Margaret Wheatley's "What I believe..." from
*Turning to One Another: Simple Conversations to
Restore Hope to the Future***

People are the solution to the problems that confront us. Technology is not the solution, although it can help. We are the solution -- we as generous, open-hearted people who want to use our creativity and caring on behalf of other human beings and all life.

Relationships are all there is. Everything in the universe only exists because it is in relationship to everything else. Nothing exists in isolation. We have to stop pretending we are individuals who can go it alone.

We humans want to be together. We only isolate ourselves when we're hurt by others, but alone is not our natural state. Today, we live in an unnatural state -- separating ourselves rather than being together.

We become hopeful when somebody tells the truth. I don't know why this is, but I experience it often.

Truly connecting with another human gives us joy. The circumstances that create this connection don't matter. Even those who work side by side in the worst natural disaster or crisis recall that experience as memorable. They are surprised to feel joy in the midst of tragedy, but they always do.

We have to slow down. Nothing will change for the better until we do. We need time to think, to learn, to get to know each other. We are losing these great human capacities in the speed-up of modern life, and it is killing us.

The cure for despair is not hope. It is discovering what we want to do about something we care about.

Wheatley, M. (2002). *Turning to one another: Simple conversations to restore hope to the future* (p. 19). San Francisco: Berrett-Koehler Publications, Inc.



Recommended Reading

NOTE: Many of the books and publications, unless otherwise noted, can be obtained at your local bookstore or through one of the many online outlets such as Powells.com, Half.com, or Amazon.com

Larry Brendtro, Martin Brokenleg, and Steve Van Bokern

Larry Brendtro, Martin Brokenleg, and Steve Van Bokern's book *Reclaiming Youth At Risk* is a fabulous primer for people who care about helping adolescents. Based on conversations with native American elders, this book is a clear and concise description of why so many youth are struggling from a lack of belonging, and what our communities can do about it.

You can order the book by sending \$21.95 to National Education Service, 1610 W. Third Street, P.O. Box 8, Bloomington, ID 47402. Be sure to include your name, organization, address and phone number

Barbara Buswell, C. Beth Schaffner and Alison Seyler

Opening Doors: Connecting Students to Curriculum, Classmates, and Learning (1999) is a helpful resource for anyone who wants to help kids to make friends and find success in their neighborhood schools. You can order the guide from The Peak Parent Center, Inc., 611 N. Weber, Suite 200, Colorado Springs, Colorado 80903. Call for a catalogue of available publications 1-800-284-0251.

Pema Chodron

Pema Chodron is an American Buddhist nun and resident teacher at Gampo Abbey, Cape Breton, Nova Scotia, the first Tibetan monastery in North America established for Westerners. Her books are remarkable for their clarity and common sense. A must, I think, for anyone who wants to bring relief to the people who suffer in the world (and anyone who wants to make friends with self).

Chodron, P. (1991). *The Wisdom of No Escape And The Path of Loving-Kindness*. Boston: Shambhala.

Pema Chodron's books are available in many bookstores (usually in the Eastern Philosophy/Tibetan Buddhism section). You can find a complete listing at shambhala.com.

Mary Ellen Copeland

Mary Ellen Copeland has written an extremely helpful book for "developing and maintaining lasting connections." While not disability-specific, *The Loneliness Workbook* can be a valuable tool for those who support people who are lonely, or for people who are themselves lonely.

Douglas Fisher, Caren Sax and Ian Pumpian

As kids get older, it can get tougher to help them to make connections, particularly in the middle and high school years. *Inclusive High Schools* (1999) provides lots of helpful information to folks who want to make inclusion real for students entering what may be the last years of their school careers. You can order the book from The Peak Parent Center, Inc., 611 N. Weber, Suite 200, Colorado Springs, Colorado 80903. Call for a catalogue of available publications 1-800-284-0251.

Sharon Getz and Dianna Ploof

Sharon Getz and Dianna Ploof have assembled a wonderful collection of stories about relationships and community from the newsletter, *The Common Thread*.

Getz, S. & Ploof, D. (1999). *The Common Thread: A collection of writings about friendships, relationships, and community life*. Harrisburg, PA: Pennsylvania Developmental Disabilities Council.

Copies can be obtained through the PA DD Council, Room 559 Forum Building, Commonwealth Avenue, Harrisburg, PA 17120. Toll free 1-877-685-4452.

Mike Green, Henry Moore and John O'Brien

A helpful resource for anyone hoping to connect folks who experience disabilities to the larger community. From the forward by John McKnight: "Citizens are, of course, the producers of democracy. And strong local communities are created when

citizens are also the producers of the future. They cannot be replaced. No professional, institution, business or government can substitute for the power, creativity or relevance of productive local citizens. That is why Asset Based Community Development is, in practice, citizen-centered community building.”

Green, M., Moore, H. & O'Brien, J. (2006). *When People Care Enough to Act: Asset Based Community Development*. Toronto: Inclusion Press.

Available through the Inclusion Press (www.inclusion.com).

Brent Hafren, Keith Karren, Katheryn Frandsen, and N. Lee Smith

Check out Hafren and colleague's book *Mind/Body Health: The Effects of Attitudes, Emotions and Relationships*. It's full of reasons why building relationships will always trump interventions and billable services. Be sure to check out the chapters on loneliness and social support and their impact on health and well-being.

Hafren, B.Q., Karren, K.J., Frandsen, K.J., Smith, N.L. (1996). *Mind/Body Health: The Effects of Attitudes, Emotions, and Relationships*. Boston: Allyn and Bacon.

You can order a copy of this book through Dean/Ross Associates, 523 Orchard Drive, Monmouth, Oregon 97361. Phone: 503/606-9678 FAX: 503/606-0970. Ask for a complete listing of their titles!

Beverly James

Many people who experience our services have been wounded in significant ways throughout their lives. They are experiencing major "attachment disorders." Beverly James' book describes how "normal" bonds are formed in typical development.

James, B. (1994). *Handbook for the treatment of attachment-trauma problems in children*. New York: The Free Press.

Charlotte Kasl

From the book jacket: "At once practical, playful, and spiritually sound, this book is about creating a new love story in your life. Drawing from Christian, Buddhist, Sufi, and other spiritual traditions, *If The Buddha Dated* shows how to find a partner without losing yourself." A great book

for anyone looking for love in all the wrong places.

Kasl, C. (1999). *If the Buddha dated: A handbook for finding love on a spiritual path*. New York: Penguin Books.

Jeffrey Kauffman

Jeffrey Kauffman's book, *Guidebook on Helping Persons with Mental Retardation Mourn* is an excellent resource for anyone who wants to help folks who experience intellectual disabilities to heal from loss. A bit clinical, but not too clinical, the book contains lots of useful information about the process of mourning for someone we love.

Kauffman, J. (2005). *Guidebook on helping persons with mental retardation mourn*. Amityville, NY: Baywood Publishing Company.

Available from the Baywood Publishing Company web site (baywood.com) and the online bookseller half.com

Craig Kennedy and Doug Fisher

As kids get older, it can get tougher to help them to make connections, particularly in the middle and high school years. Craig Kennedy and Doug Fisher provide great ideas for increasing the chance of success in middle school in their book *Inclusive Middle Schools*. You can order the book from The Peak Parent Center, Inc., 611 N. Weber, Suite 200, Colorado Springs, Colorado 80903. Call for a catalogue of available publications 1-800-284-0251.

John Kretzmann and John McKnight

John Kretzmann and John McKnight describe "asset-based community development" in this helpful manual for building stronger communities. A must-have for anyone interested in community building.

Kretzmann, J. & McKnight, J. (1993). *Building communities from the inside out: A path toward finding and mobilizing a community's assets*. Chicago: ACTA Publications.

The manual is distributed exclusively by ACTA Publications, 4848 North Clark Street, Chicago, IL 60640. Phone: 800-397-2282.

James Lynch

The Broken Heart: The Medical Consequences of Loneliness is an important book that makes the point that “companionship is an important life force.” For anyone who doubts the importance of relationships to our emotional and physical well-being. A bit dated, but still worth a look.

Lynch, James J. (1977). *The broken heart: The medical consequences of loneliness*. New York: Basic Books, Inc.

Gary Messinger and Lisa Mills

Gary Messinger and Lisa Mills, in their wonderful book *Sharing Community! Strategies, Tips, and Lessons Learned from Experiences of Community Building at Options*, provide 20 great and surprising tips for community building. Based on their experiences at Options, a non-profit organization that provides supported living supports in Madison, Wisconsin, this book is must-reading for anyone trying to build community for people who experience disabilities. Available through the Options Web site: www.optionsmadison.com or by calling 608-249-1585.

Messinger, G. & Mills, L. (2005). *Sharing community! Strategies, tips, and lessons learned from experiences of community building at Options*. Madison, WI: Atwood Publishing Company.

John O'Brien and Connie Lyle -O'Brien

This is a book about friendships and personal commitment and much, much more. A must for anyone interested in the work of building rich, welcoming communities.

O'Brien, J. and Lyle-O'Brien, C. (1996). *Members of each other: Building community in company with people with developmental disabilities*. Toronto: Inclusion Press.

Available through the Inclusion Press. 24 Thome Crescent, Toronto, Ontario, Canada M6 2S5 Tel (416) 658-5363 fax (416) 658-5067 Or through the web: www.inclusion.com

John O'Brien and Beth Mount

Make a Difference: A Guidebook for Person-Centered Direct Support is an invaluable resource, packed with helpful information and exercises for

supporting the development of relationships. I can't recommend it highly enough. Available online through the Inclusion Press (www.inclusion.com).

O'Brien, J. & Mount, B. (2005). *Make a difference: A guidebook for person-centered direct supports*. Toronto: Inclusion Press.

Robert Perske and Martha Perske

From the jacket of *Circle of Friends*, "In this warm sensitive collection, Robert and Martha Persky offer true stories and issues to ponder, concerning friendships between people with disabilities and so-called normals [sic]. They show how these circles cut across age groups, generations, and races, and how the hearts and worldviews of everyone can be enriched. The emphasis here is on pure and simple friendship."

Perske, R. & Perske, M. (1988). *Circle of friends: People with disabilities and their friends enrich the lives of one another*. Nashville, TN: Abingdon Press.

Robert Putnam

Bowling Alone is the national bestseller that examines the rise and fall of community in American life. From the back cover: "Drawing on vast new data that reveal American's changing behavior, Putnam shows how we have become increasingly disconnected from one another and how social structures — whether they be the PTA, church, or political parties — have disintegrated....Like other defining works in the past...*Bowling Alone* has identified a central crisis at the heart of our society and suggests what we can do."

Putnam, R.D. (2000). *Bowling alone: The collapse and revival of American community*. New York: Simon and Schuster.

Leonard Sagan

Sagan's *The Health of Nations: True Causes of Sickness and Well-being* contains important information about the powerful relationship between social networks and health (see endnotes)

Beth Schaffner and Barbara Buswell

Beth Schaffner and Barbara Buswell provide lots of helpful suggestions

for helping kids get connected to kids in their 1992 booklet *Connecting Students: A Guide to Thoughtful Friendship Facilitation for Educators and Families*. You can order the guide from The Peak Parent Center, Inc., 611 N. Weber, Suite 200, Colorado Springs, Colorado 80903. Call for a catalogue of available publications 1-800-284-0251.

Karen Schwier, Karen Melberg Stewart, and Erin Schwier

Of *Breaking Bread, Nourishing Connections: People With and Without Disabilities Together at Mealtime*, Anne Donnellan writes, "We've needed this book for a very long time. It's more than a meal; it's a feast." Developed by authors with extensive personal and professional experiences...this practical handbook helps you ensure pleasurable, fully inclusive mealtimes (from the back cover).

Schwier, K.M. & Stewart, E.S. (2005). *Breaking bread, nourishing connections: People with and without disabilities at mealtime*. Baltimore: Paul H. Brookes.

Linda Stengle

Linda Stengle's helpful book, *Laying Community Foundations for Your Child with a Disability* is a helpful resource for parents and professionals who understand the importance of long-term relationships. You can order the book through Woodbine House, Inc., 6510 Bells Mill Road, Bethesda, MD 20817 Toll free: 800-843-7323.

Stengle, Linda J. (1996). *Laying community foundations for your child with a disability: How to establish relationships that will support your child after you are gone*. Bethesda, MD: Woodbine House.

Clifton Taulbert

Clifton Taulbert, author of *Once Upon A Time We Were Colored*, offers a rich and wonderful resource for anyone interested in building community — *Eight Habits of the Heart: Embracing the Values that Build Strong Families and Communities*. This simple but profound book can be obtained in your local bookstore or through the Building Community Institute, 717 S. Houston, Suite 508, Tulsa, OK 74127. Telephone (918) 584-0414. Web: www.clifftaulbert.com

Taulbert, C (1997). *Eight habits of the heart: Embracing the values that build strong families and communities*. New York: Penguin Books.

David Wetherow

The Whole Community Catalogue is a wonderful resource for those who want to help people who experience disabilities to join the “heart of community life.”

Wetherow, D. (1992). *The whole community catalogue: Welcoming people with disabilities into the heart of community life*. Winnipeg, Manitoba, Canada: Gunnars and Campbell, Publishers. Available through the Inclusion Press.

Margaret Wheatley

I love Margaret Wheatley’s books about change and community because they are both simple and profound. Wheatley’s newest book, *Turning to One Another* is profoundly important to anyone who believes we can and must build strong communities together.

Wheatley, M.J. (2002). *Turning to one another: Simple conversations to restore hope to the future*. San Francisco: Berrett-Koehler Press.

END NOTES

- (1) Perske, R. ().
- (2) Gaylin, W. (1990). *On being and becoming human*. New York: Penguin Books.
- (3) Lyle O'Brien, C., O'Brien, J., and Mount, B. (1998). "Person-centered planning has arrived...Or has it?" In O'Brien, J. & Lyle O'Brien, C. (Eds.). *A little book about person-centered planning*. Toronto: Inclusion Press
- (4) The term, "enduring, freely chosen relationships" is borrowed from John O'Brien and Connie Lyle-O'Brien's Framework for Accomplishment (1987).
- (5) This entire section — "The Importance of Belonging" is taken directly from my chapter "Opening the Door" in John and Connie Lyle-O'Brien's book (2002) *Implementing Person-Centered Planning: Voices of Experience*. Toronto: Inclusion Press. Reprinted with permission.
- (6) Pelletier, K. (1994). *Sound mind, sound body: A new model for lifelong health* (pp. 137-138). New York: Simon and Shuster.
- (7) Hafren, B.Q., Karren, K.J., Frandsen, K.J., & Smith, N.K. (1996). *Mind/body health: The effects of attitudes, emotions, and relationships*. Boston: Allyn and Bacon.
- (8) Ibid.
- (9) Ibid.
- (10) Lyle O'Brien, C., O'Brien, J., and Mount, B. (1998).
- (11) Romer, M. (2002). Two is not enough. In J. O'Brien & C. Lyle-O'Brien. *Implementing person-centered planning: Voices of experience* (121-129). Toronto: Inclusion Press.
- (12) This idea that a crisis can be an opportunity to form a meaningful relationship with someone was taught to me by someone but I can't remember who. I'm sorry for forgetting, but wherever you are, thank-you. The section presented here is taken directly from my chapter "Opening the Door" in John and Connie Lyle-O'Brien's book (2002) *Implementing Person-Centered Planning: Voices of Experience*. Toronto: Inclusion Press. Reprinted with permission.
- (13) O'Brien, J. & Lyle-O'Brien, C. (1996). *Members of each other: Building community in company with people with developmental disabilities*. (p.41). Toronto: Inclusion Press.
- (14) Ibid.
- (15) I am grateful to Lou Brown for first exposing me to this idea. It has been enormously helpful in understanding why so many people who experience disabilities do not understand the concept of reciprocity.