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Inclusion NEWS

Marsha Forest Centre: Inclusion.Family.Community

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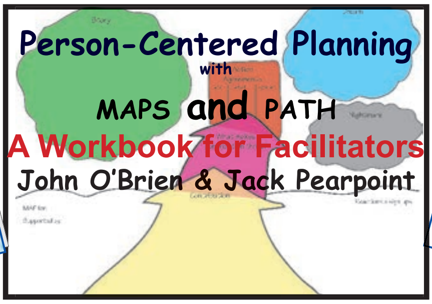
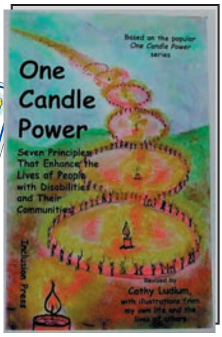
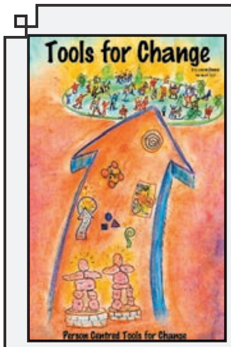
All Means All: No Buts!

Resources
for Inclusion:
Books, Videos, CD's,
DVD's - Workshops



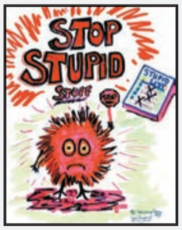
Person-Centered Planning
with
MAPS and PATH
A Workbook for Facilitators
John O'Brien & Jack Pearpoint





COMMUNITY

TOOLS FOR CHANGE



STUPID STUFF

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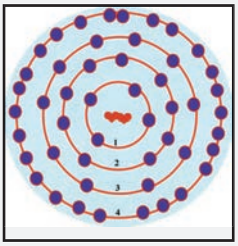

CIRCLES

KIDS & FAMILITES

REDISCOVERING
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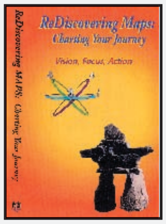


SOLUTION
CIRCLES

Inclusion Press, INCLUSION NETWORK bring you CIRCLES, MAPS, PATH, Graphics – TOOLS FOR CHANGE

Welcome from Marsha...

THE MARSHA FOREST ROSE QUARTZ WARRIOR AWARD
for
LEADERSHIP & CONTRIBUTION
Dr. Mithu Alur

In recognition of sustained contribution to the lives of students with disabilities in India.

The Marsha Forest Centre embraces Mithu Alur as a kindred spirit in the effort to realize the right of all students to a full education in community schools without regard to disability or other difference. We find our strength renewed by her work.

Mithu Alur is a relentless contributor to the welfare of humanity. She leads others to continued effort to improve the educational and social lives of those marginalized due to difference by society. She is a person who cares. She is a person who loves. This award is offered in the name of Marsha Forest with love.

To join with the Centre in supporting Dr. Alur's work in the slums of Dharavi, Mumbai, you may contact her through the MFC.

Mark Vaughan (CSIE- UK) presents
Dr. Mithu Alur
with The Rose Quartz Warrior Award,
the first ever award from
the Marsha Forest Centre,
honouring the work of Marsha and Dr. Alur.
The award was presented Jan. 27, 2003 in
Kochi, Kerala, India

MARSHA FOREST CENTRE
Inclusion – Family – Community

presents

THE MARSHA FOREST
ROSE QUARTZ WARRIOR AWARD
for
LEADERSHIP & CONTRIBUTION
to
INCLUSIVE EDUCATION

This first award is made to:

Dr. MITHU ALUR

In recognition of sustained contribution to the lives of students with disabilities in India and overseas.

The Marsha Forest Centre embraces Dr. Mithu Alur as a kindred spirit in the effort to realize the right of all students to a full education in community schools without regard to disability or other difference. We find our strength renewed by her work.

Dr. Alur is a relentless contributor to the welfare of humanity. She leads others to continued effort to improve the educational and social lives of those marginalized by society because of difference.

She is a person who cares.

She is a person who loves.

This award is offered in the name of Marsha Forest with love.

Date: January 27, 2003
Place: Mumbai, India

Marsha Forest Centre, Toronto, Canada

MARSHA FOREST CENTRE
Inclusion.Family.Community

All things change with time and need. For the Centre for Integrated Education and Community the time arrived with the passing of one of our founders, Marsha Forest, internationally known and loved originator, creator, instigator. The need was the need to honour and remember Marsha's passing in a way, which would be meaningful to her and to her, many friends around the world. The newly renamed MARSHA FOREST CENTRE is dedicated to carrying on the work begun by Marsha in ways of which Marsha would approve.

After a number of thinking and planning meetings the Centre's board has defined the outline of a new and yet old mandate. The new is to be proactive as a Centre in initiating and supporting activities which have not been central previously. We shall support directly people and organizations trying to advance inclusion in education and community, but doing so on a shoestring. We shall initiate research projects to be conducted under the Centre's aegis or in collaboration with others. We shall initiate community development projects with our old friends and our new friends. Together we are better!

The old will be to continue with the developmental and creative adventures which have characterized the Centre since its founding. We shall speak out on issues of segregation and discrimination. We shall go to people who need support. We shall write from our hearts and continue Inclusion News. We shall work across national boundaries. We shall respect and support the efforts of others to make the world more inclusive in every way.

The MARSHA FOREST CENTRE invites you to visit our web page at http://www.inclusion.com. We also invite you to support us financially and spiritually so that we can continue to work together to change the world around us.

Gary Bunch, Chair
Board of Directors

The Centre is renamed and working. Inclusion Press is in production mode. Inclusion News is out. The new web page is up. The new Ezine is ready. The Tools for Change CD is out. New courses have been designed and are booking now. The Inclusion Network is being created to expand our training and network support. Join us as we create the future we want - like Marsha wanted.

Slovenia and Beyond
Inclusion on the Road
Gary Bunch & Gerv Leyden

Gary Bunch (Toronto) and Gerv Leyden (Nottingham, UK) traveled to Elergi, Slovenia for a multinational regional gathering of people exploring inclusion. Delegates from 8 countries explored issues of segregation - and began to explore options for creating a movement towards inclusion in the region. The potential for 'inclusion' to be part of post war reconcilliation between people make this an exciting and complex exploration. Graphics introduced by Jack and Marsha years earlier were part of the event. There is hope for new ventures in Inclusive Education and Community Living. Stay posted for developments.

A Tribute to Nicola

In the last Inclusion News, Lynne Elwell published this poem. Recently, her daughter Nicola passed away. In seems appropriate to remind Lynne that the world is a better place because she was very important in the remarkable life of her child Nicola - and many other children who are not named - and need her still.

100 Years From Now
Lynne Elwell

One Hundred years from now,
It will not matter what kind of car I drove,
What kind of house I lived in,
How much was in my bank account,
Nor what my clothes looked like.

But the world
May be a little
Better because
I was important in the life of
A child.

E-mail: lynne.partners@virgin.net

Inclusion on the Road

We've been on the road. Cities, states, provinces, counties, countries. John O'Brien and Connie Lyle O'Brien have been around the world; together, and separately. John and I (Jack) have done workshops and training events in locations ranging from Hong Kong to Alaska and UK. Collectively, we've been on the road: Hong Kong, Winnipeg, Alaska, Minnesota, Maine, New Zealand, Ireland, Australia, Portland, OR, England, Scotland, Delaware, Windsor, ON, Toronto, Wisconsin, Altanta, GA, NYC, Hamilton, ON, and the list goes on.

Books and videos are also emerging. Check the web for release dates.

Community: Lost & Found by Art Lockhart and Mike Clarke - community organizing stories and wisdom - from the streets of Toronto and beyond.

Why Not Lead? A Primer for Families and Other Grassroots Leaders - By Deb Reidy - a new book focused on supporting families to take leadership to create the futures they need and want.

Each Belongs - Jointly with Jim Hansen of Hamilton Separate School Board, Dr. Gary Bunch (York U) and Gerv Leyden (U of Nottingham) a new book and CD will explore the historical roots of the first education system that implemented inclusion in a whole school system - starting in 1969!!.

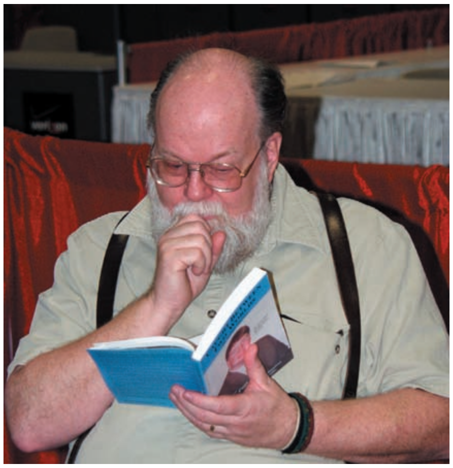
Regina DeMarasse's autobiography is emergent. Regina is a remarkable advocate & philosopher who tells tales of tragedy and triumph - passion and determination. A remarkable and inspiring tale with delightful twists of irony.

DVD's & CD's

A new collection of DVD's on MAPS, PATH and Circles is emerging. A collection of 'stories' has begun and will emerge on DVD in tme.

Inclusion Press in Australia
- Ally Inclusion -

We are delighted to introduce Alana Baker - **Ally Inclusion** - our new distributor in Australia. This is a new business venture for Alana and we wish her well. She wants her customers to know that she prefers e-mail contact - and looks forward to serving you well. Alana's e-mail: alana_baker24@yahoo.com.au



What matters most to people's safety?

What matters most to people's safety is the extent and quality of their relationships. People are safer the more others care enough about their safety and well being to keep a close eye on their situation, to stand up to difficult situations with them, to act imaginatively in response to their vulnerabilities, to negotiate on their behalf with others who control important opportunities, and to struggle with them over situations in which they are contributing to their own problems. Many people with developmental disabilities are more vulnerable exactly because they lack opportunities and assistance to make and keep good relationships. But most current policies and practices ignore these vital relationship issues, and most service dollars are spent on congregating people with developmental disabilities in settings which segregate them. By suggesting that people could be kept safe and well in settings where strangers can drop in to check on quality of life, current approaches to safety fundamentally misdirect attention away from people's most important safeguard, the safeguard that most service settings are most likely to discourage or disrupt.

-John O'Brien and
Connie Lyle-O'Brien
(1993) Assistance with Integrity

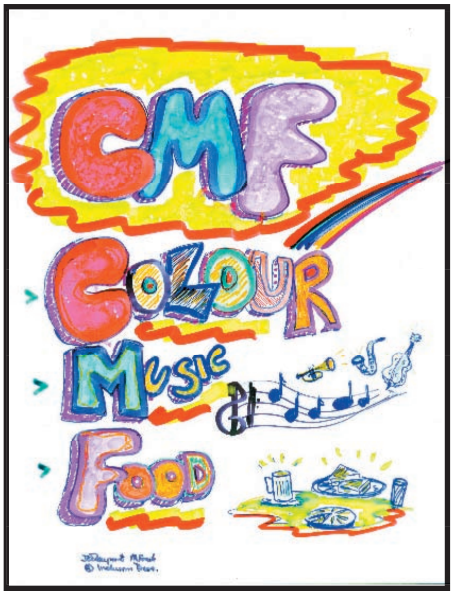
Working in Alaska

At a workshop entitled, **Action for Inclusion, Enlivening Alaska's Communities** in June, 2003, we attempted to enroll more community allies for inclusion by finding and nurturing positive links between their agendas and ours. Three of us worked in Alaska, but John O'Brien neglected some of the other Alaskan options including halibut fishing. Lynda Kahn and Jack Pearpoint are still eating their catch.

In between workshops in Alaska - Lynda and Jack go halibut fishing...

> "We must learn to
> live together as brothers
> or perish together as fools."
> *Martin Luther King*, (1929-68)

inclusionpress@inclusion.com



Janice Fialka

Nudging the Network

by Janice Fialka

When our son Micah was a fifth-grader he was on the neighborhood basketball team. He was so proud to wear the gold and navy uniform, and he never seemed to mind going to the practices, despite his lack of enthusiasm for physical activity. As parents we were happy he was spending time with his peers and getting some exercise--glad he could be a part of a "regular kid" activity. We didn't spend a lot of time informing the coach about his disabilities. We offered a few insights and suggestions, as well reassurances that if he had ANY questions or comments about Micah--ever, "Please don't hesitate to get in contact with us."

Attending the basketball games generated a wide array of feelings and thoughts in us. Micah has this contagious, winning smile--always, but the smile seemed to widen the length of the court and radiated even more when he was in his uniform, huddled with his teammates, listening to the coach. While bent over in the huddle, arms around his teammates, Micah would surreptitiously look to see if we were watching him. The moment he would catch our eyes, he'd instantly look away and feign disinterest in our whereabouts. We loved this scene.

The harder part of being at the basketball games was watching him . . . sit, for what felt like an eternity, in his hard metal chair on the sidelines. Gradually he'd get distracted and lose interest in the game, perhaps in part because following the game was challenging for him. The rules, plays, and strategies weren't always easy for him to comprehend. His eyes roamed around the echoing gym, and then he'd catch himself being inattentive. He would look to his other teammates on the sidelines and hunch forward, elbows on knees, copying them. The coach often put Micah in for the last three minutes of a period, but by then it was hard for him to get his relaxed, low muscled-tone body moving and focusing. After the three minutes were up, the screeching buzzer would announce the end and Micah would return to his seat, having barely moved or touched the ball.

What's a parent do to? How much do you say to a coach---how much do you nudge?

We made a few comments, but we felt conflicted. On one hand we were glad he was part of the team, especially because his sports abilities were still emerging, a nice way to say that he was really at the bottom end of being able to play basketball or any sport for that matter! However we knew that if he was going to improve that he had to PLAY, PRACTICE, BE IN THE GAME. We half-heartedly decided to say less that season and to let it play itself out.

As the fifth grade season neared its end, rumors started flying. Everyone, from the coaches, the referees, and the kids, were planning to make Micah's last game the best for him. Their plan was simple. He would play most of the game. The kids would constantly pass the ball to him. The referees would bend the rules--just a bit, allowing Micah's version of dribble then run, dribble then run to fit into the revised rules. Even the opposing team were in on the plan. They would help clear the way for Micah to "dribble" down the court and make his basket. Everyone imagined that at the final buzzer, the crowd would go wild and Micah would be carried off on the shoulders of his teammates, all shouting, "Micah, Micah, Micah!!"

Good intentions and wonderful spirit flourished before the game. As we settled into our seats at the top of the wooden bleachers, we could feel this spirit, this sense that folks wanted there to be a "Micah moment." The problem was that Micah hadn't really learned how to play basketball. During this final game, each time the ball was passed to Micah, he reacted as if was being attacked by a flying saucer. He'd duck, slide to the side, or just be oblivious to its coming toward him. Wham! Either the ball hit his body with a thud or flew right by him. Then you would hear the collective distressed sigh "ohhhhh!" from the bleachers.

Without success in their attempts to integrate Micah into the game, both teams became disenchanted with their plan and resumed their regular playing, with Micah on the sidelines. Micah, not really noticing what had happened, moved to his regular sitting position, feeling quite out of breath for the first time this season.

The entire experience left us conflicted. On the one hand we recognized the community's love for Micah. Here was the Village everyone talks about—that Village that must become involved in the raising of every child. These Villagers, young and old, wanted him to score! On the other hand, we knew that if Micah was going to improve his game--and his life--that he must be allowed to develop his skills and grow into a successful teammate. He must be given the opportunity to play and interact in a consistent manner and not just at the final game, when no one, except the natural athletes, could be expected to score.

The experience taught us that we had to help the school and neighborhood include Micah in meaningful ways **over time**. It had to be an intentional inclusion. We had to nudge! We had to have conversations with the coach to discuss how to include Micah in the game. It couldn't just happen by chance and good intentions. Inclusion like this is still too new, too unusual, too unfamiliar. Maybe the strategies would include allowing someone to shadow Micah when he was running on the court, whispering a few cues to him. Maybe it meant stopping the hurried action of basketball passes and leaps to allow Micah to toss the ball toward the basket a couple of times a game. Maybe it meant . . . who knows what other creative ideas would breakthrough during our conversations with the coach and teammates. But we are confident that new ideas would come into play when we discuss possibilities in a planful manner. These types of accommodations and modifications require attention and creative brainstorming. *Including Micah in the game of basketball or the game of life, couldn't be done all of a sudden and at the final stage--even if it was motivated by good intentions and love.*

As parents, we feel awkward and uncertain about what to do in these situations, especially when good intentions are involved. It is hard to be direct with people who sincerely want to be nice. It is challenging to raise these issues with coaches, neighbors, and family---unbelievably challenging, and scary too! Who wants to have these kinds of discussions with people, some of whom we don't know very well? Thus we parents of children with disabilities often allow ourselves to get trapped by our discomfort and inexperience, and that leads us into silence or anger or withdrawal or curtness or aloneness--or sitting on the sidelines.

As parents of children with disabilities we must find the energy and courage to talk with the coaches, with our neighbors, our family, and our children. We don't have to always have the answers. But we do have to have a strong commitment to begin the conversation. We can begin with such words as, "I'm not sure how to help Micah be more a part of the game but can we talk about the possibilities and see what we might create together." We, as parents must begin to form the words which will lead folks into planning how the Micahs of the world can play more than three minutes of a game. Micah and his teammates deserve to feel that kind of involvement and success. What lesson was learned by his teammates when they felt discouraged and disenchanted during that last game? It didn't inspire hope and wanting to do more with Micah.

Perhaps the goal might not be to have Micah carried out of the gym on the shoulders of his cheering teammates at the last game of the season, although I wouldn't mind seeing that once in awhile!!! The more practical, and perhaps more noble, goal is having one of Micah's teammates slap him on his back while walking out of the gym, saying "Hey, Micah, great catch. You're getting closer to making that basket." Maybe that's *really* how you score in the game of life.

Applying the Lessons We Learned

Since that fifth-grade basketball game, my husband and I have gotten better and more comfortable (well, a bit more comfortable!) with encouraging community members, peers, teachers, and others to find consistent ways to meaningfully integrate Micah. Although far from easy, we have learned to hold conversations and meetings where we have explicitly asked the question, "What can we all do to ensure that Micah has a role in the action, an assignment, a part of the play, a ride to the dance, a place at the table?" We've learned that young people have great ideas. "Hey Micah, quit hanging around the teachers at the school dance. Ask one of us to dance!" Micah listened, learned and eventually spent a lot less time hanging around the teachers!

Since third grade, we have insisted that there be a Circle of Friends with Micah. Although not always easy and clear, it has been one of the crucial aspects to his growth and that of the entire community. The Circle has changed in membership, meetings times, and focus over the years. The focus moved through the years from visiting sick kids in the hospital as a Circle in 4th grade to going to the Piston's basketball game as a Circle in 7th grade, to planning how to hang out as a cool teenager at school dances in the 10th grade, to planning a school-wide program on disability issues which involved introducing Norman Kunc, an international speaker, in the 12th grade.

The opportunity to have an intentional group of friends, as controversial as this idea is to some groups, was the right thing to do for Micah, for us, and for his community. It remained at the forefront of our efforts. It was this network that was the springboard to many successful inclusive experiences for Micah.

We've learned that it's okay--in fact, necessary to **nudge his network** a bit. In fact, it is fundamental. For example, one of Micah's major personal goals for his senior year was to **go to the prom**. After little success with hoping that he'd get a date or be invited to join one of the groups, we decided to "nudge his network"; that is, to make contact with the Circle of Friends. It wasn't easy to hear the "I-already-have-plans-sorry…" response, but we didn't give up. Micah made some calls, but time was running out. Soon we connected with one of our newest recruits to the Circle, Shosh. She had won our hearts the year before running cross country with eight pigtails in her hair, each with a different colored ribbon, and red and white striped socks pulled up to her knees. She definitely wanted to help Micah get to the prom, but there were the other 13 kids in her group who needed to be consulted. Can you imagine trying to consult with 13 teens and get consensus? The phone lines were hot. I thought about the scene from the play, "Bye, Bye, Birdie" when several teens with phones hooked to their ears sang to each other "Have you heard about Sally and Jim?", repeating it back and forth to everyone on the stage.

Eight days passed, each involving many, many phone calls--but it worked, for everyone. Micah was joining the group of 14 kids going to his senior prom--the most important dream of his senior year. Later that week, a sweet and unexpected call came from one of Micah's longest friends, Mike, asking Micah to go with him to select their tuxedos. "Yes!" we thought. Who wants their dad to take them to the rental place!

Getting Micah to the prom did not come to him in the typical way, as we had hoped and undoubtedly dreamed about. But it did come--and in the longest limousine I've ever seen, with an electric fireplace and seven couples. There was intentionality behind this event, by way of many phone calls to the kids, to a few of their parents, and the intervention of very helpful school social worker at the last minute. We've learned that this kind of careful but direct involvement, or what I've learned to call "nudging the network" is just the way it is and it ain't SO bad. The kids were happy with Micah and he, all decked out in his tuxedo, had the time of his life. Like the other moms, I sobbed, perhaps not with all the same thoughts as they had about their growing-up teenagers, but all of our tears flowed down our cheeks in the same way!

Although that infamous basketball game so many years ago might have seemed a game of defeat, it really wasn't a total loss. We scored some valuable lessons. We learned that many folks want to be helpful, but don't always know how. We learned that as parents we had to advocate for and with Micah to truly integrate him into as many activities as possible. We had to be specific in our problem-solving. We learned that we can't be silent and hope for the best (at least most of the time). We learned that it's okay to speak the truth to others, to ask them to think about some tough issues. We learned that we had to do it in a respectful manner that was tolerant of their unawareness of the issues. We learned that not all people will be on our side, but that you *can* find at least 14 teens who will say "yes" to having Micah in their limousine and will enjoy having him in their there--even if the evening took a bit of nudging.

Micah never did score a basket. He left the world of basketball for other endeavors, including cross country and track, eventually leading to a varsity letter. (That took some nudging, but that's another story.) In his senior year, Micah was elected to the Homecoming Court. (We are happy to report that we did absolutely no nudging on this one. In fact, it was a complete surprise. Perhaps his being on the Homecoming Court is evidence of what can naturally occur in communities when there has been some previous intentional nudging.) One of his longtime friends, a member of his Circle nominated Micah--and the rest is history. Micah's history.

Although Micah was never carried off the basketball court on the shoulders of his cheering teammates in fifth grade, in his senior year he was escorted down the long, red carpet of the football field one beautiful autumn afternoon by two of the loveliest teenage girls one on each of Micah's arms. Now, if you were a guy, which would you want?

An exciting outcome to all of our nudging over the years, is that now Micah is getting better at his own nudging.

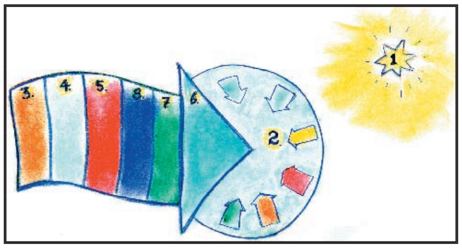
As Micah's mom and dad, one of the lessons we have learned over the years was put to some great rock 'n roll music many years ago by the Rolling Stones. The message is "that you can't always get what you want, but if you try, you can get what you need."

With some nudging of his network on our part, and some intentional planning, Micah surely got what we wanted and needed--not a bad score.

Janice or Micah Fialka Email: ruaw@aol.com

One Candle Power

Cathy Ludlum, wrote and edited stories about circles and community - a powerful book for anyone interested in the idea of circles - the glories and the complexity.



The Arrow

Eileen E. Scott

2003

Several days before a PATH gathering, I will often take some time to prepare the wallpaper with the PATH outline. An assortment of markers and tape are spread out on the dining room table and, having removed a painting or two, one very large sheet of wallpaper hangs on the dining room wall. During one such recent preparation, I realized my daughter had joined me in the process. She is use to seeing this event take place - she's been watching me do this for all of her five years. But this time, she was drawing her own arrow on a piece of yellow construction paper. While drawing her outline, she began to ask me some questions, "So, you're doing an arrow with someone?" "Yes," I replied (having come to know the arrow is my daughter's reference point for this ritual). I continued with, "I know a young man who is gathering a few people together to talk about his thoughts, ideas and dreams for his future and how he could go about taking steps towards making those things come true." "That's pretty cool," she said. I asked her what she thought was "so cool" about that and she responded, "He gets to talk about all the things he loves and wants to do." Then, she continued with, "I know what I want to do…I'm going to do my art, dance in shows, help sick animals, read a book in a tree, play in the rain, do gymnastics…" and on she went. When she finally exhausted all she could dream of at that moment, she told me that her "arrow" would have to be really really big to draw all of things she wants to do. She then told me to make sure that I take enough wallpaper for this young man's PATH. When I asked her why, she said, "I would be sorry if there wasn't enough room to write down everything that he wants to do." She then even went so far as to offer me some of her construction paper – just in case. Well, I took those offered pieces of construction paper and still carry them with me as a reminder that dreams of the future should never be constrained and need plenty of space – in order to be explored, in order to be seen and shared, in order to be appreciated and validated – in order to grow.

My Second Story of Scott

Micah Fialka-Feldman micahff@aol.com

In the last *Inclusion News* I wrote an article about my friend Scott. We met at the 2001 Summer Institute. He wasn't Jewish but his mom said that being at the Summer Institute was like Scott's bar mitzvah. A couple of weeks after the Summer Institute I went to Israel and bought a prayer shawl for Scott. I liked looking for one for him. When I got home I went to Canada to give it to him and then I took the train home ALL BY MYSELF. Scott gave me the courage to do that.

This is Part 2 to my story about Scott. Now that he had a prayer shawl, we thought he should have a real bar mitzvah because he was becoming a man (He was 19 years old) and he did good things for people. My mom, Scott's mom and I talked about how he would have a bar mitzvah. Scott is not Jewish but I am, so I could help. One day Scott had his Bar Mitzvah and it was a good one. Lots of people came and my dad got to be a Rabbi for a day. He said that Scott is a teacher and professor because he taught people about love and friendship. Everyone told stories about how much Scott had changed their lives. We lit candles and people laughed and cried. And Scott's dad said, "It was all Micah's fault that Scott was having a bar mitzvah." I was happy.

One day I got a call from Scott's mom telling me that Scott was very sick. Then Judith Snow called and told my mom that Scott died. Later I called Judith because I felt sad. I wanted to see Scott one more time.

My mom and I drove for six hours in the pouring rain to see Scott. We got to his home at midnight. I gave Scott's parents a big hug. Then I walked quietly in his room. There were lots of flowers and candles. My friend Scott was laid on his bed. He looked the same to me but he couldn't go swimming anymore. He wore his suit and a dolphin tie because he liked to swim with dolphins in Florida. The prayer shawl I gave him was wrapped around him. I got in bed and sat close to him. I touched his forehead. He was cold. I wasn't scared. I was happy because I could see him one more time.

Then I went to sleep. We woke up early and put hundreds of flower petals in the casket with Scott. I took off all the petals off his hair and face because guys don't like flowers in their face. Then we went to church for his funeral. The priest put Scott's prayer shawl on his casket. He said that Scott taught us that all religions are about learning to love.

I felt proud to know Scott. He was my Canadian, older brother (I am one year younger.) He was a good friend. He helped me get through hard times. I am still in contact with Scott's mom and dad, Gloria and Peter. I joke with them and tell them that I am their Jewish son. They came to my high school graduation party. I was happy.

After Scott died, Jack Pearpoint wrote me an email and told me to keep Scott's spirit alive and keep celebrating his life. I am doing that by writing this second part of my "Scott Stories." I will keep Scott's story around for a long time.

When Scott died, his mother said, "Follow the moon home, Scott." I like that quote. When I look at the moon, I think about my friend and brother, Scott. He was a good boy and gave us a vision of light.

Now as a College freshman, member of the cross country team, Micah continues his jouney - and continues to honour his friend Scott.

Inclusion Against the Odds

by Dr. Sharon Rustemier

CSIE (Centre for Studies on Inclusive Education) has just published a new report on the successful struggle for inclusion of Kirsty Arrondelle. It costs £10.00 (overseas postage extra) and is available from CSIE, New Redland, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QU, UK.

'Twenty-seven year old Kirsty Arrondelle is a young woman who lives a remarkably full life as a valued member of many groups in her local community. A keen and talented performer, she is currently studying performing arts at her local college of further education and is a longstanding member of the local Youth Create group. She has awards for voluntary service to the community, and is an accomplished dog handler and swimmer. She has been a member of the Girl Guides Association for many years. Hers is a successful life by all accounts.

'However, Kirsty also has Down's Syndrome which has meant that she and her family have had to overcome numerous barriers erected by other people's prejudices and stereotypes and reflected in social structures and practices that may have seemed insurmountable to many. It is this which makes Kirsty's ordinary and full life remarkable and one to be celebrated.

'This report, written by Sharon Rustemier in close collaboration with Kirsty and her family, documents Kirsty's life so far and her current experiences of social and educational inclusion. Based on observations and interviews with Kirsty, her parents, and the professionals, students and others in the various social settings in which she participates, it follows on from previous reports published by CSIE in the 1980s which focused on Kirsty's primary schooling and her parents' struggle to secure mainstream education for their daughter. It offers encouragement for families who find themselves in similar positions, and inspiration and answers for the future work of professionals and administrators. It provides an update on Kirsty's educational inclusion through secondary schooling and further education and demonstrates the successful social and educational outcomes of this mainstream inclusion in terms of Kirsty's current inclusion in her local community. By describing Kirsty's adult life in different settings – in further education, in employment, and in the community – it demonstrates the positive effects of mainstream inclusive education not only for Kirsty herself but for all those who share her life.'

Kirsty with friends and at work - making a win-win contribution. We need to choose: Isolation or Contribution.

Brendan McBride's PATH

Brendan McBride

It all started when I helped my mom do PATH training in Duluth Minnesota for an agency that supports people with disabilities to live lives they want. Before the training I helped get things ready like: treats, handouts, facilitator bags, games, videos, overheads, and prizes. The things we were putting together looked like we were going to have a party. I was a participant in the training and learned about the PATH process. What looked like creating a party was a way to help us learn. One of the activities at the end of the training was to think about what we learned and how we were going to use that experience to evolve. I told the group that I wanted to do a PATH for my thirteenth birthday.

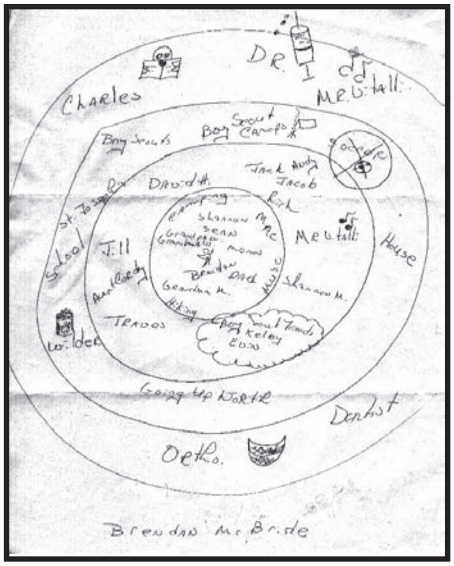
The PATH was developed in two parts because my sister and her husband from Wisconsin and my brother and his wife from Chicago could not come at the same time. In part one of my PATH, which was on my birthday weekend, we answered all the questions and in part two which was a few weeks later the next group added their ideas. There were some really bad times during the PATH when people tried to tell me what to do and did not understand this is about me and my dreams. The really great parts were talking about my dreams, what I wanted to accomplish, ways to reach my dreams, and friend and family offering to work with me.

Some of my dreams were to: figure out and understand why I have such a hard time with reading and math, I felt this was important so I could go on to college and live on my own, see the ocean, become a Star Boy Scout, go ice fishing, have some hobbies that can be life long, not get involved in drugs, and volunteer.

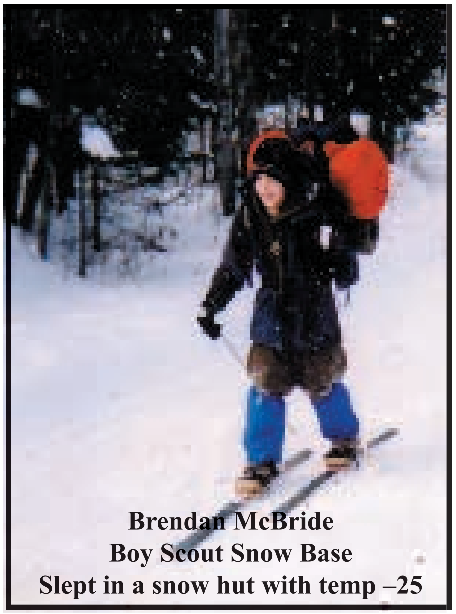
So many things have happened since my PATH started! Well I didn't go ice fishing last winter because the ice in our area was not safe. I learned things along the way like how to check for ice conditions, where to rent ice houses, I listen to a sports show, and talk to people about fishing. My PATH dreams have been incorporated into my IEP. We have been persuing why I have such a hard time with reading and math. This has included lots of appointments and tests and just this week I found out I have difficulty with auditory processing. I ask lots of questions so I understand about auditory processing and specific strategies that will be useful. I found out I like to put model cars together and I started a reading club, we are reading our second series of books by Gordon Korman. In July I became a Star Boy Scout and have completed two merit badges for Life Scout. The big thing was to see the Atlantic Ocean this summer. My mom, dad, and I took a road trip to Maine and Nova Scotia. We saw so many great things like the Mohawk Trail, Acadia National Park, Atlantic Ocean, and whales.

Wow I didn't realize how much I did in the past year. What really helped is to have people in my life that care about me, having the PATH gives clear direction of where to go so that we can use our resources to reach my dreams. One example was seeing the ocean, everyone knew about my dream. When my parents and I talked about our summer plans my dad said he always wanted to go to Nova Scotia and my mom always wanted to go to Maine. Neither had told anyone before about wanting to go to those places. Accomplishing all these things took lots of planning, time, money, energy, and other resources. Because we knew what I wanted to accomplish, we used the resources to go in that direction. Otherwise, without direction and a plan, we may have used all the resources and just gone someplace that didn't matter.

"Energy rightly applied and directed can accomplish anything." Nellie Bly



Brendan's Circle planning for his PATH



"What I believe…"

Margaret Wheatley (2002)

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

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

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

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

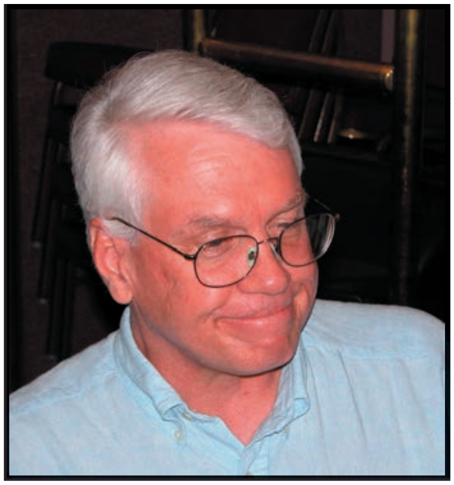
Truly connecting with another human gives us joy. The circumstances that create this connection don't matter.

Even those who work side by side in the worst natural disaster or crisis recall that experience as memorable. They are surprised to feel joy in the midst of tragedy, but they always do.

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

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

Margaret Wheatley (2002) Turning to one another: simple conversations to respore hope to the future (p.19) San Francisco: Berrett-Koehler Publications, Inc.



To Get The Right Ducks; You Need The Right Duck Call

Mike Green

My daughter Annie is now 22 years old. When Annie was about 11 years old she was a student in a school in Aurora, Colorado. Annie had been a pioneer in Inclusion in her school. At this particular time Annie was being teased daily on her bus ride to school by some kids who called Annie a "retard", "dumbo" and other very painful names. Annie was very unhappy about this—and did not know what to do. I was both very sad and very angry—and did not know what to do. We tried various things which did not work.

I had recently started working with John McKnight and the Asset Based Community Development (ABCD) Institute on community development. John was visiting us staying overnight at our home in Denver. At that time I imagined that John knew the answer to any community problem as "an expert" on community development. So I hounded John to solve Annie's problem all evening long—and he did not know what to do about the problem. Finally in frustration John started up the stairs to escape my questions. Standing on the stair steps John turned to me and pointed out at our street lined with houses. He said almost shouting, "You can't solve this problem. Furthermore Annie can't solve this problem. The problem is that people don't know that they need Annie. If you want to do something-- then work on this question. How do you organize community life so that people know there is no one that we don't need." John then went upstairs to bed. I have considered that moment a mission statement for me since that evening. How do you "get them to do it"?

This summer I had the opportunity to attend the Portland Inclusion Institute in July to present the ABCD community building approach as a workshop. I remembered John McKnight many years ago on my stairs in Denver-- challenging me about the people of everyday life. In Portland this year I heard several people at my workshop describe the challenge of, "How do we get beyond the 'special world' of people with disabilities, their families, and their service providers? How do we build a bridge into everyday life?" John's challenge to activate everyday life seems all the more the right question today.

A great success of the Inclusion movement has been to develop inspiration and practices for community building such as circles, PATH, MAP. Much powerful work has focused on people labeled disabled, their groups, families, schools, and supporting agencies. This work has helped many people cross the bridge from the edge of the community to the center. Inclusion work has helped many support organizations and schools develop strategies that truly build community. What is still needed is that everyday community life be organized on the other side of the bridge. This is the challenge ahead for us all.

How does this work happen? This kind of community work does not focus on the person labeled disabled. The key question is how to activate the wider community to recognize that all people are needed as participants and then act to create avenues for participation for labeled people. This is work to engage local community organizations (associations, congregations, businesses, non profits, and government agencies) to include people labeled disabled and to act for community development.

To me the fundamental dilemma in successfully engaging everyday life is "how do you get the right group of people together to build this bridge?" If you want to involve people outside the special world of people labeled, their families, and providers, then these '***other'*** people must be at the center of the 'community organizing group'. You need the right ducks. Hunters (or photographers) say that you need the right 'duck call' to get the 'right duck'. If you want mallards you need a Mallard call. Pintails, Bluefins, Oregon ducks each need the right call to be involved. The 'duck call' that works is built of relationship, listening, and asking. From my ABCD experience there are twelve guiding principles to form an organizing group that can call the right ducks:

Twelve Guiding Principles for Community Engagement: ABCD in Action

Most communities address social and economic problems with only a small amount of their total capacity. Much community capacity is not used and is needed! This is the challenge and opportunity of community engagement. Everyone in a community has something to offer. There is no one we don't need.

1.) **Everyone has Gifts.** With rare exception people can contribute and want to contribute. Gifts must be discovered. Gift giving opportunities must be offered. Strong communities know they need everyone. There is unrecognized capacity and assets in every community. Find it.

2.) **Relationships Build a Community.** See them, make them, and utilize them. An intentional effort to build and nourish relationships is the core of ABCD and of all community building.

3.) **Citizens at the Center** can engage the wider community. People in leadership in everyday life (associations, congregations, neighborhoods, and local business) must be at the center of community initiatives rather than just helping agency leaders. It is essential to engage the wider community as actors (citizens) not just as recipients of services (clients).

4.) **Leaders Invoive Others as Active Members of the Community**. Leaders from the wider community of voluntary associations, congregations, neighborhoods, local business, can engage others from their sector. Community building leaders always need to have a constituency of people to involve. This "following" is based on trust, influence, and relationship. Strong community leaders invite a growing circle of people to act.

5.) **People Care About Something**. Agencies and neighborhood groups often complain about apathy. Apathy is a sign of bad listening. People in communities are motivated to act. The challenge is to discover their motivation to act.

6.) **Motivation to Act** must be identified. People who are not paid as staff will only act when it is very important. People will act on certain themes strongly felt; concerns to address, dreams to realize, and personal talents to contribute. Every community is filled with invisible "motivation for action". Listen for it.

7.) **Listening Conversation** In 1:1 dialogue or in small group conversations is how to discover motivation and invite participation. Forms, surveys and asset maps can be useful to guide intentional listening and relationship building. Mapping is not a substitute for listening and talking face to face.

8.) **Ask, Ask, Ask.** Once a person's possible 'gifts to give' and 'motivations to act' are recognized; an opportunity to act must be offered. Asking and inviting are key community building actions. "Join us. We need you." This is the song of community. Judith Snow is right!

9.) **Questions Rather than Answers Invite Stronger Action**. People in communities are usually asked to volunteer for outside expert answer to community problems. Agencies usually ask community members to help with the agency answer. A more powerful way to engage people is to invite communities to address 'questions' finding their own answer--with agencies following to help.

10.) **A Citizen-Centered "inside-out" Organization is the Key to Community Engagement.** A "Citizen centered" organization means is one where local people control the organization and set the organization's agenda. Community engagement initiatives rarely succeed without residents as leaders organized to do intentional relationship building. It takes an organization of citizens to organize a community. It is also very valuable to have a staff person to assist relationship building as a 'community organizer' following the citizen leaders' agenda.

11.) **Institutions have Reached Their Limits in Problem-Solving.** All institutions such as government, non profits, and businesses are stretched thin in their ability to solve community problems. They can not be successful without engaging the rest of the community in solutions. We need to be more skillful in wider engagement. Everyone must do their part.

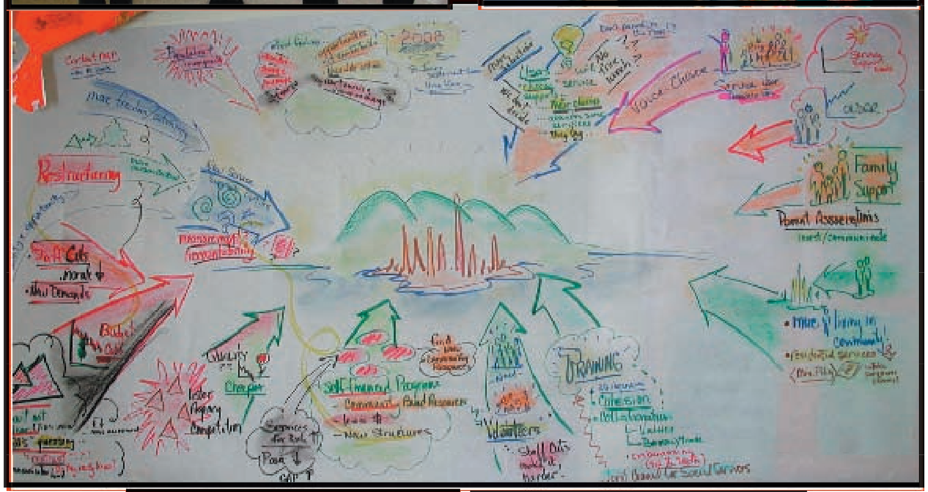
12.) **Institutions as Servants**—People better than programs engage the wider community. Institutions of government, non profits, and business can be of invaluable help supporting the work of citizens' initiatives to engage their fellow community members. Ask people what they need and offer help. Follow the lead of local community members.

Mike Green; ABCD Training Group

Mikebgreen@msn.com **303-477-2686**

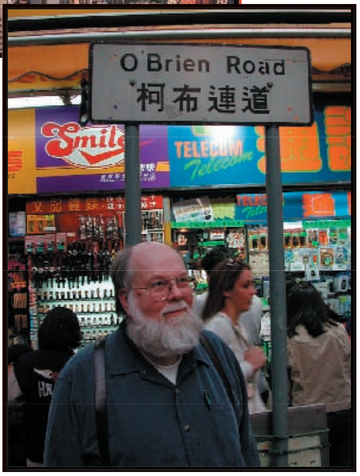
Person Centered Planning arrives in Hong Kong

John O'Brien & Jack Pearpoint conducted a week long training in Hong Kong in January, 2003



John O'Brien in Hong Kong

finding his roots?



New Beginnings in Hong Kong

Everit's Letter

I graduated in South Island School. I joined St. James Settlement in cleaning group. My job is doing cleaning in Hong Kong Stadium but not all the time. Sometimes, in St .James Settlement cleaning too. Because I'm tired from cleaning and epilepsy. I give up the job. I stay at home and my grandma s home to sleepover and watch TV.

Last summer (June, 2001) I joined *Life Forward. I feel happy in Life Forward better. I like to go out and join different kinds of activities. I feel like I have great change being like an Adult.

Now I like working in the Children and Youth center. The children ask me to borrow the toys. Children and staff call me Hui Sir; my heart beat because I'm very very happy. I stay there and it feels like my home.

I join helper job too. I use camera to video the people in the activities. I help people in youth center to sell 40 flags for a fund raising activity. I'm happy to go to camp with young people. My friend Alan, Me had to keep the camp site s door key. I feel happy. I find lots of friend in youth center, like Winnie, Fanny, Mr 5, especially Sister Kwan.

I'm very happy I can finish my dreams when I join Life Forward. I'm happy to be a Junior Police Call Leader. I'm so cool! I also joined photo contest. I had take photos of Miss Hong Kong. I join the group of Y.M.C.A. I learn how to shoot with a bow and arrows with young people.

I want that people do not think that I'm so cheap. I want people do not think that I have epilepsy and that I cannot do anything.

By: Everit Hui

Life Forward is the first Person Centered project run by Rehabilitation Services of St. James' Settlement in Hong Kong since 2001 for people with learning disabilities. Further Enquiry: Lau Miu Chun, Kari G/F., Sherwood Court, 14 Kwai Sing Lane, Sing Woo Road, Happy Valley, Hong Kong. E-mail: kari.lau@sjs.org.hk

Jim Hansen Says...

Jim Hansen, a retired Superintendent has agreed to author a series of articles based on his understanding and learning from Inclusion. Please read, enjoy and then write Jim.

The Hamilton Wentworth Catholic District School Board has a policy of admitting all children, able and disabled alike, to inclusion in their neighborhood school. Placement is age appropriate. This policy has been in effect since 1969. These articles will be part of the book ***Each Belongs*** to be republished in the near future.

> *It was my privilege to supervise the development and implementation of this policy from its beginnings in 1969 till my retirement in 1991.*
>
> *I hope that my contribution may encourage others to advocate for a "good" education for all children.*
>
> *Jim Hansen*

A Good and Complete Education

The Foundation

Each of us, over the years have been asked to express our beliefs about various aspects of life and living. It is easy to "go on" at great length about these beliefs and practices. However, it is both more difficult and more useful to express our core belief, our "philosophy", in a single word.

Most of my life has involved the education of children and young - persons able and disabled alike. The task of choosing the motto for a new school led me to my single word philosophy of education - "GROWTH" - To live is to grow. If you are not growing you are dying. Learning brings growth and gives life.

Objective evaluation of learning or education in general is not possible. A philosophy, however, provides the basis for reviewing and improving our practices.

Given GROWTH as a valid philosophy of education, it follows that the "job" of the school is to foster growth. All growth not just the three R's.

Psychology tells us that we learn only that which we feel a "need to know". For much of our learning the "need' seems automatic, for other learning we need a push. We need to be ready to learn.

Most of us are familiar with Reading readiness and other similar programs. They have some merit. True readiness comes, not from programs, but from within the person. You are ready to learn when your basic needs are met. Let me share with you my list of basic needs of students able and disabled alike. In fact we each share the same basic needs.

The Five Basic Needs:

1. The most basic need is **To BELONG.**

Jim Hansen with Maria (now deceased) and Rose Galati

We are social beings who live work and learn in groups. The family is the first and most important group. The school is a close second.

It is not simply "nice" to belong, it is crucial to our well being and growth. Most children feel a sense of belonging in the family. Children able and disabled alike are obliged to go to school when they reach the mandated age. They have no choice; they must go. They should, therefore, be welcomed and have full membership in the school community. Children who are different are frequently assigned alternate placements or refused admission totally. They are frequently unwelcome visitors in their own school.

Denying or diminishing a child's basic need to belong reduces his/her hope of a good and complete education.

Parents whose child has special needs must insist on their prior right to attend school with their brothers, sisters and friends in their local school. Advocacy groups are ready to help parents achieve this goal.

2. Our second basic need is **To Be ACCEPTED - AFFIRMED.**

Acceptance by others is easily recognized and appreciated. It could, however be seen as formal or even patronizing. Affirmation is life giving, it goes beyond acceptance. Affirmation is difficult to define but easily recognized when felt. It is a sense of personal worth reflected to us from significant others. We have each experienced persons, whose presence in our life, have caused us to glow. Imagine twenty-five pupils, each convinced of their personal worth because of an affirming teacher. Imagine teachers secure and happy in their role because of affirming pupils. Imagine families where mothers and fathers, husbands and wives and children affirm each other. Affirmation is the icing on the cake of belonging.

3. The third basic need is **To Have SUCCESS.**

We must not continually fail in our endeavors. It is important that children from an early age experience success. A backlog of success will insure future success and help us meet the challenge of that "rough, tough world" out there.

4. The fourth basic need is **To Be CHALLENGED TO EXCELLENCE.**

Every child able or disabled needs to be challenged to excellence. His/her excellence not some artificial, external measured excellence. A challenge to excellence does not mean involuntary competition. Excellence is pushing the definition of 'personal best'. Some may wish to compete with others and accept the consequences - good or bad. Involuntary, forced completion is, however, potentially abusive.

Excellence need not be recognized by the difficulty of the task. Each person has his or her own goals. One foot added to the balance beam, or two more pushups mark excellence.

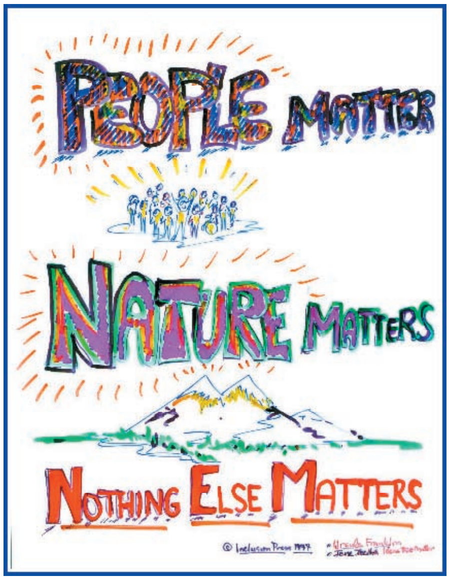
5. The fifth basic need **To OFFER SERVICE.**

There are many ways to offer service to others. Many offer service daily through their work or family responsibilities. We all need to serve. We are very good at serving those children and others in our communities that have special needs. However, we need to insist that they (those served) also offer service to others. Their need to serve is as great as ours, if not greater.

- **To Belong**
- **To be Accepted-Affirmed**
- **To have Success**
- **To be Challenged to Excellence**
- **To offer Service**

These are our basic needs - not optional - necessary. Their presence in our lives tells us that we are loved. To the extent that these needs are met we learn and grow.

Jim Hansen <jhansen@interlynx.net>)



THE BEGINNING

- Every child born into the world is a blessing.
- Every child born into the world is a gift.
- Every child born into the world has worth and is unique and unrepeatable. Learning begins in the womb and continues till death.(many believe beyond) . Clearly life long learning is a reality for each of us.
- Life is the ultimate gift and learning is its crowning.
- Learning brings growth and growth brings new life. This circle continues throughout our life.
- Much of a child's early learning seems to be random and spontaneous. It flourishes in a warm welcoming and stimulating environment. It can and should be influenced and encouraged in a non intrusive way.

Since learning brings growth ,and growth gives new life all learning is to be valued, not only learning for "earning'', not only learning that is "measured", not only "quick" as opposed to "slow" learning. Remember, learning is not a race. True learning cannot be measured only admired, fostered and valued.

Academic learning is to be valued, but not to the exclusion of other learning. Good manners, proper hygiene, physical skills, artistic endeavours, doctoral studies, service, are learnings to be valued equally with each other and with academic learning. The inability to learn academically should not disqualify any one, able or disabled, from other learnings.

We do not each possess the same skills or abilities. Each of us is very able in some areas and less able in others. Some cannot "see" well. Others may have physical disabilities. Neither abilities nor disabilities should be value laden. They are not "good" or "bad", they simply are. They should not define us a person. They frequently do. They should not determine our inclusion or exclusion from society. They frequently do.

Every child can grow and Each Belongs. Each child belongs not because of what he or she can or cannot do. Each child belongs not because of what he or she knows or doesn't know. Each child belongs not because of what he or she has to give or gain. Each child belongs because he or she "IS".

It is my hope that all who read these thoughts will begin to see "learning" as something more than schooling. We wish each of our children a "good education" Do we know what that is? Explore that with me.

Jim Hansen <jhansen@interlynx.net>)

Maresa MacKeith

Maresa MacKeith could not communicate until she was eight. Now she is doing her A-levels

Richard Garner

She was once written off by an educational psychologist. But now Maresa MacKeith is taking her A-levels at a further education college and is hoping to go to university and become a journalist. Her extraordinary story is told in a CD to launch a campaign to provide disabled youngsters with mentors to show them what they can achieve.

Maresa was packed off to a special school at the age of six after an assessment. She could not communicate with anyone until she was eight, because she cannot talk or use her arms and legs independently, She only managed to obtain a full-time place at a mainstream school at the age of 14 after years of battling by her mother. Caroline MacKeith was convinced her daughter was cleverer than the psychologist had given her credit for because she could see her laughing at complicated programmes on TV. "You just kind of sensed it - from her expressions and that sort of thing," she says.

She sought for a way to communicate with her daughter and eventually stumbled across the Facilitated Communication technique pioneered in Australia.

Now Maresa communicates by spelling out what she wants to say on a letter board (like a keyboard) and a facilitator - an adult appointed to work with her - speaks her words to teachers and friends.

"One thing I noticed was that she could spell immediately she got the communicator," says Caroline. Once she learned how to communicate, Maresa did not hold back when it came to telling people what she thought. "I'm depressed - get me out of here," she said as her mother's attempts to get her into a mainstream school full-time failed yet again and she was placed in a special unit. It was only when she had to recuperate at home after an operation and was sent a home tutor that anyone in the education world began to realise her potential. "The home tutor was just a really good teacher," says Caroline. "She came in and within 15 minutes understood how Maresa could communicate. She'd almost never met a disabled person before - she'd only met ill children. She then convinced other teachers Maresa could cope in a mainstream school."

At the age of 14, with nine years of education to catch up on, Maresa went to Ellis Guilford comprehensive in Nottingham and set about studying GCSEs. Two years later she left with six passes - an A*, two grade As and three Bs. Her favourite subject is English. Maresa says of her early education: "They [the teachers] wouldn't learn my way of communication and just thought I was completely incompetent at everything. It was awful. I felt life was hopeless." Even in successful years at school, she still feels it did not give her enough time to mix with other pupils and make friends.

"Maresa can only do one thing at a time - she can't eat and drink and talk at the same time," says her mother. "She can't chat with her friends as she moves down the corridor to the next lesson - she needs time built in to mix with the other children. "Two girls went to one of the teachers and asked if they could have more time with Maresa. They were told 'it's all right if it doesn't affect your grades'. What a thing to say. I've never forgotten that."

Maresa is now studying English and sociology at A-level at a further education college, Clarendon College in Nottingham, and hoping to go to Nottingham Trent university. "I love writing," she says. "I want to change the world. It's the only thing I really want to do - so that kids are better treated."

Maresa was in London for the launch of the government-backed campaign, "Free Up Your Life" organised by Disability Equality in Education, which aims to provide youngsters with adult mentors who are also disabled to show them what they can achieve. The scheme is being pioneered in Newham and Tower Hamlets; discussions are taking place to extend it to Birmingham.

"We had one group from Tower Hamlets who had never been 'up west' (to central London) before in their lives," says Richard Rieser, the director of DEE. "One had never seen any disabled adults in the community and said 'I didn't know what happened after school - I just thought you died'."

r.garner@independent.co.uk

Maresa dancing up a storm at the Inclusion Now Conference.

"Common Sense" and Support for People with Disabilities

Jack Pealer

I've been thinking lately about whether "common sense" is a tool that's useful to those of us who want to help people with disabilities live richer lives. It seems that it should be. After all, most of the richness that we're trying to enable people to experience is found, we say, in the varied patterns and textures of that locus of our existence we call "community." And, community is the place that runs on "common-sense" principles. Communities, by definition, function well when their lives are governed by commonly agreed upon ideas--common expectations and experiences. Shouldn't that mean that this "common sense" that supports communities will also support those community members who have disabilities?

Well, sometimes "yes", but more often "no". Let's look at the "yes" examples first. In the past several years, I've often found myself in the role of "facilitator" (or "writer-on-the-wall") at meetings where someone with disabilities and her family and friends were trying to describe a better future life and, then, to figure out how that life would happen. The remarkable thing about these meetings is that, in general, the people who come to them really listen (sometimes for the first time) to the person who is the meeting's focus. Participants really work to understand the interests and wants of that person and then try to have a vision that captures those interests. Most often the vision and the plan that results issues from what I would call "common sense." That is, the ideas that develop are usually self-evidently rational for this person at this time in her life. "Common sense" is the process at work when people understand that someone with disabilities a) can't stand living in a big group any more, or b) won't be helped by coming to a sheltered workshop every day, or c) needs a personal relationship that lasts with one (or more) other person(s). In this context, common sense is what leads planners toward the sort of plain inferences that have sometimes resulted in big changes in the lives of some people who have disabilities. So, at least one kind of "common sense" (the kind that the *Oxford English Dictionary* defines as "…the plain wisdom which is every man's inheritance.") does offer support to people with disabilities.

But, there are other definitions of "common sense", and these offer us less comfort. For example, the *OED* also defines common sense as "…the general sense, feeling, or judgment of a community". The idea here is that communities tend to develop some ideas that are held in common, including ideas about themselves (who "we" are) and about other people (who "not us" is). It is this version of common sense that actually attacks the potential membership of people with disabilities in their communities. For more than twenty years, Wolf Wolfensberger has described the "common sense" of communities with regard to people who are judged to be "not us"; this description has taken the form of a catalogue of "common negative social roles imposed on societally devalued people." (See: *The Principle of Normalization in Human Services, Origin and Nature of our Institutional Models,* or *A Brief Introduction to Social Role Valorization*). Among the roles described in this catalogue are those of "sub-human/animal" and "burden of charity." "Common sense" as community judgment is what led me and other officials of a community where I once lived to decide that the sensible place where (only) children with disabilities should be educated was at a location seven miles from town, adjacent to the county poor farm and animal shelter. Another social role described by Wolfensberger is that of "menace/object of dread." "Common sense" as the general feeling of a community is what has led countless citizens of neighborhoods across North America to abandon civility and oppose, sometimes with violence, the residence of people with disabilities in their neighborhoods.

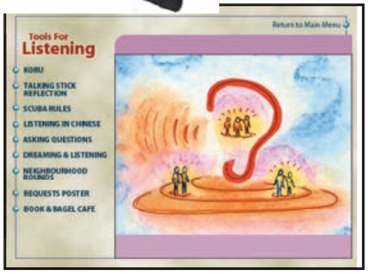
A few days ago, I sat working in the office of a school devoted to the education of (only) children with disabilities. A car pulled up outside and a man got out. He lifted from the back seat a cardboard box, and he carried the box inside the school. Coming into the office, he explained that he was from the local ("community") American Legion or Elks or VFW (I forget which). His group had sponsored an Easter party the previous Sunday (actually a week before Easter) for "the children." They had candy left over. Would these children like to have it? The candy was accepted, and he returned to his car and drove away. Now, it's possible that he drove past several other schools on his way to deliver the left-over candy. There are other schools in our town. But something--something that I'd call his "common sense" (the general judgment of our community) about difference and the exclusion that communities say must accompany it--caused him to choose this school and these children.

Why am I going on about this? I'm doing so because I want to think carefully about the extent to which "common sense"--mine and that of my fellow citizens--can be trusted, as a tool that will help people with disabilities. And, I conclude that I'm of two minds about it. On the one hand, if I'm trying to assist just one person whom I know fairly well and if I'm doing so in conjunction with others who also know and care about that person, I think that my "common sense" can be trusted, much of the time. When the "plain wisdom" that I and my fellow citizens possess is informed by personal knowledge of and identification with the person we're trying to assist, common sense is a useful guide. On the other hand, it seems likely that when I'm considering how to "help" a group (or a "batch", as Erving Goffman called such collectivities) of people with disabilities--when I'm making decisions about organized services for them--common sense or the "general community judgment" about them will not often be useful. As a matter of fact, given the history of organized services, which, after all, emanate from communities, the community sense about people who are seen as "not us" is likely to be harmful. It's not to be trusted.

But, organized human services exist, and they will for a long time to come. For as far ahead as I can see, it's probable that our communities will use organized services as implements to try to help groups of people. This probability, coupled with the untrustworthiness of "common sense", means that those who are really interested in better lives for people who use services have to work hard at developing and teaching sets of ideas about how human services can better be organized. The necessity for human service workers (who,after all, grew up learning the general judgments of their communities about people with disabilities, as those judgments were expressed in places like segregated schools) to learn about ideas like "social role valorization" has never been greater! And that's the reason why we who are involved with OHIO SAFEGUARDS keep doing the things we're doing. We offer our workshops and we write the things we do precisely because these things fight against common sense.

From *The Safeguards Letter*, March, 1991

We need to
Learn -
and
Relearn
How to
Listen



Each Belongs

Celebrating Thirty Years
of Fully Inclusive Education
In Hamilton, Ontario, Canada

a Book & and Video

The Hamilton-Wentworth Catholic District School Board has just celebrated 30 Years of Fully Inclusive Education for All. Their mission statement: **"EACH BELONGS".**

Now you can SEE and READ about the story. There is a fifteen minute video that says that all children can be included - from elementary grades through to high school graduation - if we want and believe in a system where "EACH BELONGS". A stunning segment shows two high school students telling about their experiences. One is in a wheelchair; the other on his feet. Which has benefited more will be your challenge question. The video was created by students and faculty. Show it to anyone who doubts that inclusive education is possible. Listen to parents, teachers, and administrators who, without a shadow of a doubt, know that "Each Belongs." While many systems are still debating whether to welcome all children to their schools, Hamilton, under the leadership of Jim Hansen, Phil DiFrancesco and Betty Browne, has been doing it - with no extra budgets – for thirty years. Their secret is extra love and caring for all.

The book is a documentary history of how they did it. Board minutes, reports, letters from teachers, families. If you want to see how it was done from the inside, Jim Hansen has compiled his remarkable story - with a lot of help from his friends.

Available from Inclusion Press.

On Avoiding False Hope

Regina DeMarasse

Create more regional directors to oversee things. Create more committees to investigate things. Create more supervisors to document things. Create more forms to fill out, more positions for people to fill, more areas in which to divert taxpayers' dollars.

Create more deficits in much needed programs. Create waste of potential, loss of dignity, discouragement, worry, loss of hope - but whatever you do, DON'T CREATE FALSE HOPE!! "False Hope" is of paramount concern to doctors, psychologists, psychological evaluators, physical therapists and many professionals in human services.

Ever hear of a self-fulfilling prophesy? Its the phenomenon by which a child in school, when told he is bright, motivated and bound to succeed, feels encouraged and works harder. It is the phenomenon by which workers in industry told they are producing a great product, who feel proud, motivated and encouraged, work even harder. It is the phenomenon by which members of an organization or movement are told what a wonderful future they are building, and with their enthusiasm revived, their strength renewed, they go forth to conquer and build still more.

It's healthy, you know, so why do we fear false hope as we fear splitting our pants in public? Why do professionals avoid it like a truck full of cow manure? What on earth is "false hope" anyway?

I've never heard these same professionals speak of "true hope" but it seems to me that might be its opposite. Must hope be either true or false as when on a short answer test, you have a fifty percent chance of getting it wrong or right unless you studied and have previous knowledge? Doesn't hope imply something that has not yet come to pass? If it's something in the future, then how can you have previous knowledge? What is hope?

What is truth? What is false?

Is there really something wrong with telling a despairing young person who wants to someday live independently out in the community, working, socializing, attending theaters, shopping, doing things most people take for granted that such ideas are ludicrous? He's handicapped, so you don't want to give him "false hope." Should you avoid discussing with a person residing in an institution what life could be like on the outside and what brainstorms she or others could possibly conceive? You might be offering "false hope." Should you let bright, vibrant, sensitive or just plain feeling people, worthy of dignity and love, lose all hope rather than give them "false" hope, because you assume if you've never seen it done before, it's not a possibility?

So what if you dare to dream a little, indulge in a fantasy, a scenario, if you will, and find out it doesn't work? So what if in pursuing a dream you find you keep bumping into big, sprawling, complex pillars or fall into low-lying vast caverns? The pillars might be trees branching out and flourishing in other directions and the caverns might contain precious crystals and gems. So what if you don't always succeed? Can you blame yourself for at least trying?

I used to be embarrassed to express my dreams and aspirations too openly. Despite the limitations of my blindness and quadriplegia, I had many ambitions that I could really and truly envision.

"What are you going to do about personal care attendants, about accessible housing and about all those other things you need help with?" members of the staff at the rehab center I resided in questioned. That was just it. Still, as foolish as it all sounded, I would have to find the way.

It was my good fortune that my Circle of Friends began meeting to address these matters. It was also fortunate that they were just as foolish as I and chose to see my abilities over my disabilities. We could see there lay ahead a lot of work if we wanted to overcome the obstacles then present in my situation. We began working on strategies.

"Circles of Friends" are not the answer for people living with disabilities; they are a process, a means, an approach to finding solutions or a better way. It is not without work that Circles make things happen. Nonetheless, even the process proves meaningful, bringing people together and allowing each to broaden his or her horizons, exceed limitations and experiment with real life, rather than sink into the despair that occurs when a person is not permitted the dignity to try and fail. Failures are successes in learning what other strategies need to be attempted. Even more important is the need to have hope. Without it we slump into apathy and fulfill the prophesy of "never be able to..."

Most of the staff at the rehab center didn't believe I could ever leave and survive outside. Indeed, without the support of the "crazy dreamers" in my Circle, I wouldn't have been able to. We spent nearly a year working on a plan. I was happier than I had been the previous year when I didn't have plans to work on, not only because I had something to look forward to, but also because of the experiences I had in the planning process.

In the end, I did move out of the institution and into the community; I am living with the kind of roommates I had hoped for, in the kind of quiet, country setting I dreamed about; I do have the kind of attendants and help I had hoped for; and my time is spent writing the book I always dreamed of, without the institution dictating where and when I could do all kinds of things I like best. I'm glad a group of us got together to share some "false hope."

Hope IS…

Regina DeMarrasse

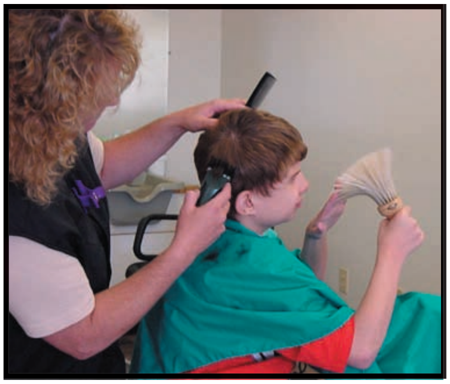
Hope is neither true nor false; it just is. It is what gets us through the night, through the winter. Hope gets us through a rape, a death, a war, the loss of a house or home, harvest, or heart. Hope is what opens our eyes in the morning, gives us a reason to open our doors and face the day, to believe things will be good or get better. It is that warm day that melts the snow in February, the robin that sings before dawn, a drop of rain in the dust. Hope manifests expectations for our daughters and sons, propels us through forest or desert, makes us strive for the moon. But hope brings no guarantees.

It was my belief that Dr. F's attempts might foster the harmony needed. Through the many years of my illness, the many healers I saw, the many remedies I tried, I always had something to hold onto - a new idea, an attempt, a new therapy that might work. Dr. F had kept my faith alive until I was able to find still another doctor and another therapy to latch my hopes onto. I do not underestimate the value of what that hope did for me. Had I not hope, Debussy's "Afternoon of a Fawn" would not have tickled my heart, had I not hope, the icicles covering every twig, every branch, every vine that cold, cold, snowy winter, would not have appeared so brilliant. Had I not hope, raspberry yogurt with wheat puffs would not have tasted so good, even with steroids. Had I not hope, I would not have heaved my body up out of bed to embroider a unicorn scene on a remnant of my father's old royal purple bathrobe - so regal on him, worn so often in his final days - the remnant we couldn't bear to discard. Had I not hope, I wouldn't have sketched the pansies I saw, read the books I inhaled, or admired the perfect gold maple leaf Raymond had picked off the ground and brought me that fall saying "It made me think of you." My body would have very soon faded to a pale void semblance of life, then the spark would extinguish.

Money invested in hope is money invested in life. Hope sings its own song.

The "healing" atmosphere could have been life promoting, however long they thought I had - ten years or ten days; until we die, we need to live.

If you like Regina's writing - wait for the book - soon from Inclusion Press



Natural Community Supports

Nancy Hartshorne

Natural Supports for people with developmental disabilities have been defined and deliberated in many forums. It is energizing to discuss this topic as a human right. It is exciting to talk about the possibilities. It is wonderful to dream about a future where this happens everywhere, all the time, for people with disabilities. It is also exhausting to facilitate, difficult to teach, and not easy to generalize to multiple environments.

Perhaps the most thrilling time of all is when it just sneaks up on us, out of the blue, in places where we least expect it. My son and I had such an experience this morning.

Jacob is 14 years old, attends our local high school, has a large Circle of Friends, and has attended school with his non-disabled peers since kindergarten. He is also deaf-blind, communicates mostly through the use of pictures and natural gestures, and has other sensory difficulties. For this reason, getting him haircuts has always been a problem. For many years he received only clipper cuts from me, his inexperienced mom, because he simply could not tolerate his hair being combed and cut.

About three years ago, we found a privately owned salon in our small town that is primarily for children. I would guess that around 200 children frequent this salon regularly. Debbie, the owner, has from the beginning been very patient with Jacob, to the point of allowing him to come in for "half a haircut" at a time, to be completed later in the day, as he could tolerate it. In recent months, Jacob has discovered the brush she uses to brush off hair when the cut is finished. You know the type: A short wooden handle with long horsehairs sprouting from it. Jacob loves this, and takes it off her counter each time before sitting down, and explores it thoroughly with his tongue and mouth. His ability to do this allows him to better tolerate having his hair cut. He is able to cooperate more with Debbie when he has this brush. Of course, I worried about hygiene, especially for those children coming in after Jacob. But Debbie has never once commented on this, nor has she ever tried to take it from him, until she needed to use it after completing his style.

This morning Jacob and I dropped in to see Debbie for a cut. We go about every two months, no appointment necessary. He immediately took the brush and sat down, and did pretty well with his cut. I noticed that she had another brush on the counter. She used the second brush to brush the excess hair off of Jacob when finished. She pointed to the brush in Jacob's hand, and said, "That's Jacob's brush." Sure enough, when he placed it back on the counter, there, in bold black permanent ink for every child and parent to see, was written, "Jacob's". As chills ran up and down my spine, I commented to Jacob about how nice it was of her to be so thoughtful to have his own brush waiting for him on the counter for whenever he might drop by. She said, "We do whatever works", and smiled. No fanfare. Nothing special. *"Just doing my job, ma'am."*

Here is a person who sees Jacob about 6 times per year, who knows next to nothing about his disabilities or his life outside of hair grooming, and yet took the time and went to the trouble to provide him with this simple, yet thoughtful support so that he could be more successful. And something I thought was a big deal was really no big deal to her. So, my gratitude to her remains, but remains relatively silent, because of course as an advocate I truly believe everyone should take steps to support each other in this life. To see it actually happen without intervention or suggestion, however, is pretty rare. So, Jacob and I celebrate this small "victory" for community inclusion in our hearts, and we are truly grateful to Debbie, because as one of my close friends puts it, "she sees what is right about Jacob." Perhaps Debbie would disagree, and would say that she just looks for what works with every child that comes through her door. But Jacob and I know better.

> **It's not our diferences that divide us. It's our judgements about each other that do.**
> Meg Wheatley

Shoulder to Shoulder: Celebrating the Important Work of Direct Support Workers

Peter Leidy[*]

I want to talk about supporting staff, particularly direct support workers, about why it's important and why it's hard to do well, about how we all move forward together when we do, about what we're learning.

What *are* we learning? We're learning to listen better to what staff are saying. People are saying: tell me what my job is, help me get to know this person, offer meaningful training, help me understand how my role fits into the larger scheme of things, give me opportunities to talk about my work, value me and what I do. These are some of the things I like to talk about and sing about.

I live in Madison, Wisconsin with my wife and two daughters. I work for Options in Community Living, which is a non-profit supported living agency.[**] We're involved with about 100 people who all live in their own homes in and around Madison. Some people have contact with Options staff just once or twice a week; others have staff with them around the clock. There are about 150 people who work for Options, the vast majority of whom are Direct Support Workers (DSWs). As we carry out our day-to-day work with people, these are the values that guide us:

1. People have the right to live in their own home
2. People have a desire for community, a need for relationships and connections
3. People have the right to make their own decisions, to have real choices

We want people to be able to live in their own homes, running their own lives, participating in meaningful ways in community life, to have opportunities to contribute, to share their gifts (because everybody has a gift). Our challenge is to understand how to do this with 100 very different people in ways that are supportive and honest and life-affirming.

Where I work, we hold the belief that supporting people with disabilities well involves --*requires*-- supporting staff well. When we fall short in our efforts, not only do staff lose out, but so do the people who are getting services from us.

Our staff plays a crucial role in carrying out our mission. At Options, when it comes to supporting staff, we do not have it all figured out. I want to be clear about this. I can't share a recipe that we have perfected, but I can share some of the ingredients that are essential to the recipe. We continue to experiment with the portions and the way the ingredients are measured and added, and sometimes we feel like we're getting it right. Other times we don't plan well or we get lazy and don't stir it long enough or take a short cut and use the microwave when we really need the stovetop.

Sometimes, even when we try hard, we make mistakes. We try to learn from those mistakes. We fail at times, fail to listen, fail to put into practice what we know to be important.

Now, I don't want to dwell on our shortcomings, but they are very real, and these are some of the reasons why supporting staff well is so hard: we don't do what we know we need to do, we say we don't have time for this or that, or a thousand other things get in the way.

And it's hard. It takes time. It takes resources.

And, as you know, not every employee wants or needs the same kind of support. But we keep trying, and we keep learning. All part of the journey. And over time we grow and change. We are in a better place than we were a few years ago, and I imagine that in a few years we will be in a better place than we are today.

Do you remember, those of you who are now, or have been, employed in a support role, what it was like to start learning about the system? I made this journey 18 years ago, when Options hired me as a Community Support Worker. Here is a song I wrote about entering humanserviceland and some of the language I learned along the way.

We need to remember that new staff are coming into a new world with new norms and a new language, and even though our work is about real life and helping people belong to the community, we need to figure out ways to help staff understand the system they are joining. Not only to survive in their job, but also so they can begin to learn ways to help prevent the system from running people's lives.

People who provide direct support are saying 3 things. They are saying:

"Tell me what my job is." Who IS this person you're hiring me to work with? Help me get to know them. Help me understand what their life has been like and what dreams we might work toward. Help me understand about difficult or unusual things. What are the expectations? What is my specific role? What kind of supervision can I expect? Who will be available when I need to talk to someone?

They are also saying **"Give me opportunities to talk about my work."** Don't leave me hanging out there. Those of you who have an office see each other a lot and can check in and get support more easily. I'm spending the weekend with someone miles away from the office. Be available to me. Return my calls. Know that there are times when I want to engage with others who do this work. I want my supervisor to reach out to me, and not just when something is wrong. I want to attend trainings, and not just trainings about rules and regulations and procedures. Some DSWs are saying I want this to be my career, and I want to talk to others about this, because my family doesn't understand. Help me find ways to have these conversations. As I get to know my job and the people I'm working with, let's talk about how it's going and if there are opportunities for me to stretch, to try new things, to grow. Or, I'm a live-in worker, I want to talk about the challenge of sharing the space and having a job where my job is at my home, only it's not just MY home...

The third thing people are saying is: **"Value me and what I do."** As you all are well aware, by and large, DSWs are underpaid. The work carries a fairly low status, the way our society views work. So when someone comes along who is a good match for this work, isn't it in everybody's interest to value that person and try to keep them? I think we'd all agree that not just anybody can do this work well.

Value me and what I do. Not just with words. If you value me and my role, you will support the relationship I have with Mary, who I support. When we are supporting staff well, and when we are supporting the people who rely on us well, an important part of what we are doing is honoring these relationships. Gerri and Jolene have an important and deep relationship, Jolene has worked with Gerri for 10 years. Together they have gone through many of the things that people who are in relationship go through together: joy, sorrow, anger, boredom, unpredictability, predictability. For EACH of them it is important that we work to support the relationship. And people like Jolene tell us, if we will listen, that one of the primary reasons they're still in the work after many years is because of the relationships. Here is something Jolene, who is in her mid-50s, said: "I could probably find a job where I make more money and a job that isn't as hard, but I get so much out of this. I feel like without even trying to, I stumbled across the most meaningful work I've ever had." A huge part of what makes it meaningful for Jolene is the RELATIONSHIP.

People are saying, I want to feel like I'm doing something important and making a difference. If you value me you will demonstrate that my work matters, that you appreciate what I do. The person I support may or may not be able or willing to show me this. And it's important.

You can show this by telling me --that's one way. Kind of simple, but too often forgotten. You can send a card! Again, something so simple, but when we do this, people say it makes them feel good. Doesn't it make you feel good to get a note of appreciation in the mail? The old fashioned mail, not email. Thanks for what you do, you make a difference.

Sometimes we send people flowers. Now who doesn't love to get flowers unexpectedly? I'll tell you who: Deborah. She's allergic to them. We don't send her flowers. And I'll tell you who else, Charlene. She's not a flower person. We know this about her. So recently we sent Charlene a gift certificate to a restaurant most people I know don't really like, but Charlene does! One size does not fit all when it comes to showing appreciation.

We also have something called "surprise time off", which is pretty much what it sounds like. Somebody's been working extra hard lately, or going through a particularly challenging time with their job, and we might call up and say, "How would you like to have Saturday off and still get paid?" (When they're done laughing we tell them we're serious.)

A few years back we started having annual appreciation dinners for Options employees. These are modest, but meaningful and fun affairs where we rent a nice place and Options management team serves dinner to everyone who's there. A couple of short speeches by our Board president and Director, a few words about each staff person who attended, door prizes, song and dance....

We also formed a workgroup, called the SWAT group, SWAT standing for Support Worker Action Team. The group was born after a survey of direct support workers a few years ago. It is open to any DSW, and has about 5 regular members, and I'm part of the group as well. Remember I mentioned that we changed our organizational structure? Part of that involved creating the position I now have, one purpose of which is to help increase our capacity to address these kinds of issues and try to keep them on the front burner.

SWAT --and with a name like SWAT, you just *gotta* believe these issues will stay on the front burner-- takes responsibility for helping Options pay particular attention to issues of interest to DSWs, and my presence is one way of providing a link to the office-based staff and management team. The group has focused on ways of improving communication, organizing social events and retreats and bridging the gap that can be felt between DSWs and other staff.

Supporting people with disabilities well involves supporting staff well. It requires us to understand we truly are all in this together, all of us. It's not "us and them", it's just us. Shoulder to shoulder to shoulder to shoulder. Moving forward TOGETHER is the key. We don't move very far forward if we are trying to support people with disabilities without really paying attention to what staff need. Nor do we move forward when we find ourselves "supporting staff" at the expense of the person being served.

Hearing what staff are saying is a vital part of the whole support picture. This takes real listening and a commitment to take action. When we listen and make a commitment and begin to act on that commitment, we begin to discover ways to meaningfully support staff, AND we create ways of keeping it alive in our organizations.

Tell me what my job is. Give me opportunities to talk about it. Value me and the work I do.

(Footnotes)

[*] *Edited from a speech to The Second Annual Full Lives Conference, Anchorage, Alaska 24 April 2003. The speech included performance of several songs most of which are available on **Greetings From Human Serviceland** and **More Songs for People Like You and Me.** Order the CDs for $10 each from Peter Leidy, 610 Miller Ave, Madison, WI 53704 (pleidy@wisc.edu). Visit Pete's webpage at* http://peterleidy.com.

[**] *To learn more about Options, read **Remembering the Soul of Our Work,** a collection of stories written by Option's staff, and **Celebrating the Ordinary: The Emergence of Options in Community Living as a Thoughtful Organization.** Both are available from Options at 22 N. 2nd Street , Madison, WI 53704 (608-249-1585)*
www.optionsmadison.com/pages/publicat.html

We can't be creative if we refuse to be confused. Change always starts with confusion; chersihed interpretaions must dissolve to make way for the new.
Margaret Wheatley:

Gerv Leyden

'One building, many schools':

Organisational barriers to inclusion

Gerv Leyden, Special Lecturer, Univ. of Nottingham
Derek Wilson, Co-founder, Inclusive Solutions

Between us we have been educational psychologists for over thirty years, visiting and working with schools throughout this time. However, it was a parent's experience that taught us one school may have many faces. Which faces do we see, and which are less visible?

A Parent's Story

'Our two sons attended the local high school throughout their secondary education. It provided them with an excellent education and a platform to pursue their university studies. My wife and I looked forward to the regular parent evenings held at the school. Staff would talk openly to us to about the boys' progress in lessons and how much they enjoyed taking part in the school's sport and music activities.

We found ourselves welcome in the school and invited to help with parent meetings, drama and other school events. We were even invited into the inner sanctum of the staffroom and on first name terms with several staff. We felt a real part of the school.

Eventually both our sons moved away to university. We had decided not to have more children but had often discussed fostering or adopting a child who lacked a family, or whose life circumstances had had been disrupted or damaging.

In fact we found there to be a desperate need for families able to offer short or long term care for children with personal and social needs. Many had also experienced breakdowns of care in their previous home arrangements and had become distrustful of adults. We wanted to 'put something back' for children whose lives had been less blessed.

After much consultation with social workers and other foster parents we were introduced to Sarah. Sarah was 13 years old and had been 'in care' for some years. Many of her placements had broken down and she had lived with several families in different areas of the UK. She found it difficult to build friendships and trusting relationships with both children and adults. These problems were not so severe in her junior school days but were acutely highlighted when she transferred to secondary school.

However we were experienced parents, knew our local high school to be excellent and felt we could offer Sarah what she needed.

We met with the social worker and teachers to plan Sarah's introduction into the school. The staff remembered our previous relationship with the school and all started well. We did find it difficult at first to 'reach' Sarah, but from what we knew of her background that was not surprising. And both she and we managed to adapt to each other after the first few weeks and established some common ground.

We were unprepared for what was about to happen.

Our first inkling came in the form of letters and phone calls from school informing us that Sarah had been rude to teachers and was not getting on with her classmates. We were invited to school to discuss this with someone called the 'special needs co-ordinator' and a 'Head of Lower School'. We had neither met nor heard of either of these staff! Nor had we been in the 'Conference Room 'where the meeting took place. Instead of the easy chairs of the staffroom we found ourselves in a formal, bleak setting, seated round an oblong table. No more hot drinks or hospitality. Totally unprepared, we froze and found ourselves adopting the clipped anxious tones of the teachers.

To our horror the teachers read out a list of incidents in which Sarah was described as difficult, rude, prone to angry outbursts, friendless and lacking respect for the teachers. We sat through this litany, stunned. A 'contract' had been drawn up and we reluctantly signed it. We felt that decisions had already been made and that we had no option. Any parent in a similar position will know how that feels.

Things worsened. After further meetings, we were 'invited' to withdraw Sarah 'voluntarily!' from the school. One of the teachers advised us that it would be easier to find an alternative school place in the area if Sarah had not been previously excluded! We were still prepared to persevere and work with the school, but when told that Sarah was being bullied by other girls and the school could not guarantee her safety we felt we had reached the point of 'no return.' We withdrew Sarah and moved her to another school.

Looking back on what had happened we found it hard to believe that this was the same school that had been so encouraging and stimulating for our boys, so welcoming to us as parents and friends of the school. But while it was the same 'bricks and mortar' building, we found that when things started to go wrong we were no longer dealing with the same teachers as before, meeting in the same rooms, nor experiencing the same welcome. It was as if they were two totally different schools.'

Derek Wilson - doing graphic recording

Reflections

These parents had put into words truths of which we were already half aware, but whose significance we had not fully grasped. And it is a lesson familiar to many parents. While the experiences they describe are appalling, we were struck by their insights and conclusions. Here are some of the points that struck us. What are your thoughts?

The key learning point for us is that a school has many faces. For instance, a 'good' or 'popular' school may have a reputation for excellence based on exam results or achievements in sport, music or other extra-curricular areas. That reputation is less likely to be based on the welcome it affords to all pupils or its success in achieving full inclusion for all children within its catchment area.

However, prevailing benchmarks about school excellence generally focus on academic achievements, an agenda vigorously pursued by government and media alike. This currently casts a great shadow on ways schools are structured and organised, and the values, social and financial, that pervade the educational community.

Do we want more for the education of our children or are schools to become no more than 'achievement factories'? What is to happen to children who do not meet these achievement criteria? What are the effects on teachers of these pressures?

When teachers are constantly dealing with externally imposed changes in the context of an unremitting achievement agenda it is not surprising that something has to give. Too often the sacrifice is the school's pastoral environment, the support offered to all children and the recognition of the importance of community building.

While all children and teachers experience the effects of this, it is especially so for teachers and support staff working with children who have challenging needs. Under prevailing values they often find themselves marginalised from participation, influence and decision-making within the school. This form of 'internal exclusion' impacts on teachers and pupils alike, limiting their access and contribution. Teachers who find themselves excluded in this way are in no position to facilitate the full inclusion of those they teach.

These effects are mirrored for parents. How can you bring about changes in attitudes, culture and practice in respect of your child if your only point of contact is with those staff who themselves are marginalised at the periphery of school decision making?

'Exclusive' internal systems within schools similarly restrict the effectiveness of external agencies. Unless educational psychologists, resource teachers and other support staff are able to engage with teachers and managers across the whole school they will also be marginalised and limited in their capacity to make inclusive education a greater reality for all children.

By working solely at the periphery they are more likely to consolidate this segregation of learning support systems within the school. Separate 'schools within schools'.

It is important for all those working to support the inclusion of children with significant or challenging needs to make common alliance with principals, head teachers, managers, teachers - and parents. By definition, inclusive education is not achieved by working alone. Isolation is achieved by working alone.

The solutions? We all have to create our own, for our own unique circumstances. But here are three that have helped in the past – we would also like to hear about what has worked for you.

1. We need to break down those internal barriers within schools that inhibit creative planning for our children, especially those with the most demanding needs. Inclusive tools such as PATH, MAPS and Circles of Friends can be the first step in creating a more inclusive school. They can also help schools clarify their internal values and establish collaborative learning experiences within their own teams and with parents. Such tools also involve the outside agencies in a more constructive role. (Check the information about videos and training opportunities elsewhere in this edition of *Inclusion News!).*

2. We need to challenge the 'top down' model of school accountability. Of course governments have a strong interest and investment in education. But schools are also accountable to their communities and to the parents who entrust their children to the teachers' care and professionalism. Become active within your local school, make common cause with staff and other parents, let the teachers know what you want for your child and give generous recognition when you see it happening. How often do we write or phone to tell the teacher when our child comes brimful of excitement over something special s/he learned or experienced today?

3. Those of us working as 'outside agents' also need to re-introduce and re-include ourselves into the community of the school and transform our relationships with teachers and parents. If education is about learning, problem solving, relationships and community building, how can we make a full contribution by standing apart?

This is not rocket science. A school is not bricks and mortar. Learning takes place in many settings, not only classrooms. A community is not created by internal segregation. Children – and teachers – do not learn how to get on together by being separated. Parents are a key element of the learning and educational process and no school can achieve inclusion by erecting barriers, which prevent or restrict participation.

Excellence in schools *is* a desirable goal. It is not achieved through externally imposed targets nor internally segregated departments but by creating a learning community where pupils, teachers and parents work together to further the growth and development of each individual within it.

In the words of the Dalai Lama: "Open your arms to change, but don't let go of your values"

We would welcome any suggestions or comments you may have about the issues raised in this paper. Email us at:

Gerv Leyden: gerv.leyden@notttingham.ac.uk
Derek Wilson: d.wilson44@ntlworld.com

> ***Never doubt that a small group of committed individuals can change the world, indeed, it is the only thing that ever has.***
> ***Margaret Mead***

BOOK REVIEW:

Implementing Person-Centered Planning: Voices of Experience (Volume II)

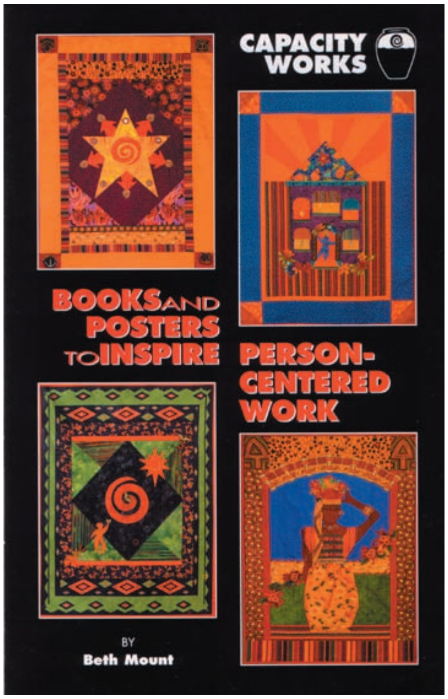
Reviewed by Craig A. Michaels
Queens College, City University of New York
Edited by John O'Brien and Connie Lyle O'Brien:
Toronto: Inclusion Press 2002
396 pages, paperback, ISBN # 1-895418-50-X,

The folks at Inclusion Press have released the second installment in their series on person-centered planning (edited by John O'Brien & Connie Lyle O'Brien). This sequel to their 1998 release, ***A Little Book about Person-Centered Planning***, should "continue and extend the discussion" by presenting the perspectives of practitioners, as they reflect on what they have learned from their work to date. This latest installment, ***Implementing Person-Centered Planning: Voices of Experience*** **(Volume II)**, describes some of the possibilities and pitfalls, through the voices and the direct experiences of 30 people who are struggling with the day-to-day realities and associated systemic complexities associated with DOING person-centered planning.

When the first volume in this series was published in 1998, it represented one of the first significant publications devoted exclusively to person-centered planning—consisting primarily of reprints of frequently cited papers from the early developers of person-centered planning. The subtitle to this second volume, ***Voices of Experience***, speaks volumes about the structure, and although the editors, John and Connie O'Brien, and the folks at Inclusion Press have carefully selected the contributors and organized this text, ***"voices"*** in the plural is what one finds here. According to the O'Briens, this was a conscious decision, rather than a mere accident.

The end result—in absolute person-centered planning spirit—is the creation of a synergistic whole that is somehow greater than the sum of its parts. The best analogy that I can offer for this experience (as I am not a biologist or chemist, and know virtually nothing about quantum physics), is that of viewing an impressionist painting. When one is one or two feet away from an impressionist painting, often all one perceives is a jumble of colors and brushstrokes that while beautiful, in some ways appear random in structures. Taking just a few steps backward, however, the viewer soon perceives that the colors and brushstrokes merge together into a vivid, unified, and alive reality—and so too with this publication. The superstructure that emerges from these diverse voices of experience and the diverse text structures beautifully captures the current moment in time as person-centered planning works to create new community roles and relationships for people with disabilities both *at the person-level* (exploring and supporting community roles and contributions of people with disabilities) and *at the systemic level* (re-designing the mission, organizational culture, and structure of human service systems) (O'Brien & Lovett, 1998).

Is another book on person-centered planning is really needed? Emphatically "Yes!" ***Implementing Person-Centered Planning: Voices of Experience*** **(Volume II)** makes a valuable and significant contribution to the expanding literature on person-centered planning, at a time when perhaps more than ever before, just such a publication is needed.



Capacity Works

Beth Mount

It is good to find that, in these times, there are those who meet to exchange their ideas concerning the ultimate goals of existence. What could be more moving in our community here on earth than to listen closely to a human heart, to hear in it the throbbings of a world, its sighs and its dreams?

Marc Chagall, 1963

The essence of person-centered planning is to listen closely to the hearts of people with disabilities, and to imagine together and work with them toward a better world in which they can be valued members, contribute, and belong. Through my artwork and stories, I am creating a language of the human heart that pulses with a song of freedom.

Throughout time, people from all cultures have used images and symbols to communicate with one another, make meaning of their experience, represent their inner and outer worlds, and map life journeys. I draw on these universal symbols and combine them with text to tell stories of hope and freedom, and personal and social change.

My interest in this work is inspired by the courage and determination of people with disabilities and the families that work with them to develop optimistic ideals in the face of limiting constraints. It is my hope that each image I create will serve as a reminder of the capacity that we have, both individually and together, to overcome challenges, celebrate our differences as well as our similarities, build lives of meaning and worth, and create communities.

BethMount GraphicFutures@earthlink.net

Self-Directed Supports & the Involvement of Self Advocates

Judy Cunio

What is the issue?

- To make sure that there are two or more Self-Advocates on every Brokerage board that is involved in Self-Directed Supports.
- To sit on boards with full & equal involvement - to be listened to.
- To NOT sit on boards as a token.

Background

For the most part, people with Developmental Disabilities have had very little to say about how we wanted to live our own lives. In fact, up until about 30 years ago there were very few people with Developmental Disabilities that were out and taking part in their community. Most of the people were away in institutions away from the public. We were not seen or heard. Most people in the community did not even know that we existed.

In the mid 70's and 80's, people with Developmental Disabilities began to get together and talking about how they felt. And decided that we wanted to be treated and respected like anyone else. At that time even they never thought that we could take control over our own lives. We have come so far but we still have a long way to go.

What Self-Advocates Want and Expect

- To be at the table at all levels when talking about issues that affect the lives of people with disabilities.
- Listen to what we have to say and DON'T make us feel like token members. We want to be equal members and to be fully included in what's going on.
- We want to be treated with respect and to be given the chance to make our own life choices even if we do make mistakes. How else are we going to learn?
- We need to be able to direct our own services and to hire own providers.
- We need to be involved in training of our Providers and to share the information with other providers.
- We want to be known for who we are, and not by our labels.

What We Need to be Good Board Members & Good Advocates

- For us to do a good job as board members, we may need help in understanding the materials.
- Always remember that TEAM means: Together Everyone Achieves More!!
- We want to have the same type of training that Personal Agents and Staff get.
- Remember that needing help does not mean giving up control.
- Remember: EVERYONE makes mistakes. But we need a chance to grow from them.

On Staff Support: How to Treat and be Treated

Judy Cunio

This is about how we want to be treated by staff and/or caregivers, AND also how we should treat them.

• **If we want to be respected by staff, we need to respect them.**

• Some of us depend on others for our everyday care. There is some risk to that. There need to be immediate options when things are not working out between the person and their staff.

• It is very important that you and your caregiver have open and honest communication with each other.

• A friendship between you is possible, but when a staff member is working for you, the relationship is professional.

Some of the things that you should expect from your staff include:

• Making sure that all of your basic needs are met the way you want.

• Having a working relationship that you can trust.

• Feeling safe from abuse and/or neglect.

• Being treated as an adult - and with respect. It's your right.

Some of the things that your staff should expect from you:

• Treating them the same way that you want to be treated.

• Maintaining honest and open communication even when there is a problem.

• Letting your caregiver know what you want. How else would they know if you don't tell them?

• When issues arise with your staff person, talk to them about it so you can get it resolved.

Rights & Responsibilities:

• You have the right to hire and fire your own staff. If possible, it is a good idea to give them notice.

• A staff member has the right to leave. But, it is his/her responsibility to give you enough time to find someone else.

• Staff should expect you will advocate for them to have adequate wages and benefits, and to be treated fairly.

Defining the Relation between the Person and their Staff:

• You should have a friendly relationship to work well with each other.

• Boss and bossy are two different things!

• Pay attention to each other's needs and wants.

• Respect each other.

• Use common sense.

John O'Brien, Jack Pearpoint, Tim Corey at the Summer Institute Portland, OR

The Damage Of Labels

Patrick Worth

As I think about how we label people, I think about my life as a young boy and how a label took away my identity as Patrick Worth. I was not known by my name; I was known by a label called retarded. I was put in a segregated school system because my parents and a lot of professionals thought that I could never learn in an inclusive environment. Because of a label, I was put in a segregated setting where I didn't learn the things that I wanted to learn, including reading and writing.

I was never really able to dream as a child. We all have dreams about what we want to be when we grow up. We are not given that chance when we teach people in society about labels instead of being human. I still remember getting on the segregated bus, waving goodbye to my brothers and sisters, and watching them go to their neighborhood school with their friends.

I remember sitting on the porch at night watching the kids play street hockey, wishing that I could be invited to play. I never got invited. Do you get angry at the kids for their ignorance, or do you get angry at the parents and adults who teach their children that we are too different? When people are stereotyped, people in society come to know the person by a label. Our identities, our gifts & our strengths are never recognized.

I remember at night, I sometimes prayed that Martin Luther King would come and rescue me. He took the courage to talk about his dreams and his ambitions. My dreams were all locked inside a label. Its important to know that this label followed me from childhood to adulthood. I lived in a group home and started going to a day program. These were all segregated systems that were based on labeling people as not being able to do anything.

Some of the labels that are used today are just as harmful. **High Functioning & Low Functioning**. I recently learned in Norway, from people (delegates) representing their own countries, that these are the most commonly used labels to identify people with disabilities in the world today. This is truly sad.

I have been told many times that I am an exception, and that others will never be able to reach my potential. I find that ironic when I look at my past - a young boy who was not supposed to be able to learn anything. I guess I was classified as low functioning then. Now all of a sudden, I am high functioning. I am **neither** high functioning nor low functioning. I am who I am! I am Patrick Worth.

Nobody has to reach **my** potential. Everybody should be recognized for **their own potential**. Everyone has the right to dream and to explore their own gifts. No one should be held back by a label. The universal labels of High Functioning & Low Functioning are holding a lot of people back from finding out about themselves and what they are capable of doing. Even today, those labels are often used to institutionalize people with disabilities.

Developmentally Delayed! While it is true that not all people have the same kind of thought process, it is not because they are delayed or developmentally handicapped. Their thought process is just different. We don't have to stereotype people because they don't think the same way as we do. I think that there are times when we all struggle to have a clear thinking process. When we struggle with difficult problems and decisions, sometimes our thinking is not clear because we don't have a clear process. We would not want to be labeled because we don't think the same way as other people do.

These are just a few labels that I hear today, but they have some of the most devastating effects. When I think about those institutional labels, (I call them institutional labels), I think about extreme poverty it causes in people's lives - in so many different ways.

Before I started working at **Options** and running my own business, I was sitting at home, just waiting for that disability pension to come in. I had been doing public speaking for a long time - but for free. That was because people really couldn't understand why they should pay someone who had been labeled. So in a way, I was still being labeled. I was not valued for what I was offering. The kinds of labels that people with disabilities have had to wear are institutional poverty labels. Although I had friends, I was very disconnected. I felt institutionalized in my own home because of a poverty label. My life became a real life when people from my circle started getting together to talk about how I could start running my own business, **Worth Consulting**. Now I travel to many different parts of the world; delivering keynote speeches; facilitating workshops and so on. I work at **Options** part time. I am a Network Facilitator with a unique role as a self advocate to help individuals to pursue their own goals in life. Although still uncommon, this represents a great change in service providing systems across the world.

When I think about freedom today, I think about a world without labels. When you think about it, we have all been labeled in some way. Take the time to think about how it felt for you when you were labeled. Try to imagine what your life would have been like if you had to live with that label - every day.

Good strong relationships are usually developed when people are seen and viewed as equal to each other. I dream that some day, we will all be able to see each other by our true names, for who we really are, in a world without labels. That would be a great day for the world, filled with real relationships for all of us.

Patrick Worth.
President, **Worth Consulting**
pworth@interactive.rogers.com

People First Havering, UK

People First Havering also has a company - a TRAINING company - 4DTC

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e-mail: "4dtc" <mike@the4dtrainingcompany.co.uk>

Naz's MAP

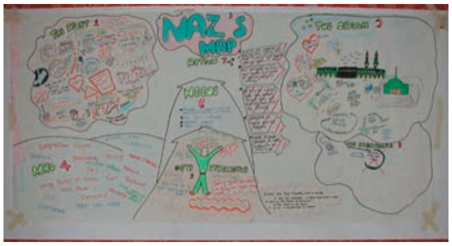
"Don't just do something, sit there!"

If you are at a crossroads in your life, or are trying to welcome a stranger into your community, MAPS might be a useful approach to consider.

Two years ago, Naz was on a training course, learning to use MAPS. Like many of us, she was very unsure that she had a dream - until she started. Then, a dream emerged. She wanted to go to Mecca, and she wanted to make the trip with her husband. Both elements were a surprise to Naz - especially since she wasn't married.

A year later, Naz was doing the training in Manchester, England, and was teaching the MAPS process by reporting on her own MAP. She held up a plate with her dream baked in the design - a wedding gift just before Naz and her husband left on their trip to Mecca.

Not every MAP is so dramatic, but it is a powerful process that unleashes powerful dreams that can take us to places previously considered unattainable. MAPS focuses our energy by listening to our stories. Everyone has stories. There are no exceptions. Everyone has a dream. For some of us, it takes a process like MAPS to help us say it out loud - and begin a new journey to the future we want - with our family and friends.



The future belongs to those who believe in the beauty of their dreams.

Eleanor Roosevelt

> It is one the most beautiful
> compensations of this life that no
> person can sincerely try to
> help another without helping himself."
> *Ralph Waldo Emerson*

Why Not Lead? A Primer for Families & Other Grassroots Leaders

Deb Reidy

Leadership is a journey which begins with a decision to act. Along the way, the requisite tools and skills can be acquired, borrowed, or shared. Although personal traits such as charisma and organization are useful to the exercise of leadership, they are not central. Motivation or will is. Families of people with disabilities often begin their leadership journey reluctantly, but they are propelled by their motivation to ensure a decent life for their loved ones. Similarly, people with disabilities themselves know that it is they who must act to ensure that their needs are met.

Why Not Lead? A Primer for Families and Other Grassroots Leaders is written as a personal guide for people motivated to bring about positive change but needing some guidance on their journey. *Why Not Lead?* aims to call forth, prepare, and encourage people who find themselves in a position to exercise leadership because they are committed to a person or a cause that is important to them.

The book is based on the experiences of ordinary people who took on leadership roles because they were motivated to act. It is written in an easily accessible and practical format, combining case studies, clarifying concepts, and exercises.

Having played leadership roles in the field of disabilities for over twenty- five years, the author, Deborah Reidy, has integrated her own experiences and insights with dozens of ideas drawn from the academic and professional leadership literature. She addresses the title question "Why not lead?" as if she were a personal coach working with each individual reading the book. Drawing from her extensive experience teaching leadership to groups of families, people with disabilities and staff, as well as providing individual coaching to dozens of people, she leads the reader through a series of reflections, step-by-step. Initial chapters explore the question "leadership toward what?" assisting the reader to clarify the aim or intention of their effort. Further into the book, readers identify the obstacles to their exercise of leadership, including limiting beliefs about the nature of leadership. At this point, having personalized an abstract topic, a definition of leadership is introduced, along with other concepts such as main elements of leadership, the work of leadership, and so on. Then, readers are assisted to develop a Personal Leadership Plan. The book concludes with chapters on the pitfalls of grassroots leadership, and strategies for sustenance and renewal.

Although this book acknowledges the important role of leadership skills and traits, it takes a very different approach than most books on the topic. By emphasizing the crucial role that motivation plays in the exercise of leadership, it empowers people who often do not see themselves as having the required leadership qualities. And then, by "walking with" readers on their leadership journey, it provides a valuable framework for the acquisition of experiences and resources that contribute to skillful leadership.

If you have vignettes, stories or examples you would like to share with Deb - and who knows be part of her book - she would love to hear from you.

You can reach Deb at: djreidy@krypto.net

The bugle

I have recently started to teach a group of Boys Brigade boys how to play the bugle in Nottingham, UK. I had not played since I was 16 but the memories and old skills soon returned. Talking with Derek my friend and inclusive partner the richness of the bugle as a metaphor for life and gifts became clear.

The bugle has only 5 notes. Yet the possibilities of meaning, which these few notes can create, are striking.

Reveille, the wake up call!

Last Post, the sound of remembrance for lost souls

Come to the cook house door boys, a call for food and fellowship

Fall in, draws attention for all to come together

Retreat, a call for all to fall back and regroup

Marching tunes, a wide range of tunes for all to march along with

All of us have notes in us. Some play all five in clear and powerful melodies. Others only one or two notes but perhaps these are rhythmic. We can all march or roll along to simple bugle marching tunes not everyone has to play all the notes for this to be successful. Some can play a few low notes; others play rhythmically without too many highs and lows. Others will play the melody loud and clear for all to hear. The combined sound is what is best!

Let us all find our notes, play them as best we can and unite in clear meaningful messages for the world to hear!

Colin Newton

www.inclusive-solutions.com

Can We find Ourselves and Be Inclusive?

by Judith Snow, MA

Recently I had several conversations with a woman with autism who lives in Montreal. She is attempting to get intervenor status in a Supreme Court case involving the murder of a teenager with autism. The young man was killed by his mother. My acquaintance is attempting to intervene as an individual, not backed by, nor representing any organization.

Several advocacy organizations are also seeking intervenor status. None of these organizations have members with autism. In fact some advocacy groups are intervening ON THE SIDE of the parents. Only this woman is both autistic herself and attempting to represent the perspective of an autistic person.

It seems that there has been a general acceptance, on the part of the lower courts and other advocates, of the description of the teenager as an out-of-control menace to family and society. Throughout the murder trial no one questioned the accuracy and validity of this evidence. My acquaintance is intent on having the court realize the presence and damaging inaccuracy of the stereotype that having autism makes a person a burden to family and society. She believes, (I hope correctly), that with an accurate perspective of the circumstances, abilities and contributions of people with autism the case will fall apart, and a new trial will be called for.

My discussions with the Montreal advocate went back and forth several times about whether I, or any other non-autistic person, could actually understand how a person with autism would be affected by this stereotype. We questioned whether someone who has not been subjected to behaviour change technology could understand the impact on an individual of being "educated" in this way.

I accept that the experience of being autistic must give a unique slant to these experiences - indeed to life itself. At the same time it is clear to me that most people labeled with disability, across all of our "diagnoses" are very familiar with stereotyping, physical and emotional abuse, and being falsely represented by others who claim to be acting in our interests.

As people struggle out of deep oppression they tend to choose to stay with "their own kind" - others who carry the same labels and have shared similar experiences. Thus, in the late 60s through recent times many Independent Living groups excluded those with emotional or cognitive differences, and many People First groups were not open to those with purely physical challenges. This search for mutually safe and empowering relationship and learning makes sense to people who are trying to find a strong identity and build a strategy for change.

The inevitable consequence, however, is that people who are labeled disabled - and our friends, families, advocates and loved ones - are as likely to segregate ourselves as others are to exclude us. What we then miss is that the human journey of defining and solving our problems - democracy - is basically the same journey for everyone, especially for all who are being oppressed. We have much to give to and learn from every journey toward human dignity and empowerment. And, as the civil rights movement in the United States taught the world, separate is never equal.

Clearly self imposed isolation has its place - but how do we set the boundaries to self absorption and find the courage to reach outside of our limitations? How can we find ourselves AND be open to the whole society around us?

Segregation based on ability is perhaps the most damaging divide of all. This is simply because the whole concept of disability is an illusion. There is no "disability" - just very different abilities.

People who are labeled disabled quite naturally start out our lives among and relating to people whose abilities are typical or "normal". Separation is forced upon us. It is not founded in different languages or cultures. On the contrary, diverse ability belongs to every sort of human community. Therefore our segregation - maintained by others, or self perpetuated - inevitably separates us from the very foundations of human strength. We are cut away from diverse relationship, wide sharing of talents, opportunities and resources, and broad ranging dialogue and communication.

People with autism grow and learn when they get the opportunity to be with and work with other people with autism. The same is true for people with any other circumstance that has been labeled as "not ability" or "disability". At the same time we need more to be fully empowered.

We need to discover that our journey is not so unique. We have much to learn from - and perhaps even more to contribute to - the human journey toward freedom everywhere.

The questions are: How can we have both - Identity and Inclusion? What does it take for us to cast aside the illusion of disability? How does a person discover that - in spite of many differences - each of us is simply human?

E-Mail: judiths@ica.net

Janice & John Fitzgerald - taking a break

Caregivers Do Not Have Special Gifts and Talents

Janice Fitzgerald, Parent to Parent of NYS

To all parents who are caregivers, we commend your dedication and hard work.

Parents, spouses and other caregivers of individuals with illnesses and disabilities do not have special gifts. We are very average people who tap into our superhuman strengths that everyone has, but don't always need to draw on.

18 years ago this fall my life changed forever. My son, John, who was six-months old at the time, became very ill. He was admitted to the medical center in Burlington, VT and diagnosed with Infantile Spasms, a rare and violent seizure disorder. We left Burlington on Christmas Eve in 1985 not knowing if he would survive, and if he did live through this period, there was no prognosis of what his future would hold. He did survive, the seizures did stop, but his mental development was delayed.

When John was a youngster, his assaultive behaviors were a challenge to be around. Regularly, his outbursts sent me, my husband and our other two sons running for cover. Between 1 and 5, he had an attention span of less than 10 seconds; he required constant and intensive monitoring. We live in a rural wooded area and John would wander off into the woods with no concept of danger. He would wake up during the night, climb out of his crib and wander in our house. He would climb to the top of a playground slide, out of my quick reach and grab a handful of hair from another child's head. It was impossible to leave him unsupervised for a second.

Through all of this, we were also trying to be good parents to our other two sons. For several years we were a house divided – one parent staying home with John, and one parent going to school functions, scouts, parties or picnics.

We never gave up and John did progress. He started to talk when he was 5 and eventually he learned that there were consequences to his behavior and there were privileges to be earned when that behavior was kept in line. He learned to ride a bike and to downhill ski at 8.

Today, John is a responsible 18 year old citizen who works hard and continues to learn and mature. He is an Eagle Boy Scout and had a part-time job this past summer.

Ten years ago, I would not have been able to write about all of this. My emotions were so jumbled and I was a bundle of nerves. It took a long time to come to grips with and accept that one of our children had special needs. There was bitterness and anger about missing many of the things my other children were a part of because I stayed home with John. There was the guilt of not being able to share an equal amount of time with my other boys. There was exhaustion, lots of exhaustion. There were times when we did not have childcare; the doors of day care providers' homes don't open so easily for children with special needs. When there was no childcare, I could not maintain a job, and therefore we went into debt.

We experienced long periods without a break in the care giving.

There were times that I wanted to give up and walk out of my house and never look back. I didn't walk out, I couldn't. When I think of those times now, I know they are the times that my inner strength had another growth spurt.

We had things to adjust to through the years. The acceptance of that first illness, and then the acceptance of the ongoing extra care that lasted beyond the terrible two's of a baby. Acceptance has come to us, but it took time and a lot of compromise and working together.

Caregiver burnout can happen at any age. It is often seen when a spouse becomes ill, when caring for an elderly spouse or parent, or, as in our case, when we faced exceptional parenting challenges of a young child.

Take a few seconds to think about what it would be like for you if suddenly you were so physically ill or injured that you could not take care of yourself. Think about the people you know. Who are your friends, your relatives, your spouse and your children? Think very seriously about who you would want to have taking care of you? Who is it that you would want to depend on? Think about the qualities of the person you would need to depend on.

Next, think about the possibility that the person caring for you has moved into your house with you. They've given up their job and their friends. They do this out of LOVE, *the ultimate love of another person.*

Now, let's say your illness or recovery time takes 10 times longer than anyone predicted. Or, you learn that you are never going to fully recover. All of the time the same kind, compassionate person has been your caregiver. Doing your laundry, helping you bathe, cooking your meals, and taking you to doctor appointments, helping you go to the bathroom.

Two years have passed and this wonderful person has not had a vacation. In fact, they haven't even been away from you for a day in two years. They have not met up with their own friends for even a few minutes because they worry that you will not be ok. They worry that no one else can understand what you need. This may sound wonderful to have someone so totally committed to you, but guess what? It can't go on forever. Burnout inevitably comes along. It will manifest itself as depression, constant fatigue, or a declining interest in pursuing any outside activities. It might be withdrawal from social contacts, or maybe an increase in the use of stimulants or alcohol. Those are some of the symptoms.

And along with those symptoms the quality of care will diminish. Impatience, anger and abuse can happen in extreme cases.

Caregivers won't see or admit these symptoms in themselves. If you are a caregiver, think long and hard about what other people are telling you. Think about the possibility of burnout. If enough people start saying the same thing to you, it's probably true. "Take a break, get out of the house…" Too difficult to do and admit that you do need a break and to reach out for the help.

For your own mental health, develop a network of friends and colleagues and attend a support group. I found it very difficult to reach out. I used to think it was a weakness to not be able to handle all that I was dealing with. A caregiver support group has benefits. Even a group that does not match the diagnosis or care you are giving will be helpful. Talking to other people who understand what you are experiencing can be a tremendous relief. They can also assist you in tapping into resources that you didn't know were around… a good doctor, a source of respite help.

Somehow, some way, get a break – respite is what we call it. Guilt free time out is essential. We do not have to be all things to all people. We may be essential and irreplaceable to the person we love and care for so dearly, but…. they will survive some time without our help. It is ok to let someone else give his or her best care so that we can take some time for ourselves.

We need time to regroup, to rest, to come back somewhat refreshed. We cannot continue with superhuman powers forever. It is important to understand that it is ok to take a break. It is necessary to get a break in order to keep yourself physically and emotionally healthy.

If we become sick or have a medical emergency, who will provide the care we've been giving? Who will take our place? Ask any caregiver who has been at it for any length of time and they will tell you that their own health has suffered when the focus was on another person and they neglected to take care of themselves.

Remember that guilt is a self-made emotion. We do it to ourselves. We internalize our actions and reactions. Guilt is wasted energy and it is energy that we desperately need to conserve.

It would be nice if there was some magical way to avoid illness, to avoid dementia, to avoid disabilities, but that's not going to happen, and denial isn't going to work for very long when faced with a challenging situation.

We will be changed forever and we will make an amazing difference in another person's life when we can draw on our inner strengths, and combine it with good care for ourselves and the person we love.

Remember: Parent to Parent staff are here to offer a listening ear and to help you find resources:

http://www.parenttoparentnys.org

Additional links:http://www.nfcacares.org/
http://www.aoa.gov/prof/aoaprog/caregiver/caregiver.asp
http://www.caregiving.org/
http://www.caregiver.com
http://www.cyfernet.org/hottopic/famcaregivers.html

Persevere

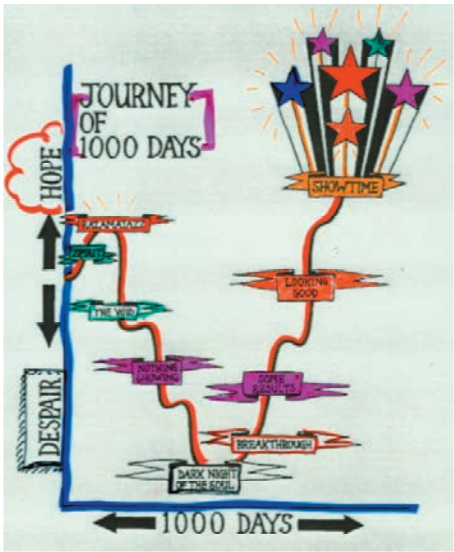
Julie Stansfield

To all partners in the deep dark nights of the soul! Perseverance is the key.

If there is one thing I have learned well in all my experiences of leadership and managing change is to persevere with vengeance!

I learned because I watched my brother be a recipient of services 14 years ago. My family including me gave up on services and persevered to find a better way. This is not how things should be! Services need to find a better way of supporting people. Not all families are as large as ours and some people need far more support than my brother, who manages quite well now - fairly independently.

Then when I was taking on the role of changing services, I learned very quickly you can't just ask for something and then give up when the first or second answer is no….you have to persevere and keep asking and asking and asking and asking, people after people after people…… someone will hear eventually.



On the Journey of 1000 Days of Change (Nick Marsh - All Star Company) taught to me by Marsha Forest) people leave courses/inspirational speeches/partners, etc and have fire in their belly and a spirit to move forward to change the world, then comes the reality when nothing shows from it, then despondency and then the DEEP DARK NIGHTS OF THE SOUL….it is only those that persevere throughout this most difficult stage that then hit the next stage of something showing, then a roll and then SHOWTIME!! But it is the knowing that you need to get through the dark days and persevere to get to your showtime.

It goes in steps:

- Spirit
- Razzmatazz
- Nothing showing
- Deep dark night of the soul
- Something shows
- A roll
- ShowTime!

The time when people always give up is the 3rd and 4th stage and that's one of the reasons why people don't stay active and one of the reasons why services do not change. You have to comfort yourself knowing this happens with every significant change and link with people who are positive not negative and cease the energy. Marsha told me a chant led by Harriet Tubman, a woman leader in the 'underground railroad' leading African Americans from slavery to freedom. It was a hard journey, really hard, carrying children, no food, desperately wanting to give up and die. But they chanted and chanted.

If you're tired, keep going
If you're scared, keep going
If you are hungry, keep going
If you want to taste freedom,
KEEP GOING

Families and individuals are now in a movement of escaping being dominated by services and having the freedom to self determine the support they want, and this is SO IMPORTANT - for my brother and friends, your family your children, for all children and children of the future! The movement has to continue, so if you are tired, keep going, hungry keep going, if you want to taste a better world you just have to keep going. Use the geese story you hear from Lynne at Partners: lay back, rest, let others lead and honk for you a while, but then get back in the middle of that formation and KEEP GOING!! We have to stick together and stay united. Together we are better! TOGETHER WE ARE BETTER!!

We need to be here for each other. And when a goose falls, we send someone down to pick them up, knowing they would do the same for us. We have to lean on each other in times of difficulty, but we cannot give up! This movement WILL happen, so BELIEVE it and contribute in whatever way you can: a little at times, a lot at times all in different ways and approaches. You are leaders of the future. See the journey you are taking. Be proud, and whether large or small, wide or narrow - KEEP GOING! You will get through the dark nights of the soul. Keep asking, keep asking and persevere.

Love Julie Stansfield
E-mail: <julie@hollycat.co>

> *"Inclusion is a battle cry, a parents cry, a child's cry to be welcomed, embraced, cherished, prised and loved as a gift, as a wonder as a treasure"*
> *Marsha Forest*

This is what we are about:

We plant seeds that one day will grow.
We water seed already planted,
Knowing that they hold future promise.

We lay foundations
That will need further Development.
We provide yeast
that produces effects beyond
our capabilities.

We cannot do everything
And there is a sense of liberation
in realizing that.

This enables us to do something
and to do it very well.
It may be incomplete,
but it is a beginning,
a step along the way.
An opportunity for God's grace

We may never see the end results,
But that is the difference Between
the master builder and the worker.
We are workers, not master builders,
Ministers, not messiahs.

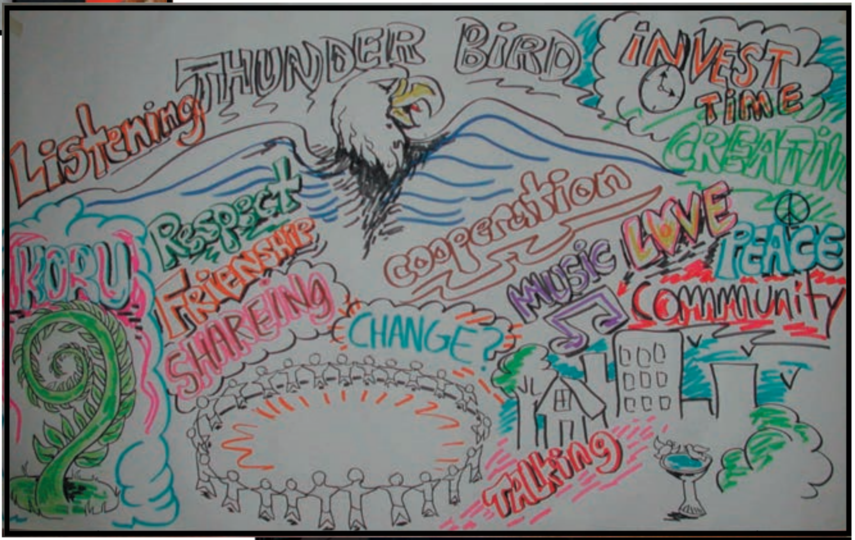
We are prophets of a future not our own.

Monsenor Oscar Romero

Winnipeg Winter Institute and the Festival du Voyageur.

Feb.17-21, 2003 - in Winnipeg
in Winter - and it was great.
Check our web site for tne next one...

The Learning Marketplace
John McKnight - glass half full?
Nerina & John Robson
Wayne Helgason - Thunderbird House
Linda Shaw from UK - staying warm
Nerina with Festival Hospitality
A Winnipeg Institute Graphic



THOUGHTS ON WILDNESS

or - Of Fish, Fowls, Felines & Orthopterans

Regina DeMarasse

Lying on my bed puffing, as is my wont to do, my hair spread wet and rippling in several directions around me like a mermaid's, I contemplate my Piscean nature. It is dreamy, sensitive, watery, compassionate. Is it wild?

"She's paralyzed; what trouble could she possibly get into?" shrug acquaintances of my mom, as well as the wives of my male friends.

"Jesus must so love you, he sent you his cross to bear," yawps the old woman meeting me for the first time, soon praising God for giving her the opportunity to be in the presence of "this suffering saint."

I like the subterfuge of the first notion - my safeness, my innocence, my purity. These limbs don't move anymore. They're bent, contracted, atrophied. Husbands wouldn't want anything less than a ten (they think); I can do things with other people's spouses that other dames would never get away with.

The second notion - my saintliness - makes me snarl...inwardly. I am too polite to dispute canonization, but my roommate, aides, my family, my friends would - the recipients of my thousand and one verbal bludgeons.

Nowadays, I'd rather meow. It is a great tension release. Try it, really, high in the head or from deep in the chest - a good yowl, and if you're truly bothered, extend it, starting a bit huskily and screeching upward. Like a cat in heat.

Meetings are the secular self-flagellation of our time, replacing the hair shirt. Have you ever sat on some hot shot committee to "rehabilitate the spirit of volunteerism," "improve relations between disparate factions," "revive neighborhood philanthropy," or have you ever participated in some icky bureaucracy's attempt to "invite public testimony," and wanted to scream, tear and claw? Try meowing.

The above arrangement of my soppy strands is as my aide left them after a shampoo. Puffing to write is what I do in Morse code on my computer. It responds to me in synthesized speech, as pressure in my cranium and spine also took my sight.

I contemplate my own wildness - how I wooed-wooed at the last Annual Congress for The Connecticut Union of Disability Action Groups. Two colleagues sang, "We've got ours, babe" to Sonny Bono's "I Got You Babe". The "ours" for which they sang was those policy makers with the lovely homes, cars and salaries who perpetuate themselves in lieu of us peons whose annual income tallies at one digit place less.

Anyway, it was very out of character for me to behave with such woosome abandon. I have a lot of muscle spasticity and am sometimes too tight to do more than a weak "yay" or bawdy "meow." My physical therapist, however, has made me a looser woman.

I'm ashamed to say there's not enough of wildness, or wilderness, in me. There are reportedly woods in back of my Connecticut suburb home, with deer, wild turkey and turtles (astounding to this girl from Queens), but other than the cricket laced quiet or the weird cackle I heard for the first time this spring, I hardly know it. Roots, grass and stones are not pleasurable to trod under wheel. Besides that, by the time I've figured out the necessities in life - the personal assistant hours to get about to grad school, medical and therapy appointments, work in activism (not to mention getting meals, baths and other aspects of personal care done) - my time and energy's shot. Then there's all the rest - tasks of daily living, computer work puffed with no small labor, telephone follow-ups on everything from the state agency paying my tuition on time to finding a health food store that accepts food stamps to getting the bank to recognize my rubber name stamp signature.

Oh, but when I think of those black smooth slick orthopteran bodies rubbing their lean little legs (or wings) together in a fury of fervent friction, my mind wanders...

In every living being, every human, I am convinced there is wildness. It seems our biological right, our genetic endowment. Still, I can't picture my neighbor across the way doing anything that wasn't boring. Her theme seems to be "It's a chore; it's a bore; it's so dull..." Everything. Then again, she is talking to me.

A number of years ago, I heard the pope wooing - not God, not even the Virgin Mary. It happened upon receiving a gift from a teenage girl. The young miss was representing "Youth" at Madison Square Garden and had handed His Holiness a tee shirt and blue jeans, "because we are individuals here in America," she said. (I never did figure that one out.) The newscaster said the pope's rather unexpected ululation was a Polish expression of appreciation.

My roommate suggests Martha, my neighbor, "might dance around naked at midnight, or even covered in whipped cream...or Cheese Wiz. You never know."

I, too, am a moondancer. Lui Collins, a New England singer/songwriter, has a song that celebrates those she knows who "set themselves free" by dancing (literally and figuratively) in moonlight "with no one to see."

"It is like a part of your lung is lassoed to this area," another of my holistic physical therapists says, working on a myofascia release in my head - a softening of tissue held taut. "Throughout the body, there are many membranes holding us together. What part of you lassos another?"

"The part of me that is 'good', and always knows the right thing to do, like my schoolwork as opposed to poetry writing, like sympathizing while my aides dump their every little problem and life story on me instead of me blasting Cajun music and hooting (or wooing) along. It nags at me when I want to have fun." It's the classic old battle between superego and id.

"Can you represent those two parts of you in animal form?"

A tiger comes to mind for the fun lover, and a blue-green-gray eleven inch parrot for the nagger.

"Ask the tiger if she has a message for you," my therapist urges.

"She gives me a roar," I reply. "Good naturedly." (Just a big meow, really.) She is laughing at me, I am certain, and the twinkle in her eye seems to say, 'Lighten up'."

I journey with Lucinda, the tiger, a while. Though I have never touched a tiger skin, dead or alive, in my fantasy I run my hands deep into plush golden fur, feeling its encompassing warmth between my spread fingers and savoring palms. It is as if, simultaneously, I can feel rolling palms at my shoulder blades and fingers drawn down my spine and looping out to my hips along my own back, a deeply scintillating massage. She closes her eyes in pleasure.

Then we're off - across the hot, breezy savannah, then into a tropical rain forest. To my further questions, she utters not a word, but brings me to the foot of a tree. She peers up into it. I follow suit.

There is the bird. He sits all alone, pecking at what? At air. He is frantic. He is furious. Lucinda simply continues her calm, languid stare.

The bird gazes down. He is held fast in time, knowing that if ever he had something to get excited about, now would be the opportunity. Lucinda, however, remains mild, fairly disinterested, then ambles off.

Completely dumbstruck, beak nearly on breast, the bird has a sad, sheepish cast to his eyes. All his pecking, for what? Things of the air - the element that represents intellect.

In ancient Egypt, cats were treated as goddesses. My Lucinda is, of a certainty, wise, dignified, omniscient...and sensuous.

My moon dancing comes as it will - in my imagination; in my fantastical politically incorrect nomenclatures of GA (Gimps Anonymous), Invalid Centered Therapy, crip self-actualization and primal spastic therapy; when I start singing and exaggerating my Brooklyn/Queens accent at a penthouse restaurant in a hotel in D.C.; in my impulsiveness when I sarcastically blurt out "Damn it, get those beds filled" at a meeting discussing financial losses to nursing homes if patients are discharged; in my insistence on cultivating long hair when it's so impractical with quadriplegia; in ways I'd rather not reveal here.

I believe we all need to moondance from time to time. It is a part of our biological and spiritual being - this wild, sensuous, sensitive, frolicsome nature. Denied a voice, it doubles in on itself, cramped and clawing at its own flesh. It bleeds internally or harbors disease and infection. We must give way to it, lest we cripple ourselves.

The Path of ME MUTU WAKA

In Wellington, the Quit Smoking campaign plans a get healthy campaign.

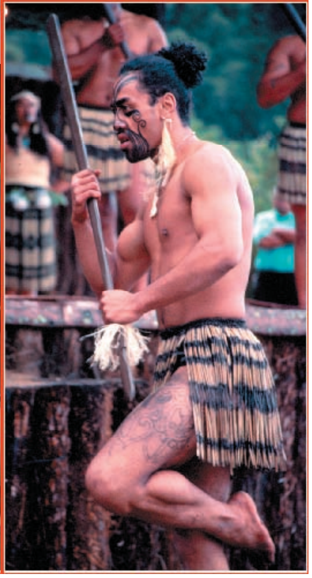
Ultra Modern Maori Exhibit in Te Papa Museum

Working to rebuild a culture.

In Aotearoa - New Zealand, Maori people have been working to renew their language and their culture for nearly three decades. Recently, Person Centered Planning tools like PATH have been added to the skill set for community and group planning. Lynda Kahn and Jack Pearpoint joined with Maori teams to assist and teach the tools.

The Tuhoe Festival - a competitive cultural gathering on maraes in the mountains celebrate tradition and work to build the future.

At the Tuhoe Festival, Lynda, Kura, and Noti make bread for masses of competition dancers who gathered on the Maraes on Tuhoe land in the mountains of Aotearoa for the Easter Festival.



Inclusive Business Options in Dundee, Scotland

Kyle Mitchell

Corine Mitchell has learned about advocacy and support because she had to - with Kyle. Now she supports other families to have full lives.

Kyle Mitchell has struggled, but now, as a buiness man with his grandfather, the future looks positive. In addition to working the skip, he practices camping for future trips while his Mum keeps a wary eye on future options.

"Injustice anywhere
is a threat to justice
everywhere."
Martin Luther King,
(1929-68)

Conversation, however, takes time. We need time to sit together, to listen, to worry and dream together. As this age of turmoil tears us apart, we need to reclaim time to be together. Otherwise, we cannot stop the fragmentation.

Meg Wheatley,
Turning to one another

ADVOCATES IN ACTION

Everyday People

We are Rhode Island's Statewide Self-Advocacy Organization

© 2003 Advocates in Action, RI. Deb Kney

Advocates in Action is directed by a board of 17 individuals who represent Self-Advocacy groups throughout Rhode Island. Each board member shares the experience and expertise of being an individual who has a developmental disability.

We also have five full and part-time staff members, and many dedicated volunteers, who work for our organization.

At Advocates in Action our team is a diverse mix of people. We come in all different shapes, colors, ages and sizes! We don't let any of our differences stop us, though. Instead, we appreciate the individual gifts that EVERYONE shares and we use them to work together to support Self-Advocacy.

http://www.aina-ri.org/aina.html

Mpambo - the Multiversity of Uganda

The 2004 Afrikan World
Encounter Conference on
Building NEW Futures
June 8 - 11, 2004
Jinja, Uganda - the source of the Nile.
We are ONE People: Multiple
Dreams for a Different World
Transforming Thought,
Learning and Action.

The International Conference on Multiple Dreams, Building New Futures, will be held at the Source of the Nile, on the shores of Lake Victoria (its Ugandan name is Nalubaale, meaning "Lake of the Goddesses"), in the city of Jinja, Uganda, East Afrika, June 8 -11, 2004. The Conference is convened by Mpambo, The Afrikan Multiversity and co-sponsored by Transformative Learning/Ontario Institute for Studies in Education (OISE), University of Toronto; Inclusion Press International and the Marsha Forest Centre; the Human Rights and Peace Education Centre (HURIPEC), Makerere University; Busoga University; Afrika Study Centre; the Uganda Adult Education Network; PRIA (India), the support of Northern Illinois University; the Lindeman Centre and Heritage Trail Uganda.

At a time when the civilizations of the world are at crossroads, it is symbolic that the meeting will take place in the Afrikan Great Lakes Region, the Cradle of Humankind. What is more, it is at the Source of the Nile, Mother of the World's magnificent classical Egyptian (Kemetic) Civilization – where participants will ponder the possibilities for humanity to rise to higher heights.

This conference will provide a platform for innovative, new frontier thinkers and entrepreneurs, including, but not limited to, scholars, researchers, students, reformers, innovators, inventors and activists, in academe, civil society, the private and public sectors. It is a conference for men and women who dare to dream of a different world, and are fired enough to be doing something about it. They will come together to share their visions and on the basis of their work, to actualize their worlds. The conference will be a cross-cultural, cross-paradigm, inter-continental, and inter-civilizational platform for dialogue and solidarity. Presenters will define their worlds: past, present and future.

Contributions are invited in diverse formats, from a wide range of visions, practice and perspectives.

For more information:
mpambo@yahoo.com.
fax (256) 41 – 348468; or mail to
Multiple Dreams for a Different World,
c/o Mpambo, The Afrikan Multiversity,
P.O. Box 7314
Kampala, Uganda
www.inclusion.com/N-Mpambo.1

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24 Thome Crescent.
Toronto, ON. M6H 2S5
Tel: 416-658-5363 Fax 416-658-5067
E-mail: inclusionpress@inclusion.com
WEB: http://www.inclusion.com
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UK Distribution:
Kevin Reeves
Inclusion Distribution
29 Heron Drive, Poynton, STOCKPORT,
ENGLAND SK12 1QR
Tel/Fax: 01625-269243
E-mail: kreeves@inclusiononline.co.uk
http:// www.inclusiononline.co.uk

Australia Distribution:
Ally Inclusion - Alana Baker
P.O. Box 651
Samford 4520 QLD. Australia
07-3289-5737
alana_baker24@yahoo.com.au

Inclusion work in Maine

We had two statewide conferences in Maine to discuss Community Inclusion for adults with disabilities. We had national speakers as keynotes, and we highlighted local people who are doing good work in this area. Still people kept asking, what is inclusion and how do I make it happen?

Behavioral and Developmental Services (BDS) supports over 2000 adults with developmental disabilities within Maine. We knew people were asking to be supported to be part of their communities. We also knew that outcomes were showing that people felt lonely and wanted more friends in their lives. We wanted to ask other allies to come together and talk, listen and plan how they could enlist more community members to link people to communities.

In June 2003 Jack Pearpoint and John O'Brien were our guides for three days about strengthening our alliances in Communities in Maine. Lisa Sturtevant, BDS and Mary Kelley, Muskie School Center for Learning compiled a list of interested community people across the state to join in a three day discussion of "Action for Inclusion: Enlivening Maine's Communities". Participants included consumers and parents, a minister, a school guidance counselor, a professor along with regional BDS staff.

The intense and exciting retreat was the beginning of the start of a project to spend a year strengthening communities by sharing stories and asking allies to assist us in this work. By the end of the three days, groups had devised action plans, which included their ideas on how they could affect their communities' capacities to be more inclusive. Plans included working with the high school civil rights teams, the Maine Council of Churches, the Maine Associations of Socially Concerned Businesses and many others. Also, some teams will also be utilizing asset based community mapping with local agencies to begin looking into local communities for opportunities. All the teams have begun by identifying who else is an ally within their local community and how can people with disabilities in that area participate in the strengthening of their own community.

All the teams that were formed over the three days were given a toolkit of resources. The "Tools for Change" CD-ROMs, numerous books and videos were purchased and are now available in different geographic areas of the state to support this work. Use of the exercise Inclusion/Exclusion was helpful with a group of teenagers thinking about civil rights and disability rights. It is hoped that the seven teams that formed will begin reaching out to communities to begin some of the groundwork on gathering allies and sharing the stories of inclusion.

Mary and Lisa are following along with the teams' work to see how things are going and help people stay connected to the work. We are interested in feedback and can be reached at Lisa.D.Sturtevant@maine.gov or Mary.Kelley@maine.gov

Community: Lost & Found

Art Lockhart & Mike Clarke

coming soon from Inclusion Press

Community Lost & Found is a 'conversation between two dreamers.

Art and Mike are both teachers - both committed to social justice, both have spent long years creatiing programs to create opportunities for those who have been excluded. Mike has worked the streets: street kids are his passion. Art knows violence and exclusion. Jointly they created the 'Gatehouse' - a safe haven for victims of sexual abuse. Mike is an Anglican priest and ex-cop; Art a Community College professor, a Buddhist, and a dreamer. Both are organizers.

This collaboration tells some of their stories - in ways that will instruct many of us to be better at achieving our dreams.

The cover painting deserves equal time. Artist Randy Charbeneau spent many years doing hard time, and now uses his very powerful artistic and healing talents to support people who need a second chance - or maybe even a first one. If you are interested in building stronger communities, you will love this book.

Art Lockhart <alockhart@sympatico.ca>,
Michael Clarke <mike.clarke@utoronto.ca>
Randy Charboneau
<megwun24@hotmail.com>

A Life Saved By Circles Of Support OR Pigs Don't Know Pigs Stink

Emma Sullivan

In the early 1990's I had the opportunity to attend my first Creative Facilitation course with Jack and Marsha. I didn't know them – had never heard of them prior to a month or so before the training. A co-worker of mine came into my office with a flyer saying that I just had to go with her to this training being held somewhere in Connecticut. Having never been to Connecticut and being willing to do just about anything once, I said sure… why not. I had absolutely no idea what was in store for me.

Picture it if you will. There I was, the good little social worker. I had managed to figure out that there was something wrong with social work. Not to offend any of you reading who wear the social work badge with pride – but I had found that doing it by the book didn't lead to people being very social; to society being better; to communities (or the people in them) working together or to unity or peace or growth or positive social change or any of the other 50 things that I thought it would lead to. In fact, doing social work the way I had been taught only led to paper work, deadlines, fitting people into their straight jacket labels and convincing them that they should be grateful for the space society had allowed them to occupy and teaching them to obey the rules. What I didn't realize was that, as I was pretending to throw lifelines to those in need, I was the one about to go under for the last time.

My eyes were opened when, as a part of the training, we were introduced to a little activity called Circles of Support. Dutifully I followed the instructions – I drew the circles on my piece of paper. In my mind I was wondering when we were going to get to the real stuff, the hard hitting training that I could really use. When were we going to be done with all this cute stuff? Sitting there, smug in my social work degree, in Connecticut, I listened to the instructions and I drew my circles. I sat in silence and began to think about my inner circle. I listened as Jack explained how and why his computer and Father Pat was in his inner circle. We were told to put down the people or things that were in our inner circle and I did. I had my children and one friend. So there I sat with three little marks on my inner circle. But that was o.k. I told myself because I was strong and I was a survivor and I was very capable. We moved on to the second circle – I had two marks on that one. Then on to the third circle – the one for participation. Well, I thought, I'll make up for it here – only to realize that I was involved in several things for my children and nothing for myself. Then came the circle of exchange. It seemed so very odd to me that there were so many people involved in my life because they were paid to do so. Then I looked at the whole thing and I saw it. I was about to self-destruct. I was one crisis away from loosing everything, including my life.

Six years prior to me sitting in that room staring at circles on paper, I had been diagnosed with a terminal illness and had not told anyone. Two years prior my husband had died. One year prior, I had adopted a child who came to me with labels. I had unwittingly yet successfully built a wall and a moat around myself. So much so that, sitting in that room, I finally felt and saw how alone I really was. I kept everyone at arms length and shared only my strength. I showed no vulnerability. I didn't allow anyone else to be strong for me or to give to me or to nourish me. There I was, a stinky pig. I had been smelling something all of my adult life. It just didn't smell right. Sometimes it smelled really bad. Sometimes I would run fast and far to get away, only to have it catch up and overtake me again. This time, I had caught a plane, flown from Indianapolis to Connecticut and come to a training, only to have that smell fill the room. All that way to realize that the smell, the stink in my life, was me. I sat there, listening to Marsha as she held up a set of circles that looked cold and barren – just like mine. She asked the group what we thought kindergartners and high school students said they would do if their life looked like mine. I heard her say, almost as if a whisper in my ear, that they said they would kill themselves. I then realized that I had whispered the same response.

While I was supposed to be teaching or helping others in crises learn coping skills and get their lives back on track, there I was, dying a little bit each day. I was supposed to be a social worker, but I wasn't very social and my life wasn't working. That day, I knew that my life stank. I say that Circles of Support saved my life because doing that little fluff exercise showed me what I would not have seen in any other way. I saw a life/a family on the brink of destruction. And it was mine. I made a vow that day to reach out to people, to be vulnerable with people, to let people into my life – into my heart and to share my life – not just live it.

Since then I have had a few crises as well as many opportunities to learn and grow. There have been disappointments and times when I have been afraid or unsure of which way to go. But through all of it, my circles of support have grown; my relationships have been deeper and more meaningful. My children and I have been supported by and have provided support to real friends. I have let my pleasure and my disappointment, my strength and my weaknesses, my joy and my sorrow all have their time in the sun.

Whatever you do, don't underestimate the power of the tools that we use and don't forget to use them on yourself. Don't ever get so caught up in how much you know and how much you help others to forget that you too are a part of the quilt that we are weaving. If you haven't done your own circles in a while, I encourage you to take out a piece of paper right now. Honestly evaluate yourself. How are you doing?

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