

Great Questions

Writings of Judith Snow



*I have lived on the margins &
fought hard to become a
participating citizen.*

I am a thinker & a dreamer.

*I have a reputation as a
visionary.*

*Let's look at what fosters
community capable of including
people in all the diversity of
their gifts & dreams.*

Great Questions
Writings of Judith Snow



A Poem
Judith Snow

Dreaming, Speaking and Creating (page 41–page 63)

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Videos on page 4, page 10 and page 18 and the audio interpretation on page 17 were created as part of *Who's Drawing the Lines: The Journey of Judith Snow*, an exhibit at the Royal Ontario Museum from 15 August 2011 to 20 January 2012. They are included here by permission of The ROM.

Thanks to Jay Klein for copies of Judith's more recent writing.



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Our friend, Judith Snow, died on 31 May 2015 in the midst of life at her home in Toronto. In her 65 years of life –its many improbabilities marked in the poem you hear in the video above– her passion for life inspired widening circles of people to build community by mobilizing hidden gifts. Her creative spirit animated her friends to join her in social inventions that have benefited many, including those who may never have heard her name. Judith's life and thinking shaped real Circles of Support, Person-Centered Planning, Community Building and Self-Directed Supports long before they became common, and sometimes hollow, terms.

Judith reflected deeply on her experience of how community grows strong, about power in society and about liberating the contributions of people who are typically pushed to the margins of society because they require accommodation and assistance in order to participate. We have collected her shorter writings on these topics here.

May her thinking continue to inspire community builders!

–John O'Brien, Jack Pearpoint & John McKnight

September 2015

More of Judith's Thought

Judith communicated most extensively in her talks, her participations in conversation and her advice to the many people who consulted her. Her presence and charisma gave power and credibility to her words, which usually challenged settled beliefs.

Three books tell Judith's story and expand the ideas that she condensed into the writings in this volume.

[*Who's Drawing the Lines*](#) (2013) is the first volume of Judith's autobiography and the only volume of three completed and published.

In [*What's Really Worth Doing and How to Do It: A Book for People Who Love Someone Labeled Disabled \(Possibly Yourself\)*](#) (1998) Judith explores giftedness as the foundation for inclusion and identifies strategies for putting her ideas into action.

[*From Behind the Piano: The Building of Judith Snow's Unique Circle of Friends*](#) (1990) Jack Pearpoint tells the story of the formation of Judith's circle and the successful fight for Canada's first individual budget for personal assistance.

A YouTube search will connect to several videos. Of particular interest is Judith's presentation to the 2014 Summer Institute on Theology and Disability, [*It's About Grace*](#).

For an example of Judith's influence on a leading social innovator who met Judith through her writing and talks, see Simon Duffy, [*A Letter to Judith*](#).

A Note About Words

Judith's description of herself and people who are at risk of exclusion because of their need for accommodation and personal assistance shifted over time; so did her term for personal assistants. We have left her changing choices just as she wrote them.


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*A great question
refuses to be answered.
So it keeps leading us
into deeper connections
with each other and
into deeper thinking.*

Great questions came early to Judith.



Judith Snow

*My life has been a journey from
professionals declaring,
“That’s who you are.”
to my being able to explore
the human question,
“Who am I?”*



*A gift is a personal quality that
–when its brought into
relationship in a valued way–
allows an opportunity to
emerge.*



*Inclusion is about willingness
to take a unique difference and
develop it as a gift to others.
It is not about disability.*



Happy Sun



Rita



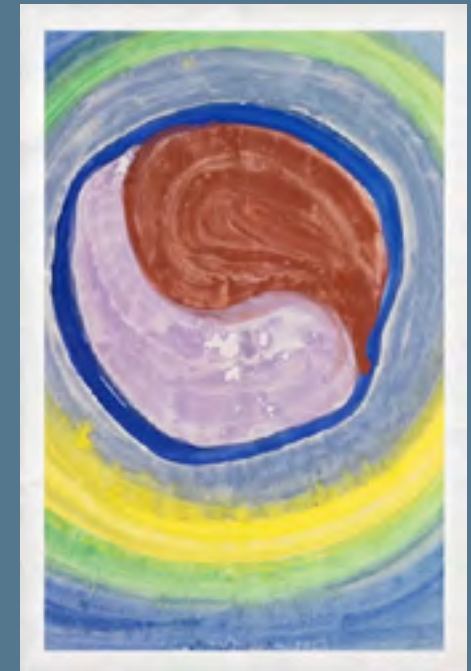
From 15 August 2011 to 20 January 2012 *Who's Drawing the Lines: The Journey of Judith Snow* was on exhibit at the Royal Ontario Museum.



Winter Mourning



Click for an audio description of Judith's exhibit and the creation of these paintings.



Vulnerability



*Being an advocate for inclusion
draws almost exclusively on
anger, courage & righteousness.
Being an artist has given me
space to express ambivalence,
awe, playfulness, fear and, most
of all, love.*

Look around for an opportunity to enter into a relationship with someone who has been exiled. Act on the faith that this person has dreams and hopes much like your own and that this person has meaning in her or his life that can be conveyed to you and that has the power to enrich your life and the lives of others.

Understand that this person may be the bearer of a deep and creative dream. Bend your will and inner and outer ear to listen to this dream. Walk into the daily activities and environments of life with this person as dream and reality interact in a creative dance that expresses the meaning of life.

Try this and may you rejoice in all that you create together.

Bradwin Address

89th Annual Meeting of Frontier College

It is an honour to give the Bradwin Address. I consider it a great distinction to be numbered among those eminent people who have given this address in the past. Frontier College has a history of being, and can continue to be I believe, an agent of social good in our nation. I hope that my words today will foster this capacity of our venerable College to bring about a better world.

There are a number of reasons, I suspect, why I would be chosen to give this talk this year. For one thing, I am obviously a member of a group of people who have been pushed out to the margins of our society. I say “obviously” somewhat tongue-in-cheek for in fact I am unusual among disabled people. I have a job, I live in my own home, I have been able to avoid ongoing poverty, I have a good education and I have a large network of friends, colleagues, and even a husband. Frontier College has had a great deal to do with these accomplishments, and I will speak more of this later. But I have lived on the margins, and have fought hard to become a participating citizen. It is an experience worth speaking about.

Another reason for choosing me is that I have thought a lot about what it takes to make real community for people. I am a thinker and a dreamer, and I have been watching the people around me. I have gathered something of a reputation for being a visionary, and today I want to explore one expression of this vision. Let’s look at

what fosters community; community capable of meeting the needs of all people in all their diversity.

There is a theme that has nurtured my pondering for a number of years. This theme is found in an ancient scriptural passage which is dear to both Jews and Christians. It was written by disciples of Isaiah at a time when Israel was struggling with political humiliation and social crisis. It was quoted by Jesus as a way of announcing his mission of spiritual liberation. I am taking this passage from the Jerusalem Bible.

The spirit of Yahweh has been given to me, for Yahweh has anointed me. He has sent me to bring good news to the poor; to bind up hearts that are broken; to proclaim liberty to captives, freedom to those in prison; to proclaim a year of favour from Yahweh, a day of vengeance for our God, to comfort all those who mourn and to give them for ashes a garland; for mourning robes the oil of gladness, for despondency, praise. They are to be called "Terebinths of integrity, "planted by Yahweh to glorify Him. They will rebuild the ancient ruins, they will raise what has long lain waste, they will restore the ruined cities, all that has lain waste for ages past.

This passage, found in Isaiah 61, verses 1-4, speaks about how those who are members of society, and those who are marginalized from society, have a great need for each other's gifts. We are told that when the captives are liberated, and when the poor have heard the good news, they will rebuild the ancient ruins and restore the places that have been devastated.

This need for each other is not perfectly obvious. On the one hand those who are on the margin are usually there for very good reasons. Society often cannot respond smoothly to these people and their

needs. Perhaps the physical environment is an obstacle to a person, and he or she is seen as physically handicapped. Perhaps this one has not learned as quickly or as well as others, or perhaps he or she is more active, or more impulsive, or more curious than most folks, and so he or she is seen as impaired in mind, or as a criminal, or as just simply dangerous. In any case the presence of this person disrupts the flow of things as they are, and makes ordinary activity and daily decisions difficult to carry out. The margin may be a dangerous place, but at least there you know who you are, and you are not constantly facing disapproval and discomfort.

On the other hand there is the "ordinary" citizen who fits in, who learns, who knows the ropes and how to swing on them. In this there is peace and protection from challenge. Why would the members of these two groups want to have anything to do with each other when this can only disrupt a workable system?

The passage from Isaiah gives us the eternal answer, although the answer calls forth other questions. Without welcoming the gifts of the stranger, society is doomed to slowly crumble under the weight of its own inertia.

It is certainly clear that breakdown is happening in every part of our world today. Everywhere the numbers of people who live in the streets and in the prisons increase, and everywhere children swell the ranks of these homeless ones, because they see no future in school or in work for themselves. Our environment is degraded to the point where its own healing powers may not be able to cope with the damage even if we were to stop despoiling our planet today. Other crises abound, so much so that there is a great temptation to bury one's head in the sand.

The sand of ordinary life is lived in community where people spend their days doing very ordinary things. They write, talk on tele-

phones, teach children, play with babies, wash dishes, go for walks, read books, and cry on each other's shoulders. All of this happens in ordinary places on commonplace streets, all the time, everywhere. This very commonness is a real gift, a real benefit not to be ignored. It is perfectly understandable that we should want to protect our ordinary lives from the kind of change that crisis and the stranger threaten to force on us. And that desire to lose oneself in everyday activity is real, for don't we all long for a peaceful and ordinary life? What do we know about dealing with these over whelming problems?

But change comes whether we are prepared for it or not. If we are to cope with the challenge of crisis then we need the gift of changing. This gift is not to be found among ordinary people; ordinary people have the gift of everydayness.

The gift of surviving and growing through change belongs to the outcast. Ancient writings tell us this and modern experience confirms it. Living on the edge of chaos changes the people who survive it. You become very aware of the value of things ordinary citizens take for granted; things like having your opinion listened to, having a chance to make a mistake, to be forgiven and to have a chance to try again; things like having friends and family who celebrate holidays with you and who will tell their friends that you are looking for a job. Living on the margin either burns you out and kills you, or it turns you into a dreamer, someone who really knows what sort of change will help and who can just about taste it; some one who is prepared to do anything to bring about change. If these dreamers are liberated, if they are brought back into the arms of society, they become the architects of the new community; a community that has a new capacity to support everyone's needs and interactions. But how can this really be, especially since these

dreamers still have the characteristics that marked them as outcasts in the first place? They will still lack good judgment, or find it hard to learn to read, or to be disabled. Solving this problem is critical, for otherwise the outcasts and the ordinaries are very good at maintaining an invisible wall between their two worlds.

This reminds me of certain parties I was invited to when I was a child. Once a year some group would put on a party and invite all the disabled children and their parents. This would always include a turkey dinner or hot dogs and ice cream, and each child would always get a present. At other times these same people would raise money to buy equipment or send us off to the camp for "crippled" children. I some times wonder if those men hated the parties as much as we did, especially after we got to be ten years old or so. Our parents wanted us to go because they depended on their charity to meet our extraordinary needs, but we always knew that these people were not a real part of our lives, and that they didn't really want to know us as friends. Otherwise I could have gone to camp with their sons and daughters, and I could have visited some of them at their homes, and they would have visited mine. As it was, we never got to see each other as real people, nor did they ever get to see me as real.

No, for the citizen and the outcast to come together, to dream and work together, to rebuild community together, something different must happen. This difference depends upon the quality of the relationship built between the one who is reaching out and the one who is reaching in.

There usually comes a time in the lives of people who are living on the margin when they are prepared to risk giving up their identities as outcasts to try to become participating citizens of community. For an ex-offender it might be a moment of finally wanting to go

straight, to get a job; for the disabled person it might come as a time of wanting to move out of a group home, to get a job. For me it came nine years ago this month when I was living in a chronic care hospital not far from here. I use the term “living” loosely because in fact I was dying from a combination of malnutrition, overdoses of prescribed drugs, and a sense of hopelessness born from ten years of fighting without success to get needed attendant care. From my earliest childhood, doctors had told me that I could not live to see my 30th birthday, and nine years ago, weeks away from that day, I figured that my days were numbered. And I was angry. I was prepared to work hard at living my own life, and I was prepared to help others where I could, but I was still looking for the break that I needed to be able to really become myself. I decided that living inside the hospital and trying to survive outside it were about equal risks for me. I moved out. Five months later I was still alive, but all my resources ran out and I collapsed. I could have ended up back in the hospital or I might have tried suicide, but something fundamental had changed in my life during that year, and so I can tell you a different story.*

I had friends. One woman had reached out to me while I was still in the hospital. She used to do things like share meals with me, invite me to her home, ask me to help her in a variety of ways, and work with me on different projects. For months I didn't know how to respond to her because I didn't know what a friend was, but eventually I opened up to her and we have become very close. While I was in the hospital and in the months before my collapse, she was introducing me to her friends and family and telling them how we worked together, not how unfortunate I was to be so differ-

* Jack Pearpoint tells this story at length in *From Behind the Piano: The Building of Judith Snow's Unique Circle of Friends*. Toronto: Inclusion Press.

ent. Her husband build a ramp on their house so that I could enter with ease. As friends together we celebrated my 30th birthday.

When my collapse happened, friends took me to her house. She called together 14 of our friends and colleagues and they worked out a plan to get me back to work, back to life, back to fighting trim again. Within six days I was living in a new apartment of my own, with a full staff of attendants, with a loan to pay their salaries, and I was back at work. Then we sat down together to work out a way to get the government to pay for this real service. Within three months we had the first contract in Canada for an individually funded attendant care programme. We had to find an agency to channel the contract, since the government was unable to give funding directly to an individual. We approached Frontier College to perform this role and Frontier said “Yes”. Frontier is still my agent.

Today there are hundreds of individually funded arrangements across Canada, standing as a witness to what will be the ordinary way to fund attendant care some day. But my support group achieved the first one. I call this group the Joshua Committee, and of course, Jack Pearpoint, Marsha Forest and I were the founders of my Joshua Committee.

Clearly that is not the end of the story. The Joshua Committee continues to play a very important role in my life. During the first year of working together there was a lot of yelling on all sides. After all we came from different sides of the picture, and we didn't know how to trust and listen to each other. I had a lot of growing and changing to do to make up for years of lack of opportunity and of living up to the definition of myself as being disabled. On the other hand, the other members of the Joshua Committee had no reason to believe that I could live the way I thought I could, or that my

dreams were based on my real gifts. We had to learn to be bound by each others dreams, abilities, and limitations. We had to become a community for each other. One other lesson had to be learned. This is a lesson that I have seen others struggle with as well. Ordinary citizens seem to believe that once a person has been brought into community with the initial problems solved, things will continue along just fine. It seems easy to forget that even though we undoubtedly have gifts, there still is a pressure that pushes us toward the margin again. In my case people will always see me as severely disabled no matter what I do or become. This expresses itself now and then as some government official deciding that it is time for me to go back to the hospital. Then my contract for attendant care money doesn't get renewed. Once this happened about six years ago when the Joshua Committee hadn't met for several months, and we were deep into a crisis before we all could work together well again. For true community building to take root, the stranger and the citizens have to make a permanent commitment to each other; one that may change in form several times but that continues with fulfilling interaction on all parts.

Frontier College has participated in a number of formal and not so formal commitments that have welcomed strangers in from the margins of society. Frontier/Beat the Street draws on what street kids already know and care about to liberate their minds and their will to become a creative part of society. Frontier/HELP depends on the smarts, the dogged perseverance and the vision of people who have been literal outlaws. In fact from the very beginning Frontier College has welcomed the stranger in the one who could not read, so that he or she could participate, making Canada a stronger place to be. The board, members, volunteers, staff and friends of Frontier College have understood what it takes to be true liberators. She has

stayed strong through building a continuing relationship with the very people she has welcomed in.

Frontier College is now eighty-nine years old. I believe that as the dust settles others will look to Frontier College as a model of how to build creative organizations in the communities of the future. Her strength comes from her tradition of allying herself with the dreamers on the edge. My hope is that this kind of partnership will continue to be the heart of the College in the future. I am confident that it will.

The Power In Vulnerability

We often think of human life as residing in individual bodies. We think about each other as if I were a Thing and you were a Thing and we two Things interact now and then, all the while remaining separate entities. This is not a very powerful model for describing how our lives are sustained or how we in fact develop our capacity to contribute to each other and to our society at large.

I believe that it is more powerful to think about human life as if it were a thread floating between and connecting bodies –giving each body the capacity to be a person. Alone I am alive but not revealed or fulfilled. In relationship with one person I am able to become the qualities that the relationship allows for. For example in relationship with my mother I am enabled to be a child, a student, a loved one, a potential caregiver as she becomes older, and much more.

When I come into relationship with two people I acquire the capacity to become more than twice of what I am with one person. The presence of both individuals to each other creates possibilities that don't exist with each alone with me. For example my mother and my mother's friend each see me as a very different person, drawing different capacities from me. My mother and her friend together create their own new possibilities in the world and, connected with me, we create yet even more possibilities of me, more than either one does with me alone.

As an individual's relationships increase in number and diversity the possibilities for that person give great room for that person to both

become themselves and draw forth new capacity in others. In other words one or two threads will offer little support but a gossamer network of even five or six threads has strength to sustain a rich life. Euthanasia and other Sanctity of Life questions are raised very often these days when people with disabilities are being talked about. The focus of discussion is inevitably on the person's physical and cognitive functioning. The concern is to determine a benchmark of capacity that would allow experts to say with certainty when it is appropriate to end a "damaged" life. But physical and cognitive functioning are virtually no more than a necessary condition for life. In the presence of a body from human parents –breathing, if only assisted by a respirator– I am in the presence of the first essential for human life. The condition of having a breathing body really only sets a background for me to have capacity.

When I am in relationship with other individuals and if these others are networked with each other and especially if these others are different from each other, the possibility exists for all of us to have a rich life, drawing on each other's gifts. Differences in each other's physical and cognitive functioning, our interests, history and experience, our possessions and resources only add to the mix of possibilities that increase our total capacity.

Many people, especially parents of a newly labeled child, establish their relationship with a person who is handicapped through a process of identifying a need the person is struggling with or through empathizing with an experience of injustice that the person is undergoing. Taking on the role of therapist and advocate, one person stands by the other.

Therapy calls for the person with a handicap to be seen as needing to be fixed in some way. Advocacy calls for the person with a handicap to be viewed as a victim of some outrageous misfortune

or circumstance. Both these stances have value and can lead to good for the person and the community. But neither approach calls for a contribution from the labeled person in order to sustain the relationship or the work. And if success in therapy or advocacy is not quickly forthcoming the relationship must suffer. Paradoxically even success can destroy such a relationship because success erodes its foundation.

Sustained vibrant relationship demands that the person with a handicap be viewed with a different vision and listened to with a different ear. Foremost of the alternative possibilities is to see and hear the person as a welcome fellow traveler. We must see our shared life journey as one of transforming human suffering by creating the supportive relationships we all need to sustain life and of celebrating together life's joys, victories and surprises.

As fellow participants in an imperfect community many persons with disabilities have valuable gifts to offer. Some show a capacity to take a great deal of satisfaction from very simple everyday occurrences. The unusual behavior of others can be a contribution to those who find society's restricted codes too tight for self-expression. The silent ones may be the best listeners. The very presence of many people with handicaps is a means out of the overwhelming individualism imposed by society's norms. Then there is an unlimited number of possible gifts that individually each person with a handicap can develop, like everyone, the nature of which can only be determined by those who stand close enough to watch, listen, care and share.

Welcoming into community those who have been excluded and recreating community so that these people's giftedness becomes part of everyday life – this is the strong road to building the capacity of communities everywhere.

The Story

Prologue

Many groups of people who are marginalized today have a history of their people that gives an explanation of present day reality. For example Afro-Americans and Afro-Canadians have stories that tell how their ancestors were enslaved and brought to North America. Stories tell how some were guided by maps encoded into songs as they traveled the underground railroad and escaped to freedom.

These traditional stories give current members of the group, especially the children, an explanation for the poverty, discrimination, exploitation and hostility they experience in the present.

As the child grows, she or he may reject these interpretations and adopt or invent others. Even so the stories have served a purpose. The stories give members of the group a way to defend themselves against the negative stereotypes that are attributed to them by others who have the power to discriminate and exploit.

Even while the material effects of marginalization are being experienced the child has an inner anchor to sustain a positive identity for herself or himself. It can be remembered that it is not her or his inevitable fate to be so abused. The opportunity remains to find a way to work for greater freedom and respect.

Children labeled with disability come to this world as members of every cultural group that occupies this world. Almost always they are born to parents who are not themselves viewed as disabled.

Those who surround them are almost always unfamiliar with the fact that handiappist stereotyping disguises and renders invisible the person's actual abilities and contributions. Their parents have no story to counter the negative beliefs about bodies and minds that function in unusual ways. In fact their parents may very likely be champions of these stereotypes.

In such situations children have no way of knowing that there are other ways of knowing themselves. They cannot know to resist adopting these beliefs about themselves. In other words a labeled child has no choice in understanding themselves as broken, as being a "mistake" or a "defect", as being fundamentally incapable and irresponsible, as being a helpless misfit who is less than able.

For better or worse, human beings are easily molded by and adapt to the symbolic realities that we proclaim to each other. If I say the little white pill will take the pain away, sugar becomes a powerful analgesic. If enough of us believe you are dying, you are very likely to die. Consequently, the child who is labeled disabled inevitably becomes a disabled child – broken, helpless and unable.

When I was seven months of age, I was diagnosed as having Spinal Muscular Atrophy, a form of Muscular Dystrophy. I was labeled 'severely physically disabled'.

When I was six years old I remember my Father telling me that some U.S. doctors were putting children labeled 'mentally retarded' to death saying that society should not have to bear the burden of caring for these children. Dad, who grew up in rural England, explained that in his youth children with 'mental retardation' were able to grow potatoes along with everyone else. They were a regular, accepted part of his community. But children like me were killed. People felt they did not have enough resources to support someone who would likely not be able to grow food.

My Father's story was harsh. But that is not what I heard when I was six. I heard that I had enemies and that I had better pay attention. I heard that he and Mom were going against the mainstream and that meant they loved me and that we were all vulnerable. I heard that the way to gain acceptance among strangers was to contribute to the well being of the community.

Outside of this one occasion I was raised without an orientation to the prejudice daily inculcated into my being. I was in my thirties before it really began to occur to me that I was my own worst enemy. I had adopted all the ableist stereotypes as being realities of my true self. Consequently I cooperated, while others, wittingly or not, hurt my body, deflected my mind, impoverished my circumstances and diminished my abilities and contributions.

I have long thought that living as a labeled person requires the skills to live as an alien in a misunderstanding, often hostile, foreign territory. It would be helpful to have an orientation to the ways of the foreign inhabitants. I often have wished to have a reorienting story, such as might have been told to me as I sat in my Mother's lap, still a babe, if my Mother had known I needed such a story.

I invented such a story.

The Story

(In my mother's voice)

You are not from here. You are more like the people who are from here than they can imagine. But they find it difficult to see you as you are or to like you. You –and others like you whom you will meet in time– have chosen to live your life among us. This is a dangerous choice.

You made this choice because you love my people. We need you.

You must remember: it takes a long time for most of my people to see that you are alive and that you have a heart, and that you are trying to give something to us. Some of us will never see you as anything more than a puppet at best. You must find people who will see that you are alive. You must help them over and over again to keep on seeing that you are alive. If you do not help people to see that you are alive, you will fall asleep. The only life you will have is the life of a puppet filled with other people's stories. They may grow tired of playing with you; they may break you; they may throw you away; they may destroy you.

When you find people who can see you, you must learn to live among them. You must learn to believe most of what they believe, and to act in most of the same ways as they act. People who can see you will tell you how to do this. You must listen closely and watch carefully even when it is tiresome. If you do not strive to become like them, the others who cannot see you will drive you away. Then even those who can see you will not be able to hold on to you.

However, you must not strive to be completely like my people or you will break yourself.

While you are among my people, you must constantly search for ways to hang on to your true self and your true way of being while you are acting like us as much as possible. As my people get to know you better and better they can help you find your true self and your own way of being. Be courageous in asking them to help you find your true self. Be courageous in doing this even when it hurts you and when it hurts them.

It is your way to love my people. It is your way to heal us. It is your way to help my people renew ourselves. It is why you came to live among us.

Notes on the Gifts and Assets That People Who Are Vulnerable to Rejection Commonly Bring to Community

Hospitality

- ... making people feel happy
- ... listening

Grounding

- ... slowing people down, reorienting people to time and place
- ... leading people to appreciate simple things
- ... causing people to appreciate their own abilities

Skill Building

- ... pushing people to be better problem solvers
- ... causing people to try things they've never done before
- ... causing people to research things they never encountered before
- ... improving education
- ... improving technology
- ... modeling perseverance - being unstoppable

Networking

- ... reaching out to people and breaking down barriers
- ... asking questions that everyone else is too shy to ask
- ... bringing people together who otherwise would never meet

Economic

- ... providing jobs to people who want supplemental income, like artists
- ... providing jobs to people who need to work odd schedules like homemakers
- ... providing jobs to people who otherwise have few or no marketable skills
- ... filling odd niches
- ... providing a home, bringing people home

Emotional/Spiritual

- ... often modeling exemplary forgiveness
- ... offering opportunities to do something that clearly makes a difference
- ... reorienting values from accumulation to relationships
- ... making people more peaceful

Dreaming, Speaking and Creating

What I Know About Community

First, A Story

For many years I have known and learned from a young man named Peter. He is now in his early twenties and when I first met him he was 12 or 13 years old. I like to tell people about Peter because in reflecting on the events of his life I have been introduced to many realities about how people can achieve positive community together.

Peter is a person who doesn't speak. He uses no verbal language and he employs only three signs. The sign he uses most reliably is the one for "more," usually to indicate that he would like to continue to eat. Peter does walk and with a great deal of assistance and guidance he looks after his own personal needs. He enjoys participating in a variety of simple daily tasks such as setting table for a meal, serving food, and the like. He most often enjoys swimming or listening to music, but otherwise is not particularly athletic or recreationally minded. He is more comfortable just hanging around with a gang of familiar friends. Many people would label Peter severely mentally retarded.

When I first met Peter he had just finished elementary school. For two years he had been part of a regular class of students at a private school that was consciously trying to provide the best educational opportunities to a diverse group of children whose families could

afford to send them to that school. His participation with the other students and in the curriculum was supported by a young woman whose role was to do what was necessary to maintain the students' and teacher's connection to Peter. The family had borne the cost of Cammie's presence in the school.

When Peter's days at elementary school were finished, his parents had few options for further schooling for him. There were no junior high schools where Peter would be welcome to participate with "regular" teenagers. Among segregated schools and classes, Peter was offered only a place where he would share his days with a small number of students, all of whom had significant difficulties in learning and speech, often coupled with physical limitations. Peter's parents struggled with the school system to gain, at a minimum, Peter's participation with children who spoke. But they were refused even this source of stimulation and challenge for him.

Let me say at this point that Peter's family recognized that he had very important gifts; in particular, the gift of trust. Peter is unable to predict a great deal about the world around him. When he enters places he has never been before, for example, when he climbs a flight of stairs that he has never been up before, he cannot know that there will be a room at the top of those stairs, complete with a floor, ceiling, perhaps chairs to sit on, perhaps food to eat. This uncertainty disappears after a first experience with a new place, but it also can be very difficult for Peter to know where he is going at any given time. He simply doesn't have the language to have a conversation with people about where he is going with them and what they will be doing there. In spite of this Peter likes to go places with people and will often go happily where he has never been before, expressing complete confidence in his guides.

At the special school, when Peter was about 14, his family and friends began to notice a real change in him. Inside the classroom he spent more and more time sitting quietly by himself flipping the end of his sock back and forth. In this state, called "disappearing" by his mother, he became increasingly less interested in doing even the few things that went on in the classroom that he enjoyed; things like getting out lunch bags and arranging the room for a meal. When Peter was doing something he did enjoy, like swinging in the schoolyard, it became difficult to coax him to move on to a new activity. He began to resist others' guidance frequently. What was happening to Peter's great gift of trust? If he learned to resist others' guidance how could he live anything but a very restricted life? His parents and friends were deeply worried.

After trying unsuccessfully to get Peter's school principal to move him to a more stimulating class, his parents decided to hire someone to go to school with him. With their own money they recruited a young man, David, an artist who had extensive experience with the sort of life situations that often confront people labeled handicapped. David's fundamental job description was to find interesting things for Peter to do at school, helping him to keep connected with his world.

Within three weeks David was saying that either Peter and he had to get out of that school or he would have to resign. The basic problem was that there was nothing of genuine interest or importance happening at that school and so there was nothing to connect Peter to. David was going crazy there, much less Peter!

Peter's parents were faced with a real crisis. They feared that if they withdrew Peter from the "special" school system and if things did not work, their relationship with the segregated school board could be difficult to establish again. However they knew that David wasn't

exaggerating and that Peter was losing ground. They decided with great trepidation to permit David to withdraw Peter from school. And so David and Peter began to wander the city of Toronto. There was some direction to their travels but not much. They created a list of friends' homes to visit on a frequent basis. They tended to follow the subway line because David doesn't drive. They often dropped in on coffee or doughnut shops or grocery stores because there their presence wouldn't be remarkable and because Peter likes food. Here and there they found jobs that they could do for neighbors like sorting stuff or stowing boxes. Often they seemed to be just wandering.

In a short period of time David contacted a number of alternative high schools run by the public school board. At one in particular he found a friendly welcome. The administrator took the opportunity to get to know David and Peter better. After continued exploration it seemed that the students also were interested in Peter and had some ideas about how he could participate with them. The structure of the school allowed the students some real say in the way their curriculum was developed. It became clear that at this school there would again be a genuine opportunity for Peter to be involved with his peers in interesting ways. David and Peter were once again going to school.

Peter soon had several regular activities. His day would often include setting up the cafeteria for lunch and tidying up afterwards. Food preparation for himself and others, and eating, were regular events along with frequent trips at recess and breaks to the local coffee shop with other students. Students worked with Peter on different ways that he could enjoy using the class computer. David and Peter often handled the mail for their school plus another high school nearby.

But perhaps the most unpredictable activity that Peter got involved in was a sound poetry class. It seems that there is a form of poetry based on inarticulate sounds, building words and phrases around the impressions that these sounds evoke in the artist. The students were fascinated by the sounds that Peter makes and, at one of the planning sessions that were held to design Peter's participation at school, the idea was born to have a sound poetry class. The class was coordinated by a friend of David's who is a poet, and the students, including Peter, worked on a variety of compositions based on his and other people's sounds. At the end of the year the class put on a performance at a small club in downtown Toronto, with Peter taking part in the show. After approximately two years at this school it seemed time to move on. Peter was now 17, an age when many teenagers are thinking of leaving school. David and Peter hit the bricks again. But this time there was a great deal more focus in their travels about town.

David lived in the west end of Toronto, occupying a former warehouse where he had plenty of room to construct large sculptures. His neighborhood was culturally and functionally diverse with a rich variety of people and activities in all sorts of small interesting places. Peter lived in a much more subdued part of town. David decided to bring him daily to be part of the general hubbub of the west end. Once again in a remarkably short period of time a pattern began to emerge.

Daily the pair would travel throughout the neighborhood and along the east west subway line. Frequent stops included coffee and cheese shops, small stores, and local churches. They had time and inclination to stop and chat, have a snack, do a chore or run an errand. David soon discovered that there were small organizations in the area, working on a shoestring to achieve a more peaceful

world, a cleaner environment, or other similar projects. Peter and David began to help run off brochures, get mailings out, deliver packages in the area, etc. In a short time they were just part of the regular scene, fulfilling their very much appreciated function. Peter was chosen as Volunteer of the Year one Christmas and was written up in the local newspaper.

Other neighbors took notice of the presence and activities of Peter and David. People on the regular route would talk about this pair to each other, and if David happened to be seen without Peter people would inquire about Peter's health and whereabouts. A local United Church minister opened his church hall for meetings of people interested in responding better to the lives of vulnerable people among us. Neighbors began to talk about the west end as a community. Peter's parents moved into the area to foster and be a part of this new life.

One of the frequent stops became the residence of some Anglican monks. Quite possibly the initial attraction was that these men liked to put on some of the best lunches in town. But one of the monks was the priest at the nearby Anglican church and he invited Peter and David to participate in the Sunday service with him. Soon after that he invited Peter to serve the altar during the Eucharist. Peter continues in this role more than two years later. The priest says that this is one of the best things that has ever happened to him and the parish.

You see, one of Peter's greatest gifts is that he likes food, and the Christian communion service is about sharing a deeply significant meal as a community - rich and poor, young and old, stable and vulnerable together. Because Christians believe God is both food and nurturer, Peter, in his deep, respectful, and radiant understand-

ing that a meal is being prepared and served, recalls the priest and the congregation to a renewed appreciation of their shared ritual.

In a short time the brothers began to invite families with "different" children and other vulnerable members of the parish to take a more active role in the community life. Some began to be altar servers as well and others began to be involved in other ways. All expressed that they felt welcome in a way that was virtually unique in their lives. The congregation came to life with a renewed interest. Meetings were held to decide how the congregation could respond more effectively to their vulnerable members. They looked for a way to help these people find the supports they require so they would not be forced to move out of the neighborhood into group homes and nursing homes.

The congregation decided to set up a trust fund to help raise funds and channel government dollars for hands-on support to these vulnerable members. In addition a group formed a planning and action body to help each of the affected families and individuals clarify their needs, prepare proposals and find the necessary resources and personal support.

All this is the result in good part of the presence and participation of Peter, a young man who has never spoken and who is labeled by health professionals as severely mentally retarded. Yet, within the space of less than six years and while still in his teens, Peter's impact on his community rivals that of most mature, active, capable, and able-bodied, adult citizens. Peter has been a poet, food handler, odd job man, messenger, neighborhood organizer, peace activist, community builder and evangelist. He has never acted alone but few successful people do. David and others have been key to every development, but the impetus has come from Peter.

Reflecting on these facts has caused me to notice and learn much about what it means to be a fulfilled human being. Peter's contribution impelled me to think about what it could mean to be a person who doesn't speak. Finally Peter's life, as well my own physical disability and my reflections on the lives of others who have been labeled handicapped, have caused me to ponder many issues around disability itself. I am writing this to bring you Peter's story and some of my own ponderings as well.

Gifts

Once my father told me that in ancient China the very rich or powerful families would bind the feet of young girls. As these girls grew up they became unable to walk more than a few hobbled steps. If a woman were truly rich and powerful she would give up walking altogether and she would also grow her fingernails until her hands were heavy and functionless. She would be carried about all day by slaves who bore her chair and her cushions to support her hands. They would feed her and look after her every need.

Now what is interesting to me about this story, and the reason my father told it to me, is that my body works as if I were one of those ancient Chinese ladies. I get around in a fancy motorized wheelchair and a van adapted with a wheelchair lift. I type on a computer with a breath control that reads my puffs and sips as Morse Code and translates the code into letters and computer controls. Otherwise my every physical need from eating to driving the van must be met by a team of attendants. These attendants cover a 24-hour shift and their wages are funded with government dollars.

One critical difference between my life and that of an ancient Chinese lady is that she was considered to be of value in her society just because she was there. Her mere presence as a symbol was of more

value than any other potential contribution she could make and she was supported and shaped through great suffering to become that symbol.

In my world, people are valued according to their conspicuous function and activity. Few things are viewed more negatively than disability in my society. People with apparent disabilities are usually subjected to endless efforts to "cure" them or like Peter, educate them out of their differences. All the time this is going on they are also being segregated out of everyday life and being denied ordinary, obviously desirable experiences such as work, play, income, friends and intimacy. In a great many parts of our society, people with disabilities are also being selected for death. Today doctors regularly use amniocentesis to discover Down Syndrome (which Peter has), or Muscular Dystrophy (which I have), or Spinal-Bifida, and then recommend abortion for this reason only. Others are denied ordinary health care or important services, leading to death from treatable infections, starvation, etc.

Many years ago I started to ponder how one society could value one physical and mental state so highly that people would put their children through torture to ensure they attained it while another would value the same state so negatively that it would kill any children if possible if they happened to develop it. Even more important to me, I began to try to figure out how people could be persuaded that disability is not a threat. Although disability may be viewed as a negative itself that does not mean that the people who are disabled could not be seen as also embodying other possibilities. On the other hand, is disability so negative as to have no redeeming qualities to celebrate?

Here is an important clue I had. People who know a person with a handicap very well, someone such as a parent, sibling or a family

friend, will often say about that individual that he or she is a wonderful person and that this was not apparent to them at first. For example, a young man I know is a person who doesn't speak. He is attending a neighborhood high school. His support circle publishes a newsletter for family and friends to tell of his goings-on. In a recent edition of his newsletter the support worker made a point of saying how unexpectedly enjoyable her time with him has been.

My point is both that people virtually always discover something that brings them pleasure when they get to know someone who is labeled handicapped and that this pleasurable discovery virtually always comes as a genuine surprise. But, in general, when we meet new people we usually do discover something about them that we like. Hardly ever do we hate everything about someone both on first meeting and after getting to know them better. So why are people so surprised by this discovery when confronted by a person who is called handicapped?

By following this question I came to this realization: Everyone is gifted.

This realization is partly masked from us because we usually think of gifts as being extraordinary qualities. We think that only a few people have them. But giftedness is actually a common human trait, one that is fundamental to our capacity and need to be creatures of community.

Gifts are our capacity to create opportunities for ourselves and others to interact and do things together, things that have mutual meaning. So, for example, if you are interested in an evening's fun of softball and you have six people on your team, you have an opportunity you can offer to several people, including some innocent bystanders who might just end up watching. But you can't play softball without at least seven people per team. So when the seventh

person comes along, willing to play, that person's presence is a gift to many other people, even if she or he doesn't play very well.

Our presence is the fundamental gift that we bring to the human community. Presence is the foundation of all other opportunities and interactions, of everything that is meaningful.

In addition to our presence each of us has a grab bag of other ordinary gifts that allow us to create and participate in daily opportunities. From getting up, making breakfast, washing dishes or loading a dishwasher, talking on a telephone, writing on a piece of paper, listening to another person, getting from one place to another, enjoying some music, expressing an opinion, going to a meeting, playing with a baby or having fun with a friend, a variety of simple activities taking place in ordinary places on streets make up the fabric of the vast majority of our work, family life, private life and public contribution.

Beyond ordinary giftedness there is extraordinary giftedness, the kind that extends opportunity for interaction and meaning to a larger number and variety of people. One person is not just nice to be with but is a truly funny comedian; another doesn't just get around but dances on skates beautifully; another not only shows up for the PTA regularly but has ideas that are engaging and changing the face of the local school board.

Each person has a variety of ordinary and extraordinary gifts. The people whom we call handicapped are people who are missing some typical ordinary gifts. However such people also have a variety of other ordinary and extraordinary gifts capable of stimulating interaction and meaning with others.

Seeing disability somehow prevents us from seeing the gifts in a person, at least at first. And so we are surprised when we find

ourselves experiencing pleasure, meaning, and opportunity in the presence of a disabled person.

Furthermore, giftedness grows from different roots making it possible to speak of three different sorts of gifts. First, some gifts seem to arise simply because of the unique makeup of the individual. One person picks up whistling at age five, another has always enjoyed listening to others' stories. Secondly, some gifts are tied to a general characteristic. Only women bear babies. Lastly, many gifts arise from the efforts that an individual makes to deal with her or his experience. After a long fight with cancer a person may develop a high tolerance for pain, an appreciation for beautiful sunrises and the desire, time and capacity to visit severely ill people.

I began to play with this analysis while considering Peter's life. Clearly some of the events around him arise because of the uniqueness of Peter himself. For example, Peter's love of food and his great gift of trust have shone through virtually every aspect of his participation during these many years. Some of his gifts have emerged primarily because of the interaction of the world on Peter and Peter on the world. His participation as a sound poet falls into this category. But other gifts are grounded in Peter's disability itself.

People around Peter often report that they feel more in touch with, more grounded in time and space. One of Peter's contributions has been to give many people a sense of neighborhood in west end Toronto. A common aspect of disability is a relative slowness or awkwardness of movement. Peter walks in a slow, deliberate manner, often slowing the pace of his more typical peers. He also relates very much in terms of the familiarity of the space he is in. When you walk with Peter you have a beautiful opportunity to relate to the unique character of the time and space you are in right now.

For a few moments space is more than distance to cover and time is richer than a measure of how long it takes to get from here to there. Thus being with Peter can be a spiritually grounding experience for a modern citizen who is frequently dislocated from time, space and neighborhood. This gift of Peter's arises directly from his Down Syndrome.

People with mental and physical disabilities have a common experience in today's world which makes them bearers of some gifts that are typical for them but not for ordinary citizens. For example, services that are directed toward people with disability are usually driven by motives that are based in charity, therapy or protection. In almost all cases these services are directed by professionals who view themselves as experts on what the client needs because of being disabled.

In contrast, ordinary citizens receive services which are driven by the understanding that the citizen desires to be and must become an active participant in society, playing some roles in keeping regular daily life going. Thus ordinary services attempt to maintain the participation of people, keeping the roads open, fuel in cars and buses, food in stores, information universally available, water on tap, sewers flushing and children introduced to the meaningful symbols of the culture. Although not everything runs smoothly all the time and one can always criticize and imagine a better way in which these things and others could be done, it is clear that the basic purpose of ordinary services is to nurture the capacity of the ordinary citizen to do whatever that citizen decides she or he wants to do.

When I was in high school one of the students was an Olympic diver, a veteran with many medals. My community seemed to know just what she needed to continue to be both a gifted diver and one

of our classmates. We knew that she needed access to the swimming pool at 5:30 a.m. every morning, she needed tutoring to keep up when she traveled, she needed friends, recognition and to graduate along with us. She needed a volunteer sports club locally and various national and international organizations to maintain her opportunities to dive.

Now a student with disabilities needs exactly the same sort of opportunity and structure to participate along with fellow students. But in our world it is fun and exciting to support an Olympic diver and a burden to support a child with disabilities. The way we view giftedness makes all the difference.

My point is that disabled people live in a world that fails to foster participation for them. Also the existence of this *special* set of services often blocks people from access to regular services. The most blatant example of this is special education. As more and more special classes and schools were established in the 50s and 60s, more and more children were segregated from the regular classroom. But special education leads more than 90% of the time to sheltered workshops and institutionalized poverty. Thus children who might have coped on the margins of society have been systematically cut off from true participation in the name of therapeutic education.

In what way is this tragic situation a gift? Many people labeled disabled have discovered that they can find no automatic place for themselves in society. Instead they have found the capacity in themselves to dream for and build something new. Just as Peter created a poetry class where there was none, a neighborhood out of a collection of lower middle-class stores, houses and churches, and a community out of a bored congregation, so do many other people pushed beyond the margins find they must create the very opportunities they require out of the scraps of the world.

As it happens, this society functions less and less well for ordinary citizens, with increasing breakdown everywhere in our time. In this context the creative capacity of people with disability has become a gift of great importance. This gift is bound up with the ability to dream, an ability which I will describe below.

Dreaming

How did David know what to explore to find a way to support Peter 's accomplishments? Is there a way that Peter and others like him can let us know about themselves and their needs and desires other than simply going passively along when things are going well and resisting when things are not to their liking? I thought about this for a long time and then another experience gave me a clue.

In the mid 80s, I was giving a workshop on Building Supportive Relationships to a small group that included many parents, some of children with handicappist labels. I remember one woman in particular who was in her mid-to-late 50s. I was exploring stories of how people solve problems and develop their life path. I was doing this as much for my own edification as for theirs.

This woman told me that when she had been a teenager she had wanted to be a missionary. As time passed for her, however, she had gotten married in her early 20s and had three children. To her it seemed as if she had had to put aside the dream of being a missionary and carry out the life script of being a homemaker. But all the while she kept up an interest in theology and religion, taking a Bible study here and there, reading theological works or joining a prayer group. When her own kids were teenagers her marriage seemed rocky and she began to attend some of the newly formed Marriage Encounter groups. She found these very fulfilling and soon persuaded her husband to join with her in these groups.

Together they became very active in Marriage Encounter and at the time of my workshop they were leaders in the movement. One day she had realized that for her Marriage Encounter had become the concrete fulfillment of her much remembered dream to be a missionary.

I have asked many people about dreams. For me dreaming is like a delightful mystery constantly teaching me something and always eluding me just a little. But this is what I have come to understand about dreaming so far:

Dreams are threads of meaning and insight that run throughout the daily life and fabric of everyone's individual life. In fact dreams in some way seem to be part of the very structure of our life, being part of the very impulse that gives purpose, meaning and shape to living. But dreams are not confined only to the individual's experience. They are part of the glue that brings us together as social beings.

Dreams form a basis of the impulses that cause and allow us to find purpose and fulfillment in relating to each other. When we dream we are dreaming about something essential to ourselves and also significant to others in our lives, others that may not actually come into our lives for days or years to come. So dreams are not a phenomenon of the moment but communicate, preserve and carry a form of living energy across people and time.

As mystical as all this sounds, the actual working of dreams is basically quite simple. Imagine for example two six-year-old children. You ask each of them what they dream of being when they become adults and they each tell you that they want to become firefighters. But a person who knows them both well would know, or could ask to discover, something quite different in the dreams of these two children. One is expressing her interest in being of service to

other people, and being a firefighter is the most challenging and service-oriented adult experience she has yet encountered. For the other, lots of color, light, noise and excitement are important. Being a firefighter seems for now his best opportunity to star in a splashy, dramatic life. Twelve years later we may find a young woman studying at a community college to become an ambulance paramedic and a young man apprenticing in summer stock Shakespearean theater. They would laugh if you reminded them about being firefighters but the thread is there, alive and strong enough to guide these young people.

Dreams have a great deal of power in themselves but they do not act in a vacuum untouched by other factors. In fact there is a constant dynamic process going on between the dreaming of people and the real opportunities that a community offers to its citizens. Dreaming shapes reality and reality shapes the conscious face of dreaming. Thus there is a political dimension to dreaming.

The story of my missionary friend illustrates this. When she was a teenager there was no Marriage Encounter. She couldn't have said at six years of age, "I want to be a Marriage Encounter leader." Those around her during those young years probably were at least tempted to say to her, "You can't become a missionary. There is a war going on. Find a nice young man after this is over and concentrate on raising your kids, rebuilding your country's economy and supporting the returning men to start life over again."¹¹

But by putting even a little energy into discovering and fulfilling the meaning of the dream, the conscious expression of it changed in fantasy for her and different opportunities emerged at the same time. Even reading and Bible study gave her more understanding of her own impulse. They also led her to new people, new prayer and other groups, ultimately to discover that other people shared some

of the same problems and aspirations that she experienced. Eventually dream and reality interconnected for her and many others in a new opportunity, never before available in that form in the human community.

Experience shapes the never-stopped energy of a dream like banks guide the waters of a river. And the dream creates a new dimension of reality like a river wears a rocky cliff into a sandy beach. Thus dreaming is actually one of the powers that shapes the human community.

It is important to recognize that in this way dreaming is like speaking. Both dreaming and speaking seem to be driven by our conscious will and both seem to be going on completely within ourselves. They seem to be taking place as fantasy and as talking to ourselves. But they are also and most importantly a public phenomenon in that both exist to shape our relationships and opportunities. Like speaking, dreaming has the power to create. Dreaming and speaking create each other like white allows us to see black and black allows us to see white. Together dreaming and speaking are the stuff of communication.

Ancient philosophies acknowledged that *lithe wordli* was a creative power. Dreaming is a deep form of communication and is as much a part of *lithe wordli* as speaking is. Just as speech flows from person to person and through communication media, dreams are also communicated. Dreaming must be taken seriously as a powerful force shaping our lives.

Gifted Dreaming

It became clear to me from Peter and David that dreaming and listening are human capacities that also are subject to giftedness. In other words nearly everyone dreams and nearly everyone listens

to the dreams of others but some people can take these capacities to extraordinary powerfulness. And like all giftedness this extraordinary power to dream or to listen to dreams may be spurred from an individual innate capacity, from membership within a particular class of people and/or from interaction with personal circumstances.

Let me focus on Peter for a moment. Peter doesn't speak. He is also perceived as being profoundly handicapped. In my opinion these two forces have shaped Peter's being so that he has become an extraordinarily gifted dreamer.

On one hand, not speaking has left wide open Peter's opportunity to communicate through dreaming. In fact it could be that in not speaking Peter is not expressing a disability at all but in some way choosing to not speak in order to become a better dreamer.

On the other hand, Peter has experienced the greatly reduced opportunity to participate in society that all people with disability experience at this time. This prejudice and lack of support and opportunity mean that people with disability have a very narrowed choice of ways to fulfill their dreams.

Several consequences result. One is that the individual's dreams fail to be shaped by an ongoing interaction with reality and may thus seem to others to remain fantastic, childlike or unreal and unrealistic. Another consequence is that the individual squarely faces a choice. She or he may give up and become a puppet in life, controlled by everyone else's vision of how this life should unfold. Not giving up means searching and fighting for even scraps of opportunity to bring dreams to life.

Another critical consequence of being pushed to the margins of society is that the individual has a particularly clear view of just how

the opportunities of society itself are becoming more and more inadequate. Thus, for example, a young woman from North Toronto may have several options to fulfill her dreams but all of them leave some part of herself unfulfilled. As she moves through her lifetime she may feel many years of dissatisfaction, but never be able to definitely decide what is missing or discover that her ennui is shared by nearly all her typical neighbors. The woman on the margins is much better situated to see that not only is the margin no place to get genuine fulfillment but that, in fact, North Toronto leaves much to be desired as well. With less to give up she is free to dream of a completely new society with newly created opportunities. Her dreams may remain naive in detail but they can become powerful in their vision of the possibility of something fresh and creative.

The person who doesn't speak and who is labeled handicapped has an exquisite possibility of becoming a powerful, highly gifted dreamer. If such a person is offered the power to interact with daily reality, he or she may become the cornerstone to some intense and beneficial changes. The realization of this wonderful gift depends on at least two factors. One is that the individual does not give up and give in to the

handicapped role assigned to him or her. The other is that the person must be empowered to begin and carry out the necessary interactions with reality.

Through his parents, Cammie, David and later through many others, Peter had just this sort of opportunity. It is a blessing that Peter did not give up as a child.

Gifted Listening and Waiting

The last subject I would like to explore is a process that I call listening or, sometimes, listening and waiting. Dreamers are empowered

to bring their dreams to life by a combination of factors. The principal characteristic of this empowering force is that it is willingly offered to the dreamer by other members of the community. David provides a good model of the empowerment that dreamers require.

David could have joined the numbers of people who were, and are, convinced that they knew what Peter was all about. Many are the individuals who are certified in the ways and means of deciding what Peter and his "kind" need and how they should spend their days and lives. David definitely could have furthered his career by using his time with Peter to get on the professional ladder toward such certification.

Instead David put himself in the position of trying to listen for Peter's uniqueness, his dream. He experimented with a method of trying to observe and sense the activities and environments, the encounters and relationships that would provide Peter with opportunities to rub his dreams against reality. He kept the process going for years, not moving too far ahead of Peter, but also not stopping at some point of either frustration or success.

This listening involves a complex process of putting the other person first. It involves repeated trials and many experiments. Listening is often done best by a person who is more familiar with the territory than the dreamer, as this person knows at least some of the doors that can be opened, though perhaps in a new way. The listener must be prepared to act in a trustworthy way while freely giving trust to the dreamer even when that person is floundering.

The listener must encourage and challenge the dreamer or else he or she may never really interact with daily life as it is. This forcefulness must be kept in balance with "waiting," or moving forward only when the dreamer is truly ready to move. Otherwise the dreamer loses control of the process, becoming subject to the will of the

other who would again define the uniqueness out of the dreamer's vision.

The listener may set aside some of her or his own dreaming for awhile in order to truly empower the dreamer.

In a listening relationship like David's and Peter's, however, it becomes clear that it can go on for many years because it is part of the listener's dream and gift to be a good listener. The listening relationship thus has the potential to be a mutually fulfilling one.

In small ways we have all listened and waited for one another at some time. But like all gifts, the humility and willingness that characterize true listening have been honed to a fine edge by only a few.

Listening and Dreaming a New Community

In the past and at this point in history we offer the greatest gift and power of listening to another's dreams mainly to a few powerful members of our world. We freely give the power and resources to make dreams a reality mainly to a few individuals favored by relationship, wealth and other lucky breaks.

Other more typical citizens depend on the community as it was presented to them and other strokes of fate to be able to live out their dreams and enrich the world with their presence.

Still others, like the majority of people labeled handicapped, have been denied the empowerment of being included in the listening circle. People, influenced by prejudice and structures that declare that the people who are disabled are not truly human and have no meaning in their lives, have cut off this listening relationship. This has also closed off the opportunity that our communities would be strengthened and enriched by the vision and efforts of people with disabilities. Tragically these exiles are sometimes the very

gifted dreamers that the world could rely on the most to engender creative, renewing change.

These thoughts are offered in the very personal hope that they may encourage the reader to enthusiastically take on a new challenge. Look around yourself for an opportunity to enter into relationships with someone who has been exiled. Act on the faith that this person has dreams and hopes much like your own and that this person has meaning in her or his life that can be conveyed to you and that has the power to enrich your life and the lives of others.

Suppose for a time that this person may be the bearer of a deep and creative dream. Bend your will and inner and outer ear to listen to this dream. Walk into the daily activities and environments of life with this person as dream and reality interact in a creative dance of meaning.

Try this and may you rejoice in all that you create together.

On Dreaming

Dreaming is a process of communication that all human beings participate in. However in our culture dreaming is not well understood,.

It is possible that dreaming will tell you exactly where a person needs to go in their life and also what it is that they have to contribute along the way to the people that they play with and work with and learn with. If we become very good at listening to what a person's dream is –as we can through the MAPS process*– we become very good at supporting them to find their way of life.

Many cultures have understood that dreaming is an essential part of being a human being. In those cultures people often spend time sitting around and just talking to each other about what it is they would like to do in their lives.

In our culture most dreaming is done through a process of fantasy. So, for example, for many years I had the fantasy that I would love to be a truck driver. And my truck was a very, very high tech truck. One of these very large, more than eighteen-wheelers, rigs, that has a bed in the back so you don't have to stop on the road. And the

* MAPS is an approach to person-centered planning that supports a person and those who know them to name the gifts the person can offer and create opportunities for the community to receive those gifts. To learn more, see John O'Brien, Jack Pearpoint & Lynda Kahn (2010) *The PATH & MAPS Handbook: Person-Centered Ways to Build Community*. www.inclusion.com



purpose of my truck was to drive things from Toronto to California, I would get lots of money for doing this, and I would work for six months of the year and the rest of the year I wouldn't have to work

because I would make that much money. And in the rest of the year, I would rest and reflect and do other things.

This was my fantasy. And I used to be very embarrassed about this fantasy because obviously I'm not going to be a truck driver. But over the years I've met a number of people who don't use words, and they began to teach me to really pay attention to what I was dreaming about. They taught me by showing me that they could really communicate with other people even though they were not using words. I began to look for where this communication is coming from.

I got over my embarrassment about my fantasy, and I began to tell it to other people. Now I have a very strong support circle. And my support circle listened to my dream and what we figured out very easily was that **my dream had seeds in it**. These seeds are ...

- ...that my work is very important to me.
- ...that I want to get around, in fact I want to get around the whole continent as part of my work.
- ...that I want to bring something to people that is very important to them
- ...and, that I want to make enough money by doing my work that I can spend time at home resting and reflecting and learning other things to bring to people.

I now travel internationally talking to people about how we can support all of our diversities so that we have gifts to contribute to each other in society. My dream has come true. And my life is very satisfying to me and it's also a life of contribution to other people. And all the information that we needed was in that dream about my being a truck driver.

In the MAPS process we listen to what the person's dream is. We don't listen with ears that say, "Oh, this is very unrealistic! This could never come true." No. We have ears that are listening for the themes of life that are very important to this person. What do these themes mean to this person? And as we disclose what those themes are, we can ask everyone in the room, ***What are some ways we can actually take the seeds that are in the dream and plant them in our community right now. How could we be at work with this dream right now? What are some ways we could do that?***

This is where the other side of the dreaming comes to reality. Because in the seeds of the dream are the ideas about the gifts this person has to contribute to other people.

The problem with most kinds of planning around people who are vulnerable is that we focus on what's wrong with the person or with their family. And as we focus on what's wrong with them, we end up with ways to try and fix them but no way to move forward in their life. And very often this kind of plan leaves people stuck.

With MAPS we're not looking at what's wrong with the person. We look for what it is that this person is trying to contribute to other people in their community? What gifts does this person have that the community needs to grow richer and grow stronger?

The dream has in it the seeds of the person's gifts. In my truck driving dream, my getting around and giving things to other people is a

very important part of my gift. And in fulfilling that gift, I actually employ other people. I hire five other people to help me get around the country. I use a van, so I'm paying for the the van and for van repairs. I use airline tickets so I'm keeping the airlines in business like thousands of other people. Those expenditures are are also part of my contribution to other people.

So in the dream we will find some ways that the person that will be a real contribution to other people. It can something that is very, very simple, but makes a solid beginning. For example, many people disclose that they really like to make other people happy.. If we use that gift, we have somebody who is going to be a really great generator of relationship in the community.

Whatever the gift is, we then have the opportunity to sit down together in the circle, in the MAPS process, and say, "OK, how can we use these gifts, these particular gifts, in the community?"

Centering Our Planning on People

In the early '80's something surprising began to happen. People set about designing ways to create plans with individuals who have some sort of disability label. This new type of plan was focused on one person only— an almost extravagant idea.

People started to do workshops to teach such planning and share new techniques and insights. I attended just such an event in 1983. It took place over an entire week. We examined the activities that usually occupied us as busy working adults throughout a day, a week and a year. We experimented with planning a similarly full day, week and year with some people who were living in group homes. It was exciting to realize that people could break out of isolated, boring situations and, with the right supports, be active participants in the communities around them.

By the end of the 90's the available selection of planning processes ranged from quick and easy to implement through to comprehensive and intricate techniques. Person-Centered Planning had become a distinctive and rich approach to supporting people who are labeled disabled. Many, many stories accumulated showing how useful such planning is when friends, families and service providers aim to support a vulnerable person to participate as an ordinary citizen with other citizens in ordinary places.

The activities we call Person-Centered Planning were inconceivable forty five years ago. Today's widespread adoption of Person-Cen-

tered Planning marks a deep shift in our culture. A welcome change is taking place in how we view people, diversity and ability.

The first aspect of this cultural shift is that there is a growing appreciation of the personhood of a person who has been labeled disabled. This has not always been the case. Throughout history—and too often today—people with mental, physical or emotional challenges were and are viewed as something other than human.

What do others see in you when they recognize that you are a person? They see many things, of course, but three things are fundamental.

First, people see that you can play a significant role in the economy—the rich network of activities that gets things done in our communities. As economic participants people create and produce things, pass along information, buy and sell goods and services, form formal and informal work teams, hold down jobs, employ others and make demands on “the market”.

Secondly, when people see that you are a person they see that you are responsible. Responsible people set the course of their lives, make choices, carry out decisions, solve problems, ask questions, make judgments, seek out better information and resources, hone their skills, and reliably support other people’s participation.

Thirdly, a person builds and sustains relationships. People typically have a wide range of family, friend, casual, work, neighbourhood, close and distant relationships. Most people know hundreds of other people. Being in relationship is a core experience for human beings. We define our identities in terms of these connections. People expect people to enter into and sustain a wide variety of relationships.

If someone falls short in one or more of these areas of economic participation, responsibility and relationship then people could use this as evidence that they are not a person. People with disability labels typically are jobless and play few or no roles in the economy except to “consume” services. They rarely carry out responsible roles, and frequently are extensively supervised—by educational assistants, case managers, social workers and more. People who are labeled disabled also typically experience isolation. They nearly always know fewer people than their typical counterparts, and the relationships they do have are shaped to a large degree by the human service system. So instead of knowing and contributing to a broad range of people based on interest, neighbourhood, employment, family and history, labeled folk usually know and contribute to a smaller range of people largely drawn from people who are paid to be in their lives, family and other people who are labeled disabled.

Given this reality people with disability labels have often been considered non-human throughout history. Even today some “experts” actively promote the notion that the personhood of people who are labeled disabled should be “measured”, and, if they don’t meet the standard, these “non-persons” should be permanently isolated in institutions or even killed.

It could be natural to assume that lack of economic participation, responsibility and relationship are the inevitable outcomes of having clear physical, cognitive or emotional limitations. It could make sense to believe that all this adds up to diminished or nonexistent personhood. Why not believe that disability is a tragedy that must be accepted and coped with and that these limiting circumstances deprive a person of their essential identity? The evidence points to this!

There is a cultural shift in play, however. This change in beliefs declares that difference is not a tragedy but rather something to be understood and celebrated. The cultural shift I am referring to is the growing awareness that all human beings are persons by virtue of being born. One benchmark of this new understanding was the proclamation of the *United Nations Charter of Human Rights* in 1949.

With this change in the way we value people has come an alteration in how we perceive limitations in people's minds and bodies. More often today we recognize that people who are labeled disabled are people with the same rights and possibilities as anyone else.

Once the truth that everyone is a person is accepted it becomes possible to see that society has placed many barriers in the way of people with unusual differences. These barriers destroy relationship, prevent contribution, and diminish capacity. The isolation, non-participation and lack of responsibility that seem to be caused by disability are in fact the result of the lack of appropriate support. What is appropriate support? Citizens everywhere require the same sorts of support in order to take their places in society –transportation, housing, stable minimum income, education, information, relationship nurturing, etc. Different people need these supports in different ways. People with unusual bodies, minds and emotions need the same supports delivered in different ways, too!

Person-Centered Planning is playing a significant part in shifting negative ideas about people with differences that get labeled 'disability'. Person-Centered Planning is a set of powerful tools for discovering what roles a person can play and what contributions he or she can make. Person-Centered Planning gives us a way to design and establish the citizenship supports a person needs so that

places for them to play roles in the community can be revealed and sustained.

Person-Centered Planning has three great strengths. First every method of Person-Centered Planning has a way for us to discover the unique strengths and gifts of the person at the center of the plan. Disability labels and environments often make it difficult to see a person's current contributions and how these contributions might fit into the community. For example a fascination with cars might be viewed as a behaviour problem if someone is living in a group home on a busy street. The same interest in cars is a requirement for working at the auto body shop in the same neighbourhood. Planning with a person in a personal way gives us a way to find the context that will give them opportunities to be respected and responsible.

Secondly, Person-Centered Planning reveals the value of planning. To plan is to believe that the future is not already given –not fixed by physical and cognitive limitations or other circumstances. We are becoming more willing to say that something new can come into being for someone, then go about finding the people and resources to make it so. We are discovering that planning alternative futures is better not just for the individuals themselves but also for the various communities that they may come to participate in.

One young man I know has no eyes and is very vulnerable in his health. Throughout his high school years he has had a close group of friends who go to theme parks with him, create weekly musical gatherings at his house and regularly challenge his school environment to make a bigger space for him in their bureaucracy. For some months now they have been giving presentations at local schools about all they have gained from their many shared activities as a close band of friends. Their story also has been featured in their

local community newspaper. Many, many people have been moved and enlightened by these young folks –their words and antics, their caring for each other and their spirit.

The planning that people do with this young man in order to create and sustain his public life is ongoing and creative. The results are not only beneficial for him but bring great value to his high school peers and to all the people of his town.

Thirdly, with Person-Centered Planning comes the recognition that our efforts must not be focused first and foremost on caregivers and providers –as important as these people are. We are learning to take direction from the individual made vulnerable by being physically or functionally different.

Formerly, and –all too frequently still– planning comes down to little more than resource allocation. For example a service agency near where I live inherited a small warehouse eighteen months ago. From that day to this the agency’s planning has focused on developing programs to carry out in this building. All the people served by this agency will be taking these programs whether the programs’ objectives make sense in their lives or not!

Person-Centered Planning makes us realize that the individual themselves can state the direction of their own life. Rather than assign prearranged lives to individuals, or turn only to caregivers to make decisions, we now have the means to turn on everyone’s creative potential. For example, one young man dreamed of being a doctor. Rather than focusing on his lack of academic ability, the friends, family and service providers on his planning team carefully examined what it was about being a doctor that appealed to him. Now he has an important paying job at a hospital packing and distributing sterile surgical supplies. He is a respected member of his community.

Person-Centered Planning gives us the flexibility to discover the right places for a person to be in and contribute to. It also opens up the invitation and opportunity for people to relate to the central person in ways that are more fulfilling and bring new resources, places and people into the picture.

For example, one middle-aged man is living in his own apartment. He loves music and riding around in his car. His friends and personal assistants discovered that there were many small businesses in his neighbourhood where cars are repaired. Each one requires the daily services of a courier who picks up car parts from warehouses and delivers them to the garage. This man now has an independent business of his own, delivering car parts on short notice, working just as much as he wants to, and enjoying riding around in his own car.

Before having the opportunity to have a personal approach to planning his life, this man was served in a group home and an adult day care center. He was isolated and expensive to serve. Now, for a little less money than traditional services require, he contributes to the community, and is a member of a housing cooperative and an informal ring of independent couriers and mechanics. His supporters are backed up by a large network of interested and understanding neighbours and colleagues. Clearly he and his community are much further ahead.

Person-Centered Planning is one aspect of an important cultural change. This change is one of recognizing the value of diversity in every aspect of life and relationship. This new perception focuses on the value of each individual and the importance of each person’s unique contribution to the broader economy and community. Person-Centered Planning is not just a new fad in support service tools

of the trade, Instead Person-Centered Planning is part of a bigger desire to build a world that works for all its citizens.

Person-Centered Planning: A Key Element of Inclusion?

Imagine! Imagine a society where each and every person was respected and interacted with, from birth, as if their particular interests, perspectives, capacities and challenges were fertile sources of valuable goods, services, opportunities and relationships to everyone else in that society, and beyond.

Imagine that it was recognized as obvious that the more diverse those interests, perspectives, capacities and challenges the more vibrant and resilient society would be. Citizens with rare characteristics would quickly be drawn into processes designed to ensure that their uncommon gifts were as widely available as possible in communities of their choosing.

Such processes would include deep listening, relationship building and enhancement, brainstorming, frequent revisiting, encouragement and challenge, and perseverance. The element of planning would certainly be present, but no plan would supersede the need to stay deeply connected with the person's growing awareness, relationship network, dreaming, and willingness to participate and contribute in the community.

Everyone would believe that they had a right to several such creative gift connecting processes in their lifetime and everyone would expect to be included in such processes with and for their neighbours.

We do not live in such a society – yet. Today we struggle to release diversity from the oppressive social processes that try to fix or suppress almost anything human beyond a narrow range of “normal”.

[We must be inspired and informed by] stories and learnings from many who have struggled against “normal” in order to value diversity in our world – people who are building Inclusion.

Participation Through Support Circles

Most people who work in a professional capacity vis á vis people who have been labeled disabled have been shaped and trained into viewing disability as the focus of their efforts. Regardless of what one's role is, disability is the reason for that role to exist. If one does therapy it is because a circumstance limits the client's physical or mental functioning. If one finds residential placements it is because the client has a limitation leading to a need for unusual support in typical daily activities. Even if one is an advocate it is because the presence of disability in a person's mind and/or body often puts that person at risk of negative social circumstances.

Most family members and friends of people who acquire disability labels are shaped by our surrounding culture to adopt similar approaches.

This simple fact leads into the greatest dilemma facing people everywhere who are, or who work with, or who care about people labeled disabled. That dilemma is captured by the slogans adopted world wide by people who live with these labels: "Label jars not people." and, "Call us People First."

Even those who try consistently and faithfully to relate to people as people find that disability inescapably remains at the core of most interactions. The very nature of our culturally given perception of disability and our response to it seems to obscure our perception of the people behind the labels. What can a concerned person do?

You may find that by becoming a circle builder you may find an opportunity to actually make a difference in the lives of some people.

Support circles break through the disability focus in several ways. Most significantly, circles are powerful because they exist to honour, support and make available a person's capacities and interests, not his or her deficits. Support circles are formed to be vehicles for people to discover and to talk about ways in which a person could be contributing to the wider community through, often overlooked, interests and talents. They struggle to communicate to a wider world what capacity the focus person has to enrich others. They discover or create places, supports and contacts that will make this person's participation grow and develop.

Secondly, support circles are powerful because their focus is on relationships and not individuals. Circles function primarily by bringing the focus person into a richer, more diverse network of listening people. The person's nature and ability is unfolded by the interactions fostered by the network. Disability loses its power to focus people's time and energy. Disability is disempowered.

A support circle belongs to the world of participation. Just the initial establishment of a circle is already a step forward to having someone participate in the community. The focus is on one person yet all the members of the circle typically will experience their participation in the circle as a vehicle for examining and improving their own contributions to society.

Although a support circle is not always necessary it has a unique power for rapidly changing the life experience of an individual who is facing great barriers to participation. A circle is a creation in the area of relationship, meaning and interaction. People experience

being part of a circle as 'natural' and they 'know' how to offer both formal and informal support to each other.

Circles also empower circle members and builders because they are unpredictable. Energized by multiple, complex relationships they often become magnets of synergy, taking advantage of 'lucky accidents' - opportunities that cannot be predicted or bureaucratically managed into existence. This living essence of circles drives out the deadening spirit of disability thinking.

The lives of people who have been 'helped' are usually scarred by disrespect, physical and emotional abuse, and broken relationships. Often these wounds are the result of well-intentioned interventions. At the beginning and throughout it is important to recognize that support circles have power - both to support or to hinder. The person who is interested in starting circles can still be drawn into disability as a focus. A personal discipline will help restrain them from doing this harm in a vulnerable person's life. This practice is outlined below.

Build a safe course by following these steps.

- Give up disability, its language and its forms. People are opportunities and people have opportunities to enrich community. Learn to see these.
- Practice inclusion to learn Inclusion.
- Dream. Invite people to listen to your dreams.
- Listen to other people's dreams.
- Say 'Yes'.
- Listen.
- Give up doing what doesn't work.
- Invite diversity into your own life.

- Recruit a coach. Be a coach. Together support each other to learn circle building more deeply.

In the gathering of the circle the intention is established to listen to a person's dream and to create the resources and openings required to bring this person's dream into the community. The focus remains on the person who is vulnerable to being isolated and to being a non-participant.

The following are the steps required to create a support circle:

1. Figure out who the circle is for.
2. Invite.
3. Ensure that dreaming, story telling and listening happen at every circle meeting.
4. Keep the circle meeting.
5. Make sure that the focus person says 'Yes' to something that the circle offers.

First of all it can often be a little mind-bending to figure out who the circle is for. In the situation where the focus person is an adult who speaks for themselves the scenario is fairly straight forward. Such situations are rare. More typically one person is the named focus but the real focus is on a parent or an advocate who typically speaks for this person.

There is nothing wrong with a parent or an advocate being the focus. In fact when the circle involves children it is essential that the circle be formed around the parents). The issue is simply that when the focus is confused the process gets unclear and the action stalls. Therefore it is essential that this issue be sorted out, likely on many different occasions.

Occasionally the focus of the circle will shift for a short period of time. This is a good thing unless for some reason it is difficult to return the focus to the person the circle started for. In such a situation consider starting two circles that are interconnected by having some joint membership. This is a useful strategy in situations like a teacher with a vulnerable child in a regular classroom or a parent with a teenager who is vulnerable to being labeled. For example the teacher could have a circle of adults including the parents of the child and some of the child's classmates and the child could have a circle of children from the class and from the neighborhood.

Inviting is a critical stage often full of struggle. People typically say that they do not know anyone to invite. This is absolutely not true yet in a certain sense the experience is quite real. After all it is to be expected that the person's life is full of paid people and others focused on therapy and advocacy plus lots of other people who have been carefully trained by society to see this individual as limited and in need of fixing. The dynamics of the disability focus make it almost a certainty that all these people have been interacting in ways that push each other away. It doesn't occur to the individual in question that some of these very same people are able to and in fact would love to have an opportunity to foster participation.

Keeping the dreaming, story telling and listening alive is not difficult. Yet someone must always watch that dreams don't drop off the agenda. We have all been carefully trained to become busy planners and behavior police. Listen for dreaming, stories and listening and keep the circle going.

The job of keeping the circle meeting arises because circles typically experience either great success or unexpected overwhelming barriers right at the beginning. In either situation the disability focus teaches us to give up because if we have succeeded then the situation

must have been fixed and if we have failed it must be unfixable. It usually takes time for people to catch the rhythm of dreaming, story telling and listening. In fact the person is included as soon as the circle begins to meet since it is the journey of interactions and meanings and the listening to dreams that counts much more than the outward successes. In time, as the circle experiences the invention of its own story and as 'successes' emerge from unexpected directions, the issue of meeting will be less critical.

The point is that the support circle is the vehicle of listening to dream. The listening must continue until there are enough other possibilities of listening in the individual's relationship network. Even then, life is very fragile, and the circle may need to be called together if the ghost of 'disability' raises its head again.

Perhaps the biggest surprise will be in how much work there is in getting someone to say 'Yes'. In many subtle and devious ways people have learned to say 'No'. When a circle listens to dreaming the listeners will begin to offer all sorts of opportunities and resources to the focus person. They do this because they are human and not because anyone asks them to. People will make suggestions of other people that might like to join the circle; they will offer to find jobs; they will offer to come and help out; they will offer to go to meetings or write letters; they will offer to make cookies; etc., etc., etc. And the focus person will say 'No' to it all. They will say 'No' because it is the wrong people; They will say 'No' because it's the wrong job; they will say 'No' because they can do it better themselves; they will say 'No' because they don't like cookies; etc., etc., etc.

Saying 'No' is a behavior encouraged by disability focus. People don't realize that 'No' limits possibility and that giftedness can only grow out of 'Yes'. In the world of participation the decision to say

'No' must be taken only after careful reflection and because there is a boundary to possibility that you want to make. It is the facilitator's job to get people to say 'Yes'.

In summary, circle building is a five step process liberating a person's participation in community. Like all simple things in life, there is an underlined integrity which must be honoured if support circles are to be effective. This integrity requires a commitment to give up disability and its focus on fixing people.

Building relationships, building participation and building community take time and commitment. They are a slow process that often takes years to reach full fruition. Yet, paradoxically, participation and relationship are the road to truly supporting vulnerable people. Nothing else works.

Personal Assistance

What It Is and What It Is Not

Personal assistance is a form of support for people who are labeled disabled. People who have been given a disability label are people who have an unusual limitation in their physical functions, their thinking and/or their emotional expression. For example, they may use a wheelchair for mobility, or their speech may be inarticulate or they may have thoughts and perceptions that other people don't have.

Until recently society has had only four responses to a person who becomes classified as disabled as a result of birth anomalies, injury or illness. The first response is to go to great efforts to bring or return the person to "normal" functioning - whatever "normal" is in any particular society. When these efforts are successful a person can keep their status as an "ordinary citizen".

For example, great strides were made in medical and rehabilitative technology to support injured veterans of World War II. In addition governments provided housing and education vouchers to any soldiers who could use them. As a result many veterans that formerly would have not survived, or would have remained isolated and dependent in hospitals, instead became neighbours in communities everywhere.

When a person cannot achieve "normal" status, sometimes their differences opened a specific role for them in their community. For

example, until very recently, a person with visual impairment would expect to learn to cane chairs and the community would expect that role to be reserved for that individual. Formerly, in some aboriginal communities, a person who had thoughts considered irrational would become a wandering storyteller, freely seeking and receiving friendship, food and shelter for weeks at a time in different homes.

When these responses to troubling differences don't work, compassionate custodial care has often been the next response. People with different abilities frequently spent their lives in home-bound or institution-bound situations, being looked after and/or guarded by others. Thus communities everywhere often supported, and still maintain, asylums of various types.

Sometimes there has been no available and willing caregiver, no "special" role and no asylum. To this day vulnerable people are sometimes killed or "allowed to die".

In the last fifty years many people with physical, cognitive or emotional support needs, along with family and friends, have fought for the opportunity to live, work, and participate like "regular folk". They needed a different response than society has been accustomed to providing. They weren't going to become "normal", they didn't want to settle for stereotypical roles, they didn't need to be "cared for" and they certainly weren't prepared to die. Leaders invented the unique support they required and fought to make it widely available.

They invented personal assistance. What is personal assistance? It is not being a nurse, a butler or a housekeeper although at times it may resemble these roles. Personal assistance is functional support provided through a personal relationship. It is a response that makes it possible for people with unusual abilities to participate fully in the community, contribute to society... and have great lives.

Personal assistance involves assisting in the daily tasks that a person cannot carry out by themselves or that they find so time consuming as to interfere with other important activities. These tasks fall in the areas of hygiene, nutrition, grooming, mobility, and communication. The need to perform these tasks can arise anywhere, any time—at home, at work, out shopping, visiting friends, etc. Personal assistants are the important "sidekicks" who assist people with these essential activities, making everyday participation a reality.

The types of tasks performed by personal assistants are the same in all situations. The actual functions vary depending on the individual who is being supported. For example, one individual who uses a wheelchair and is an accountant may require help with showering (hygiene), food preparation (nutrition), support to get into a suit and tie (grooming), chauffeuring of their accessible van (mobility), and filing and desk set up at work (communication). A person who has cognitive differences and owns her own baking business may require someone to remind her about showering (hygiene), make a shopping list with her for her home and business kitchens (nutrition), coach her on clothing selection (grooming), assist with budgeting for bus tickets (mobility), and do invoicing and bookkeeping for her baking business (communication). A third person who has extreme mood swings and is an artist may need physical assistance to bathe when depressed, coaching in food selection, reminders about the need to shop for clothes, support to recognize when not to drive, and assistance with advertising and selling creations.

Personal assistance is paradoxical in nature. Like other forms of support, well executed personal assistance is nearly transparent. Just as I don't want to be conscious of the elevator that is transporting me hundreds of feet in the air, and I soon stop noticing the hum of the refrigerator that is preserving a week's supply of food, a skilled

personal assistant can perform his or her functions without overshadowing the contributions and personality of the person who is being assisted. When I am giving a speech to two thousand people, the audience remains unaware of the bathing, grooming, wheelchair maintenance, chauffeuring, and note taking that got me to the podium.

Unlike an elevator or refrigerator, though, the person of the personal assistant is an essential element of the job. Personal assistance is an ongoing transaction between two people. It is a dance which is led by the person who is building and fulfilling their place in the community and who relies on the interface their assistant provides to be able to function in an otherwise inaccessible world.

Each person in the dance must be fully committed to the dance. The personality, interests and skills of the assistant and the supported person must complement each other. Each must bring a willingness to be with each other, open themselves to each other, be honest, straightforward and respectful, and each must responsibly ensure that the leader of the dance really leads. The leader is, of course, the supported individual.

Personally, I hire only energetic people who love to drive, are physically well and strong, and who are motivated to change the world. Why? Because I travel a lot as part of my work, I am active for fourteen to eighteen hours a day, I go into inaccessible places fairly often and I am an activist building an Inclusive world. My personal assistants have to be quick, strong and motivated just to keep up with me. Another person with the same sort of quadriplegia could be much more interested than I am in neighbourhood activities, like gardening, church and going to movies and theatre. Their personal assistants would need to very different persons.

These essential qualities of personal assistance –transparency and relationship– are rarely understood or recognized. A number of standard practices still exist that diminish the potential of this support. First, individuals are rarely provided with the money and the opportunity to hire their own assistants. Instead money flows to agencies and schools which, in turn, hire a cadre of workers and assign them a “case load”. Supported individuals have no choice over the identity of their assistants, their job descriptions, or the type and means of their training. Consequently, the personal nature of the working relationship doesn’t get established and the support doesn’t become transparent. The subsequent activity cannot lead to sustained community participation.

Another limitation on the full development of personal assistance has been that resources are typically doled out in meager amounts. Most personal assistants are underpaid and so leave their jobs too soon. This creates instability and emotional stress for the supported individual, their family and friends. Also, because of lack of funds, many people who use personal assistance have fewer hours of support than they really need to become full participants in society. While nursing and group homes still have ample resources and continue to contribute to isolation and dependence, the support that truly leads to community participation is rendered inadequate.

Yet another limitation on the full development of personal assistance has been that resources typically are allocated only to individuals who can already show that they can direct their own “care”, or to family members of those who have the “potential” to be self directing. This leads to a vicious circle. Personal assistance creates the capacity to be responsible. Without personal assistance many individuals who function in unusual ways have no means to develop and demonstrate their own capacity to create and manage their

community roles and personal accountabilities. If access to personal assistance depends on first demonstrating capacity, many individuals will forever remain segregated and helpless.

In 1979 I was a chronically ill patient in a state supported hospital for people who are expected to die of their physical problems. In 2001 I am a self employed homeowner who works internationally, employing four individuals. Neither my physical limitations nor my mental acuity have changed much over the years. What did change was that the province of Ontario, Canada was persuaded in 1980 to pay me to hire my own personal assistants. I was put in the driver's seat of my own life.

Another limitation on the acceptance of personal assistance as the ideal support vehicle is that the powerfully personal nature of good support rarely gets recognized and nurtured. A well supported individual and a truly attentive personal assistant typically form a good friendship - one that often lasts long after the job has ended, and may even deepen into love. Agencies often try to ignore or forbid such intimacy, leaving both supported individual and assistant vulnerable to a host of difficulties.

Confusion of roles, emotional fragility, misunderstandings, even abuse are rampant in agency-driven support. Caregivers blame the clients and the service users blame the agency and staff. In reality, the problems arise because the essentially intimate nature of personal assistance is being ignored or suppressed. Rather than guide and encourage two people to take on a uniquely vibrant journey in their lives, agency driven policy usually assumes that nothing is going on and mandates that nothing will happen -- instituting denial. Both people are expected to act like robots, and the capacity of the relationship is diminished, leading to less participation from supported individuals and dissatisfaction among workers.

In reality intimacy is an ordinary aspect of personal assistance. This intimacy is not sexual. It arises because people are in physical and emotional contact, sharing a deeply personal experience. Their communication has the potential to reach profound, nonverbal levels. Any intimacy has the capacity to spark love and hate. Personal assistants and supported individuals experience this emotional, spiritual roller coaster as an almost daily matter of their lives. This must be recognized as a fact. People on both sides of the relationship must be offered support to recognize the true nature, value and power of their experience.

I have an active support circle of friends and colleagues. I also have four to six personal assistants at any particular time. Several members of my support circle make themselves available to hear assistants' concerns, explanations and proposed solutions. My support circle does the same for me. From time to time, and especially when there is a problem, a circle member will bring us together so we can talk about our realities.

Many of my personal assistants have worked for me for at least three years. Several have remain my friends long after working for me. I believe that this has been made possible because we are sustained by my community in negotiating the intimate aspects of our journey together.

Personal assistance is an essential evolution in human support. It makes it possible for a much wider diversity of people to live, thrive and take their place in the world. As a community support, personal assistance deserves better funding, deeper understanding, greater visibility and wider availability. Governments must adopt personal assistance as the support of first choice, not last. Schools must list personal assistance as a valued career choice. We all must recognize that this support is as essential to fifteen percent of our population

as transportation and sewage disposal is to all citizens. Our communities will be stronger when we recognize, celebrate and adequately resource this relationship-based vehicle for creating and sustaining full participation.

In the Spirit of Inclusion

There is in the world today a vibrant new culture. It is young and rough, but its birth has been true and with proper nurturance its life and growth promise to be dramatic. It is the culture of inclusion.

The culture of inclusion begins in the affirmation that all human beings are gifted. This statement sounds strange to many ears because our traditional world reserves the adjective “gifted” for only a chosen few whose talents and abilities, usually in very circumscribed ways, impress, enlighten, entertain or serve the rest of us. The inclusion culture views giftedness much differently.

We affirm that giftedness is actually a common human trait, one that is fundamental to our capacity to be creatures of community. Gifts are whatever we are, whatever we do or whatever we have that allows us to create opportunities for ourselves and others to interact and do things together –interactions that are meaningful between at least two people.

So, for example, if you are interested in an evening’s fun of softball and you have six people on your team you have an opportunity to offer to several people, including some bystanders who might just end up watching. But you can’t play softball without at least seven people per team. So when the seventh person comes along, that person’s presence is a gift to many other people, even if she or he doesn’t play very well.

Our presence is the fundamental gift that we bring to the human community. Presence is the foundation of all other opportunities and interactions –of everything that is meaningful in our lives.

Also fundamental to each person's presence is each person's difference. In fact presence is not possible without difference since even on a very simplistic level difference is essential to life. For example none of us would be here if the male and female difference did not exist. Meaning depends on difference as well since if we were all the same there would be nothing to share or contribute to one another. Therefore, not sameness but presence and difference are fundamental to life and community.

In addition to our presence each of us has a grab bag of other ordinary gifts that allow for us to create and participate in daily opportunities. From getting up, making breakfast, washing dishes or loading a dishwasher, talking on a telephone, writing on a piece of paper, listening to another person, getting from one place to another, enjoying some music, expressing an opinion, going to a meeting, playing with a baby or having fun with a friend, a variety of simple activities taking place in ordinary places on ordinary streets make up the fabric of the vast majority of our work, family life, private life and public contribution.

Beyond ordinary giftedness there is extraordinary giftedness, the kind that extends opportunity for interaction and meaning to a larger number and variety of people. One person is not just nice to be with but is a truly funny comedian; another doesn't just get around but dances on skates beautifully; another not only shows up for the PTA regularly but has ideas that are engaging and changing the face of the local school board.

Each person has a variety of ordinary and extraordinary gifts. The people whom we call handicapped are people who are missing some

typical ordinary gifts. However such people also have a variety of other ordinary and extraordinary gifts capable of stimulating interaction and meaning with others.

In fact it is not just that walking is a gift and not walking is not a gift or that knowing how to put your clothes on right is a gift and not knowing how is not a gift. Rather walking is a gift and not walking is also a gift; knowing how to dress is a gift and not knowing how to dress is also a gift. Each creates the possibility of meaningful interaction.

The affirmation of giftedness creates the need for us to organize our homes, schools, work places and other establishments differently and this is what has given birth to the inclusion culture. In the past we became efficient at separating people into classifications of supposed sameness. Now we are struggling to build our community life up from the foundation of our enriching differences.

In North America the Canada geese fly south every fall and north in the spring covering thousands of miles each way. The birds fly in a V-formation, with one bird in front followed by two diverging lines of flyers. The lead bird breaks the wind resistance for the two behind who in turn are shields for the bird behind each of them down to the end of the line. But in the course of each flight the leader drops out of position to go to the end of the line and to be replaced by one of the following birds over and over again. In this way no one bird is ever leader so long as to be exhausted or to deny opportunity to another bird. In turn each bird is the guide. This a model of organizing a community so that the gifts of all benefit everyone.

In the schools we see classrooms of creative learning being founded on the support that children and teachers can offer to each other in the spirit of co-operation. In housing we see people forming

inclusive, intentionally mutually supportive developments where vulnerable people anchor circles of caring. In decision making bodies we see people taking leadership in turns based on their energy, experience, desire and availability, being able to give way to one another at the right time.

Of course these efforts at inclusive community are isolated and foundationally weak. But the seed has been well sown. These efforts support each other and inspire others to change. The story of inclusion has a vigorous beginning and promises a very creative future.

Building the School Community

The foundation of school inclusion is community. The student who has been excluded can only be welcomed to the extent that people work together and rely upon each other for support and inspiration. Regardless of a person's role in the school community, whether student, teacher, principal, administrator or parent, all must recognize each other's significance and build relationships with each other. The uniqueness of one student often is the stimulus to bring these relationships together.

We can look at the school community in at least two different ways. From one point of view, the school is an institution with a purpose; to fill each new group of students with as much knowledge as possible. To fulfill this responsibility schools are organized as hierarchies with a chain of authority and responsibility. It is not easy to see how everyone can belong in this chain of control.

But schools are also places where people gather to become involved in freely chosen relationships. People find their own identity here and create their futures out of living everyday. These lived relationships can cut across classes, titles and other boundaries and divisions. These relationships are created out of the discovery of one person to another, of a sense of enjoyment in each others presence and contribution, a sense that " you help me get through my day ".

David Hasbury is co-author.

There is no limit on who can belong in this network of meaning. People who are seen as handicapped or unusual in other ways have a great deal to contribute to relationships and to the meaning of their own lives and the lives of others. Hierarchies tend to exclude these people because they have no obvious place. But by recognizing and calling upon the people in the school as members of the community, a place can be found for the person who was excluded. Indeed it will soon become obvious that the community has been missing this person.

Inclusion is fundamentally a community building process. Those who are carrying it out will welcome people with many different roles together, including the excluded student and members of his/her family. In particular fellow classmates will be supported and encouraged to use their strengths and creativity in welcoming the new member. A process will be put in place which allows each person to struggle with the problems that inclusion evokes. In this way the entire community can be responsible for each member.

Taking direction from the child

The energy that fuels the inclusive community comes from the dream that the parents have for their child. But just as importantly, the direction that the work of building community must take is set by the excluded child and his or her dreams.

This may not seem obvious at first, but in fact this is not a complicated reality. Each of us dreams about the same things. We dream about having friends, being loved, doing interesting things, and having a sense of importance or that our life is not wasted. We hope to be healthy, to be secure, and to have privacy and intimacy in our lives.

At the same time each of us has a unique expression of each of these dreams. One person wants friends to go skiing with; another would rather play chess or rap about politics. One person likes long walks in the woods; another can relax in a crowd. To know that would really meet the requirements of someone's dream, we have to know their story and you have to be willing to spend the time to listen to their ideas. You also have to walk the road of life for awhile with them while they participate in all those daily activities which shape them toward one expression of their dream and away from others.

As someone gets near to having their dream satisfied and as they are involved in activities which help them grow in their understanding of their dream, she/he becomes more and more of a gift to the others surrounding her/him. In other words the person becomes an exciting skiing companion, a stimulating chess player, a relaxing person to stroll along with or what ever.

The inclusive community can only be built on a solid foundation if the dreams of the excluded child are heard, understood, and enacted in daily life. By doing this the child becomes a gift to the others just as they become a gift to him/her. Therefore it is imperative that the bridge builder or those who are building the community hear the child's dreams and his or her ideas on how the dream can best be fulfilled. Even when these ideas seem to be completely unrealistic, steps must be taken to move in the direction that the child sets. Even small steps will offer the child opportunities to experience the interaction of dream and reality. This in turn will shape the child's dream, his /her giftedness and the welcome that the community offers.

The knowledge and understanding of the child that comes from this enables the bridge builder, family, etc. to now speak about the child not as a handicapped individual, but rather as a person who

has dreams, hopes for the future and a capacity to contribute to reaching them. Having a greater understanding of a person's capacities also allows the community to recognize how this individual might actually contribute to the nature and quality of the community.

The Circle of Friends

A circle of friends is a form of support that helps a student to become included. A child has many gifts to offer, but people often feel that they do not know how to interact with or discover the best in this child simply because of his or her differences. The circle creates a place of listening and welcome. It allows people to break down the barriers that prevent the child from participating as a full member of the class. The circle can become a place where people both grow in love and respect for the new student and also learn to challenge him or her to be a responsible and sensitive friend.

Sometimes support circles can be started without a facilitator, but there are many reasons why a circle of friends needs a support person to help it get off the ground and to protect it from coming apart. For one thing, people may not believe in the new relationships that are being established and put pressure on the members to deny the reality of their experience. For another children do not have access to the opportunities of the world to the same extent that adults do, and so they often need an adult to help them gather together all the resources that will help them find their way and meet their challenges

Because the facilitator has such a significant impact on the circle and therefore on the inclusive community the selection of the person to play this role is critical. The person should have the respect of most members of the school, be a good and creative listener and

have the support of those in charge to allow the children to experiment with new ways and activities. This person must love and be loved by all sorts of children and have the energy to be a real part of their lives. Added to this must be the faith that the children can be responsible, communicative, and loving.

Sometime just before or after the new student arrives, the facilitator invites the class members to join the new circle. The first meeting begins with telling the story of the new student in a way that helps her to talk about her dreams. The children will respond with suggestions about how they can do things together and what problems they expect to encounter. The facilitator should encourage them to carry out these projects, and support their own problem solving. The facilitator needs to be in touch with the natural rhythm of the circle, helping it to meet as often as necessary to foster mutual support and relationships. At the same time meetings should not be overly formalized, and a simple get together at lunch time is often sufficient. Above all help the children to get a sense of when and how their meetings should be conducted.

As the circle continues to spend time and do things together they will have their own story to tell. The facilitator should support them to tell their story to each other and to other people on a regular basis. It is important to make sure that the new child's dream is always part of the story, so that each member of the circle, as well others in the community will see how the child's gifts and participation are growing. This will help the circle to keep its energy and its membership strong.

At times a very difficult problem will arise. The facilitator must help the children to talk over these difficulties and to come up with solutions. In turn the facilitator must protect the children's right to try out their own ideas. This will cause their relationship to grow

strong. It will also show the community that new and creative means of living and working together are possible.

When the time comes to build a new curriculum for the new student, the students of the circle have become the experts who can tell the teachers, parents, and principal a great deal about what will work and what their friend has to offer and gain from participating in the life of the class room.

Sheenagh Interviews Judith* on the BMX Model of Inclusion

Judith, can you tell me about your BMX model of inclusion? Can you tell me what the letters stand for and explain what each one means?

The BMX Model of Inclusion** proposes that three distinct states of Inclusion co-exist.

- **State B (Basic):** Groups allow the presence of people with diverse characteristics. State B's principal quality is that the includers share presence with diversity, but no other changes are anticipated or offered. The includers like their community as is, expect no major shifts, and the included are expected to adapt to the ways and means of the includers and to get along as best they can. Typically the included express gratitude for the opportunity and work hard to not cause difficulties.
- **State M (Mechanical):** Includers recognize that the excluded are struggling to get along, and are willing to make "accommodations". Those seeking greater inclusion move beyond simply being grateful for the opportunity to coexist and begin

* Research on Researchers is a regular feature of the [101 Friends](#) website. Sheenagh Morrison, a self-advocacy leader, conducts the interviews.

** Erica McFadden and Judith (2013) co-authored a more theoretical presentation of BMX in [What sorts of people should be included... and how? Introducing the BMX model of inclusion](#)

to focus on their rights and to advocate for support. Resources are directed to programs; policies are implemented. The dominant feelings are pity, concern, worry and anger.

- **State X (Crossover):** Both includers and the included recognize that another world is possible, one that benefits from the gifts and contributions available in the cultures, characteristics, and experiences of members of both the including and included. The perception fades that there are two sides and the distinct boundary fades.

Examples:

<p>State B (Basic)</p>	<p>A teenager with autism and no speech is kept at the back of a regular classroom, with no attention is paid to whether he is building friendships. He is permitted to develop his own learning strategies and it is noticed that his reading level surpasses his more typical classmates.</p>
<p>State M (Mechanical)</p>	<p>All teenagers with “disability” labels are given opportunities to be in a homeroom for 1st period. The school has a resource room for tutoring, an “inclusive” lunchroom, and Special Olympics classes to replace regular gym.</p>
<p>State X (Crossover)</p>	<p>Ninth grade students are invited to form a support circle with a teen who loves music, and who also has autism and no speech. Twenty-three students meet regularly and enthusiastically for the next four years. The teen who focuses the circle enjoys participating in the school band, gym and many more classes than anyone originally expected. The other teens express their appreciation at having an alternative to being “Nerds”, “Preps” or simply left out. The school administration notes a dramatic decrease school wide in fights and vandalism.</p>

You often talk about giftedness. How can self advocates get started in getting people in their circles to move away from disability thinking and towards gifted thinking?

The title “self advocate” belongs to the **M** category of the BMX model. In the **M** state there is no room for seeing an unusual characteristic or circumstances as a gift or opportunity. The characteristic or circumstance must be categorized and labeled, then addressed through generalized programs, policies or other impersonal means.

In other words, the person who is seeking to be seen as a full participant and contributor must themselves step out of thinking in categories, such as “self advocate”, and instead seek partnership with others, seeing themselves as a whole person interacting with other whole people. The aim is to work together bringing value to each other.

You are an artist. How long have you been involved in the art community and has your art had any influence on your work on inclusion and giftedness?

I have been painting with the support of art facilitators since early 2004. In 2010 the Royal Ontario Museum invited me to put on an eight month exhibit called *Who's Drawing the Lines*. The exhibit of 23 paintings and other artifacts expressed how inclusion is developed and sustained through dance-like partnerships, such as in the work done together by artist and art facilitator.

After developing the exhibit, one of the ROM staff wrote:

For museums, someone like Judith Snow presents a greater challenge than may seem apparent at first glance. The presence of her work signifies (or demands) a radical change in attitude on the part of museums. It means moving away from the role of transmitting a dominant, mainstream ideology toward a broader

view that accepts and encompasses a wide diversity of opinion, condition, and worldview, and gives voice to people and groups that have hitherto been silent in these halls. The ROM realizes that this process will not be easy, but knows that it must pursue it nevertheless. A museum's life is also a journey...

Can you tell me about someone who has been a role model for you in your research on giftedness and inclusion?

Helen Keller – because she fully participated and made an impact on the entire culture of her time.

Jean Vanier – because he has created ways for thousands to build new life through relationship.

My father – Edwin Snow – because he taught and lived that full participation is the road to a good personal life and to bringing greater good to the world.

The BMX Model – Defining Inclusion

Introduction

Policy makers, practitioners, families, advocates and individuals continue to grapple with a meaningful, universal conceptualization of inclusion that will advance community cohesion. However, there is debate over what inclusion should look like. Some theorists have viewed it as increased community participation among those that are excluded, others perceive it as accessible structures and environments, while still others see it as relationship-building between those that are in power and those excluded. This last perception of inclusion has had policy implications in the U.S.

The U.S. *Developmental Disabilities Act of 2000* defines community inclusion as “acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities.” Subsequently, definitions such as these that are formalized in policy have driven outcome measurement. Current instruments that try to operationalize and measure progress towards a specific inclusion definition and goal such as the Personal Outcomes measure, the Community Connections Index (CCI), and the National Core Indicators (NCI) project – take a piecemeal approach to inclusion. Each instrument defines inclusion differently by only partially measuring specific thematic areas while leaving

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out others. For example, the NCI measures the number and type of relationships, while the CCI measures how Included people feel in communities. None of these constructs of inclusion are incorrect. They just err in their assumption that there is only one way to define, measure and ultimately to reach inclusion. Thus, confusion often results in how society should progress towards full inclusion – for there is not just one way define the path to get there. And often these assumptions may collide in a given situation.

The BMX Model Defined

The BMX Model of Inclusion offers an alternative approach for conceptualizing “inclusion.” This model recognizes the idea that inclusion is subjective. Building on this foundation, BMX provides a conceptual framework for defining and measuring inclusion, and how various constructions of it can co-exist simultaneously for an individual. The BMX Model describes three constructs of “inclusion” that are clearly distinct in their characteristics and outcomes: B (Basic), M (Mechanic), and X (Crossover). Distinguishing these constructs will increase the clarity with which people design their goals for greater participation, so that they are more aware of what is needed to achieve them and why conflict may result at times.

The framework of BMX was selected based on a literature review of previous constructs of inclusion. Much of the inclusion research focused on either power relationships between dominant and subdominant groups; participation activities and opportunities for subdominant groups; or perceptions of subdominant groups by dominant groups. None of the research defined inclusion from all of these areas in addition to the perspectives of the Included (subdominant groups) and the Includers (dominant group). In effect, this model provides a comprehensive definition of inclusion from

the perspectives of both the Includers and Included by defining inclusion using five different criteria:

- Attitude of the Includers towards the Included
- Attitude of the Included towards the Includers
- Actions of the Includers towards the Included
- Actions of the Included towards the Includers
- Relationships between the Includers/Included

It is from these five criteria that the three different constructs of inclusion were developed, B,M, and X.

The B (Basic) Construct

In B, there is a clear separation between the Included and the Includers, thus they can be easily distinguished from each other by each other. The Includers offer nothing more than the opportunity for the Included to be present in the same space and/or activity, while the Included ask for nothing more than to be allowed to show up and do whatever they can possibly do inside of an inherently inaccessible situation. Attitudes towards the Included by the Includers can either be hostile, dismissive or paternalistic. The Included and Includers share space, but there is very limited interaction between the two groups. If there is interaction, the Included are treated as objects of pity and in need of support. There are no meaningful friendships between the Included and excluded in this construct.

‘B’ Examples

B is expressed when:

- A group of refugees from the same threatened territory are permitted to find homes in an identifiable area of a town which formerly did not accept immigrants at all.

- A person with a disability label is permitted in a classroom without any accommodations
- A Rastafarian male, who is forbidden to remove his hat in public, is permitted to attend the Christening of his niece in a church where men typically remove their hats inside the church building.
- In a hospital where late abortion is generally recommended to women who have an amniocentesis indicating a foetus with Down Syndrome, the infant is allowed to be born.

The M (Mechanic) Construct

In M the Included and the Includers can be easily distinguished from each other by each other. In M there is an expressed desire on the part of the Includers to help the excluded. Members of the including body, frequently expressing either a charitable or human rights focus, raise awareness of the social and economic limitations faced by the sub-dominant (or Included) groups. On the other side of the Gestalt, the left out individuals and groups complain and get organized to have their rights established and met, and advocate for, use and get on waiting lists for services. In this construct the Included individuals and groups make demands to be helped basing them on rights, equality and advocacy.

Inside of this construct of inclusion, the only thing that matters about the nature of the Included members is their category. The category that reflects the reason for exclusion becomes the foundation of the group or individual's identity. Names spring up such as "Black Panthers", "Grey Panthers", "visible minority" and "TASH – The Association for People with Severe Handicaps." A term such as "self-advocate" or "consumer" will be applied to an individual whether or not s/he has ever advocated for anything or used a

human service simply because her/his physical characteristics that fit the profile.

It is important to notice here that the Includers' perspective is hegemonic. The Includers' point of view is so much the background context of the M construct that it occurs to no one that there might be some genuine value in the personal and social circumstances of the Included individuals or groups. Attitudes of the Includers towards the Included tend to be based on pity. Representative statements might be: "There but for the grace of God go I", "Isn't it tragic that he is aphasic," or "He is a survivor."

M' Examples

M is expressed when:

- A person who is categorized as "developmentally delayed" can be placed in a work training program for twenty years and never progress outside of this system to actual competitive, employment that is inclusive, yet still believe that s/he is receiving help.
- Special education classrooms are set up to modify education to a group of children of different ages with disabilities. These programs base individual education plans on deficits, thus many are limited in the education opportunities they are offered, although they are adapted. They are also allowed to visit mainstream classes, but are not seen as peers by students with no disabilities.

The X (Cross-over) Construct

X State is personal and transformative. In X something about the Included becomes directly valuable to the Includers and vice versa. Partnership is sought and established.

The identity lines blur. Statements occur such as: “Well, we’re all disabled!” or “He (She) is my friend.”

The defining quality of X is that when it is present all involved find that the contributions are mutually rewarding and reinforcing.

In other words the occurring situation is sustained because everyone involved feels that, in some paradoxical manner, they are all personally in the center of the action, both a valued contributor to and a cherished receiver of the benefits of the interactions. X Stage is sustained by intention and requires personal involvement and commitment from at least some of those in the situation for its X quality to survive for any great length of time.

X Examples

X is expressed when:

- An artist with a disability is recognized and appreciated for her work and belongs to a guild of other artists in the community. They help her to adapt her equipment when she needs assistance. She offers help in reviewing their work as well.
- A child with a disability is in a classroom with children with no disabilities and excels in his academics with the help of an assistant, who other children with no disabilities also have access to. The other children invite him over for sleepovers, and he is known as “Chuck”...not as the kid in a wheelchair with a learning disability.

Discussion

The previous constructs provide a framework to better understand how inclusion can exist in different categories. In the case of B, inclusion can simply mean, at its most basic definition, just being allowed to be Included. M implies inclusion with the extension of rights to accessibility from the Includers towards the Included;

however meaningful relationships do not exist. The X construct defines inclusion from a perspective between the Includers and Included based on the value of each other and mutually beneficial relationships.

It would be incorrect to look at the BMX categories as building on each other or as one being more valuable than another; for even in the most ideal situations, different constructs of inclusion can co-exist. For example, X usually takes place in the context of B and/or M, and is rarely found as a stand-alone occurrence, while B and M often can stand alone. Thus, the various constructs of inclusion can co-exist in any situation, leading to confusion and conflict in expectations and outcomes among actors.

Example: A mother who takes her child, Vanessa, with epilepsy to gymnastics, believes that her child should be able to participate in the same activities as everyone else in the class without any accommodations or labeling. The teacher, however, who is aware of the disability, mandates that the child wear protective gear in order to participate. The children in the class enjoy Vanessa. They think she is funny and consider her a friend. Vanessa doesn’t care if she has to wear the protective gear or not. She just wants to be Included, because she loves gymnastics.

In this situation the mother and the other children in the class take an X assumption, considering her valuable and not seeing her for her disability. Vanessa assumes B – she just wants to be Included in the activity; and the teacher assumes M – requiring that the child have accommodations to keep her safe.

Consequences can result due to these different assumptions of inclusion that can be present in a situation, which can result in exclusion.

Example: If Vanessa assumed an X role and the rest of the children assumed a B role, Vanessa would feel alienated, because she would not be able to participate in meaningful relationships with others. She may choose to exclude herself from future activities.

Example: While employers may feel that they are including people with disabilities by allowing them to be present under B, the individuals with disabilities are not treated as valued members of the team under X and are paid sub-minimum wages to be present. They are not allowed even a job coach under M. This often results in their termination, and their ultimate exclusion.

The following table provides further clarification of each category and the assumptions under each.

	BASIC	MECHANIC	CROSSOVER
Assumption	The presence of people with diverse characteristics is permitted; they are seen as holding no value.	Dominant group makes accommodations to allow participation, but the value of those included is not seen. The difference becomes the foundation for the Included's identity.	All involved find that the contributions are mutually rewarding & reinforcing. There are no labels.
Attitude of Includers to Included	Paternalistic, hostile &/ dismissive.	Veiled paternalism, may view the Included as object of charity; expressed desire to help the excluded become included.	The Included are seen as valuable to the Includers.

	BASIC	MECHANIC	CROSSOVER
Attitude of the Included toward Includers	Grateful for the opportunity to be present.	Empowerment: Included have a right to be included & have accommodations.	The Included know they are valuable and see the value in the Includers as well.
Actions of the Includers towards the Included	No changes anticipated or offered to remove barriers to participation.	Raise awareness of the issues facing those with diverse characteristics.	Personal involvement & relationship building based on those things they have in common over differences.
Actions of the Included toward the Includers	Included ask for nothing more than the opportunity to be present.	Complain; organize; advocate. Use of formal services.	Personal involvement & relationship building based on those things they have in common over differences.
Relationship between the Includers & the Included	Very limited interactions between these groups.	Segregated in services & supports. Professionalization of relationships occurs.	The boundary between the two groups disappears as meaningful, purposeful relationships between the two are commonplace.

Conclusion

Person-Centered Planning initiatives need to recognize that various perceptions of inclusion exist and that individuals sometimes may want to be Included differently, i.e. as an advocate, a friend, or they just want to be present. Individuals are comfortable and productive with diverse ranges of inclusion. What is needed are concerted

efforts to articulate and describe what such a range may look like for each person and the actors that are involved in that situation. In this way needed efforts and resources can be effectively directed to building and sustaining the mix of inclusion that an individual can personally undertake, commit to and make efforts to sustain. Further, understanding these nuances in definition will help practitioners, community members, family members and individuals realize how their perceptions of inclusion may lead to conflict and or exclusion.

Judith's Great Questions

John O'Brien

*A great question
refuses to be answered.
So it keeps leading us
into deeper connections
with each other and
into deeper thinking.*

Judith's engagement with the great questions she investigates in this collection was existential. From her earliest self-awareness until going to bed late on the night she died she never knew herself apart from the need for personal assistance with the most basic of life's tasks. Her survival depended on her gift of drawing people into deeper connections and deeper thinking—a gift so strong in her as to precipitate her circle of support at a time when she herself was exhausted to the point of hopeless silence. Always her quality of life depended on the openness of the people who attended her.

*It is essential that the attendant willingly give their mind and their body to the person being assisted so the person can tell the attendant what it is they want to do, how they want to do it, and thus live and work through the body of the assistant. If the attendant is unavailable, then the relationship doesn't work. It just falls apart and becomes abusive for both people.**

* *From Behind the Piano*, p. 111.

As Judith established relationships with teachers like Peter (see page 41), whose gifts many people overlooked because of the attention and imagination required to understand his communication, her understanding of the integral relationship between the gifts of outsiders and the strength of community came into focus. Peter's gifts had affect because of his identity and presence in a social setting that discovered its receptiveness to him. As Judith saw it, this was a matter of relationship, not a deliberate effort to help him or remedy a deficiency in him. It's power does not even depend on explicit recognition of his gift or conscious effort to include, though recognition and reflection are the foundation of Judith's learning from Peter.

Through the 1980's, alliance with children excluded from school and parents and educators struggling for schools where all are welcome and each belongs opened the question of how to create positive relationships that bridge difference in ways that benefit everyone. Willing school and classroom leaders –both adults and students– could act with purpose to cultivate belonging and mutual support. (These arts have since too often drowned in the sea of organizational anxiety over test scores.)

The struggle for inclusion influences everyone's capacity to draw others into deeper connections and deeper thinking to respond to the great questions in their own life. What is my life's highest purpose? How do I serve my community and its diverse members? How does my love and desire find expression? How do I cope gracefully with fallibility and failure in myself and others? Judith was extraordinarily passionate and daring in her personal involvement with these questions. Her many adventures and experiments in living gave color and credibility to her advice and teaching.

The frame for addressing great questions involving people likely to be excluded became clear to Judith soon after she established the friendships and self-directed system of personal assistance that supported her in pursuit of a full life. Communities flourish when they welcome the gifts of those who have been outsiders. Gifts are revealed by listening deeply to dreaming and identifying seeds for contribution. The cultivation of those seeds is the work of a committed circle of support who overcome obstacles by living the conviction that *together we're better*. People have the right to a secure home of their own and reliable ways to get where they want to go –including across oceans. Some people will require adaptive technology, accommodation or personal assistance to bring their gifts to their community. Such assistance, and the public funds to pay for it, should be under the direct control of the person or those who know and love them.

Judith never stopped sharing her well reasoned conviction that gifted listening encourages dreaming and dreaming reveals gifts whose continual exchange create inclusion and strengthen community. Throughout her life as a teacher and advisor she wrestled with the great question of how to understand and respond to disability as a social category.*

Judith was convinced that gifts easily rejected were essential to a thriving community. Her recognition of the burden of bringing these gifts to a culture disposed to overlook, inhibit or destroy them

* I am writing about this because, as far as I know, Judith spoke but did not write about her best developed understanding of this question. What is here is based on personal conversation (sometimes in the form of intense arguments, as was our frequent conversational habit) and from listening to her speak.

led her to compose a story that a mother might tell her child as an orientation to being a gift-bearer in an alien culture (page 35).

Judith knew, almost at the cost of her life, the negative cultural power that the social and political category of disability has to obscure attention to giftedness. Pursuing a life outside the boundaries prescribed for a nursing home patient brought malnutrition and abuse inside the facility and deprivation and unbearable strain when she escaped alone.

Under the category of disability, I am a lack, a problem that is supposed to be fixed if possible, hidden if I can't be fixed and, at the very least, considered something that shouldn't have happened. Those of us who have been labeled tend to go through life as if people do not see us because they are looking over our shoulder at somebody they think we should have been. Someone looks at me and sees the person that doesn't use a wheelchair, the person they think I would have been if I didn't have spinal muscular atrophy. Because to see me as I am is somehow not right, not bearable.

*The culture constantly is telling me, "This kind of body is right and your kind of body is not." So even though I know myself as a whole person, I still daily experience the sense that this is not the right way to be.**

The disability category draws people into limiting relationships.

Many people, especially parents of a newly labeled child, establish their relationship with a person who is disabled through a process of identifying a need the person is struggling with or through empathizing with an experience of injustice that the person is un-

* Unless otherwise attributed, the quotations in this chapter are paraphrased from the video [It's About Grace](#).

dergoing. Taking on the role of therapist and advocate, one person stands by the other.

*Therapy calls for the person with a handicap to be seen as needing to be fixed in some way. Advocacy calls for the person with a handicap to be viewed as a victim of some outrageous misfortune or circumstance. Both these stances have value and can lead to good for the person and the community. But neither approach calls for a contribution from the labeled person in order to sustain the relationship or the work. And if success in therapy or advocacy is not quickly forthcoming the relationship must suffer. Paradoxically even success can destroy such a relationship because success erodes its foundation.**

The disability category not only contaminates perception and limits relationships, it distorts public policy in a way that people who need public funded support cannot avoid because it goes unquestioned. Without a willingness to advocate from conviction that individual control of adequate public funding for individualized assistance is a matter of human rights, bureaucratic blunders will rob Judith of the assistance she needs to live, as from time to time they did. But it was clear to her that advocacy, necessary as it is, competes for attention with relationships that allow giftedness to flourish.

Judith experimented with different approaches to the disability category. She challenged herself to find alternative language that allowed accurate descriptions without resort to language based in the disability category.** She provocatively challenged audiences with the argument that ***There is no such thing as disability.***

* *The Power in Vulnerability*, page 32.

** You can read an extended example of this experiment in Judith's autobiography, [Who's Drawing the Lines](#)

This last attempt at exorcism didn't really work. It wasn't true to her experience: maintaining her own supports intermittently engaged her own considerable advocacy skills to make financing for personal assistance that is structured by disability category work for her. Many of those she advised benefited from assistants highly skilled in responding to their impairments with knowledge gained in professional study. And most audiences had trouble grasping her point in a productive way.

Her struggle with the disability category was fruitful. Attending to the positive effects of relationships with people whose lives could be swallowed whole by the disability category* clarified her understanding of the duality that the culture creates with the disability category and the choice it frames.

Disability is an expression of a world of categorization along with race, class and other distinctions that divide us. Within the category of disability I have certain rights and privileges. But inside that kind of thinking I'm not able to move very far out of my space and my space does not allow me to express my deep personal giftedness, or my deep personal relationship with life itself...

I live in a world that's about categories and structures. A world in which the category of disability is powerful in my life. I am also in a personal relationship with the Creator of the universe. Both are true. I am both disabled and not disabled at the same time.

The question is, from which stance can I live my life most powerfully both for myself and for the community. From which position am I more able to contribute? More able to experience a fulfilled life? More able to bring richness as a legacy beyond when I will personally be present in the world?

* See Gifts on page 39.

I don't think disability is the position from which I can be powerful. I think disability is the position from which I can be controlled.

This both/and understanding sharpened her teaching about inclusion and led her to articulate the BMX Model of inclusion (page 107, page 111). The X (Crossover) stage of the BMX model is a formal statement of this deeper insight.

The point of inclusion is not to help a people who would otherwise be excluded. The point is that when we live separately we all cut ourselves off from the power of joining people's different kinds of relationships and experiences. Separation simply limits our experience of life. Inclusion brings us a much richer community. To be inclusive means to open up a dialogue. This is not a discussion about "How can I help you?" It is not an intellectual exercise. It is a dialogue in action for all those involved to discover what the others bring that has not been seen before, what the others makes available that has not been possible before.

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