

In the Stream

Summer 2008

Lives Lived: Remembering “Bobby” Sarlina

By Tracy Odell

Bobby passed away quietly, and unexpectedly, in her own home on Saturday July 12, 2008 at 56 years of age.

Bobby went to work as usual on Friday, but the next Saturday, she woke with a headache and called her attendant to get her up earlier and give her a couple of aspirin. A short time later, Bobby died of heart failure. As endings go, and apart from it being too soon, it was how Bobby might have preferred it.

She did pretty well for someone who wasn't supposed to live past the age of 12, according to the medical profession. Bobby lived with a form of muscular dystrophy all her life, and although her physical strength was compromised, Bobby never did. She had full use of her voice, her mind, her thumb and other body functions – and she used everything she had to its fullest potential.

Bobby grew up in a children's institution, maintaining very strong ties with her Mom the whole time she was there. This was rather unusual for that place, in that time. As a young adult, the institution had nothing to recommend for services for adults, other than nursing homes for elderly persons. Bobby was forced to leave when she became of age, and with nowhere acceptable to go, she lived with her Mom for a while. It was no surprise to either of them when their relationship rapidly became strained to the breaking point. After all, Bobby, like any young adult, wanted to focus on her social life and plan for post-secondary education and a career. Her Mom, already working, had limited time and energy to meet Bobby's needs.

Eventually, Bobby accepted an opportunity to move into a living arrangement with two other women with disabilities. This was a pilot program – the first to provide attendant services to adults with disabilities in the community. Its goal was to demonstrate a successful and cost-effective alternative to placement in a nursing home. One of the things that made it cost-effective was that no service was offered between midnight and 6 am. When Bobby moved in, she quickly got that changed. She was attending night school at York University's Atkinson College, and did not get back home until 11 pm. She had to eat, look after her own needs and then go to bed. Because of Bobby, we finally got the night service that so many of us needed, and Bobby and her Mom were able to repair their relationship and grow close once again.

Bobby did not have an easy road. Many times all that stood in the way of her goals was a person who disagreed with or disapproved of Bobby's desires, despite the fact that Bobby was a competent adult who knew her own mind. Bobby often was forced to fight for every service she required – and she fought hard. For example, Bobby wanted to go to university and applied for support from Vocational Rehabilitation – a now defunct government department that used to pay the cost of schooling and related supports. “Voc Rehab” rejected her, on the grounds that Bobby would not live long enough to make their investment worthwhile and/or that she would find the curriculum too challenging. Bobby persuaded the Ontario March of Dimes to fund her first year, thereby proving that she could do it and shaming Voc Rehab into reversing their decision. She graduated and sought work with the City of Toronto as a social worker, where she interviewed, assessed and supported social assistance recipients. The City was very proud of its ability to successfully accommodate Bobby, who had a full-time attendant at work to be her scribe and provide physical assistance, as well as voice-activated software. Bobby ensured her supports enabled her to do the job she was hired to do, and she did it for almost 20 years. Bobby was a quiet, yet powerful example of using whatever you've got.

Those who knew Bobby know that she didn't take any crap from anyone, which earned her a few enemies in her day, but also many close friends. When Bobby accepted you as her friend, as she accepted me, Robin, Angela, Katie and many others, you were her friend for life.

Many of my recent memories of Bobby involve our long rides on Wheel-Trans from Scarborough to work downtown. We would chat, join forces on issues, or just joke around. One time I told her she was like a pit bull when she dug in about an issue, and she laughed at that image. She agreed it was true. In the summer, she'd get on board wearing sunglasses that gave her an uncanny resemblance to Roy Orbison. And when drivers asked her about her nickname of “Bobby” (she was Helen Sarlina on their run sheets), she never contradicted me when I claimed it was a street name, or that she was in the witness protection program. Bobby liked having a reputation as a tough woman you didn't want to mess with.

Bobby was one of the earliest registrants for Wheel-Trans. When services did not go smoothly, or if drivers were uncooperative or rude, she did not hesitate to complain. I have no doubt that numerous service improvements and protocols were put in place to address her concerns. Once again, these improvements would benefit others.

On the attendant front, things were not easy there, either. Bobby found herself frequently pitted against able-bodied managers who disagreed that Bobby had the right to live her own lifestyle, have a personal life, and do things her own way. Over time, Bobby developed less and less tolerance for people who got in the way of her desire to lead a normal life. Her successive battles helped pave the

way for many others to live with a partner, marry and have children while living in a supportive housing setting.

Bobby was involved with the Attendant Care Action Coalition, as it was developing proposals for what was later to become known as “Direct Funding”. Ironically, the number of hours of service she would require were to exceed the parameters of the program, and she remained where she was, fighting continually for service and acceptance. Over 900 people in Ontario now have autonomy and control through the Direct Funding program. About three weeks before she died, Bobby was at my place preparing another application to press for the extended hours of service she needed to help her now aging mother – services that were not being granted by her current attendant service provider. She remained very protective toward her Mom throughout her life, and was fighting for the right to be the kind of daughter she wanted to be – nurturing and caring.

In Bobby’s own way, she believed in helping people when she could. I, for one, will always be grateful to her for connecting me to Aldebrain when it was getting ready to open an accessible apartment building, making sure each floor had two accessible apartments that were two- or three-bedroom sizes. At a time when it was assumed that people with disabilities, if they lived out of an institution, would live alone all their lives and have no need for anything more than a small one-bedroom apartment, this connection was a life-line. Our growing family had already burst out of a one-bedroom, then a two bedroom, and then, out of the blue I bumped in to Bobby at the “Ex”, and she told me of a perfect setting: an accessible three-bedroom apartment with attendant services, all planned and managed by like-minded people with disabilities.

Bobby was a member of Aldebrain’s inaugural board, and eased my family’s way like no one else could have at the time. Bobby moved into Aldebrain herself once it was up and running, and the attendant services she needed were in place. She commented many times that it was a vast improvement over her former arrangement.

In the last few years, Bobby was hospitalized on two occasions. She hated hospitals and especially their staff’s paternal attitude that they know best what needs to be done. Bobby never forgot their dire and entirely erroneous prediction that she would die before she was 12, and so took little heed of medical advice. Bobby knew her body, her priorities and her values and preferred to be empowered to make the decision she felt best for her. After her last hospital stay, Bobby contacted the Toronto Star’s Helen Henderson to do an expose on a disastrous episode where staff refused to feed her orally in accordance with her wishes. The doctor had warned her, “You could die next time you try to swallow,” to which she replied, “So could you, every time you cross the street.”

Bobby died at home, with an attendant nearby, and with a few advocacy irons in the fire. She did not aspirate, as predicted, but instead died of heart failure – proving the medical establishment wrong one last time. Bobby would not have wanted to endure a long illness or hospitalization again, so in that sense, the way her life ended might have satisfied her. Nevertheless, I'm saddened that so many people in her life made these fights necessary. How much easier her life could have been if a few key people had just listened to her and respected her from the beginning.

To my knowledge, Bobby was never thanked or publicly acknowledged for all of the good things she did for the rest of us. Bobby deserves to be recognized for the role that she played in improving services – transportation, employment, attendant services, housing, and medical awareness of disability – without compromise.

Thank you, Bobby, for your legacy. You have inspired many others to fight for their right to live the life they choose, just like you did. I will not be the only one to miss you.

Notes: Tracy Odell knew Bobby for 42 years. They met at Bloorview and frequently shared Wheel-Trans rides and attendant service providers over the years.

Theresa Cornell MacNeil set up a site on www.facebook.com;

“In Loving Memory of Helen “Bobby” Sarlina.

NOTICE FROM MINISTRY OF HEALTH AND LONG TERM CARE

DIABETES STRATEGY

Today, about 900,000 Ontarians live with diabetes (8.8 per cent of the province's population) and this number is expected to grow to 1.2 million by 2010. Diabetes and its complications, including heart disease, stroke, kidney disease and blindness cost the health-care system over \$5 billion annually.

Ontario is launching a new \$741 million diabetes strategy that aims to prevent, manage and treat diabetes care across the province. This strategy builds on internationally accepted best practices and the recommendations of the Diabetes Management Expert Panel. This panel was established by the Ministry of Health and Long-Term Care in 2006 to provide advice on improving diabetes care in Ontario.

Increasing Access to Team-Based Care:

Two hundred and ninety million dollars is being invested in expanding current programs, aligning care and funding new programs. Ontario is increasing access

to team-based care closer to home by mapping the prevalence of diabetes across the province and the location of current diabetes programs in order to align services and address service gaps. Depending on patients' needs, the health care team could include a family physician, registered nurse, registered dietician and/or an endocrinologist.

Diabetes Prevention:

The diabetes strategy will invest \$6 million in prevention programs, including education campaigns to raise awareness of risk factors that contribute to the onset of type '2' diabetes, such as physical inactivity, poor nutrition and obesity. The campaigns will focus on high-risk populations, including Aboriginals, Hispanics, South Asians, Asians, African-Canadians, lower income families and people aged 50 and older.

Diabetes Registry:

A \$150 million investment over the next four years, in a diabetes registry, is set to begin in Spring 2009. All Ontarians living with diabetes will be entered into an electronic registry that will provide people with diabetes instant access to electronic information and educational tools to help them manage their care. Physicians will be able to use the registry to check patient records, access diagnostic information and send patient alerts. The registry will result in faster diagnoses, treatment and improved management for Ontarians living with diabetes. The diabetes registry is the first step in Ontario's e-Health Strategy that will provide all Ontarians with an electronic health record by 2015.

Insulin Pump Therapy:

In December 2006, the Ontario government began a program that provides funding for insulin pump therapy to children and youth aged 18 and under who met the clinical criteria. Funding was then extended for those patients in the program turning 19 (while the Insulin Pump and Supplies for Adults Expert Panel, chaired by Dr. Bruce Perkins, assessed the clinical needs of adults with type 1 diabetes) for insulin pump therapy. As of September 2008, this \$62 million investment will allow funding for insulin pumps and supplies to be extended to all adults with type 1 diabetes who meet the clinical criteria for funding under the Assistive Devices Program. Today, about 1700 children and youth benefit from the Ministry-funded insulin pump therapy, and in September 2008, over 1300 adults will receive funded insulin pumps every year.

Approximately 30 per cent of patients living with type '2' diabetes rely on insulin. In the next 18-24 months, the Insulin Pump and Supplies for Adults Expert Panel will review medical literature and consider expanding the pump program to adults living with type '2' adult diabetes.

CHRONIC KIDNEY DISEASE SERVICES

Kidney disease is one of the complications of diabetes that affects roughly 40 per cent of Ontarians living with diabetes. Diabetes is the most common risk factor associated with kidney disease. As a result, Ontario will also be investing \$220 million to expand its Chronic Kidney Disease (CKD) Program. This will improve access to all the services available under the CKD program which strive to identify kidney disease as early as possible; prevent/delay kidney function deterioration as long as possible and manage end-stage kidney disease through renal replacement treatments. This will include increasing dialysis service capacity at CKD regional centres, dialysis satellites, long-term care homes and independent health facilities. Ontario will also work to increase the availability of home renal replacement therapies (hemodialysis and peritoneal dialysis), both which can be done day or nighttime, so that patients who currently rely on dialysis treatment in hospitals and other health care facilities can experience less interruption in their daily lifestyle and receive treatment in the comfort of their own home.

Bariatric Centres of Excellence:

Obesity is one of the main risk factors associated with diabetes. More than 50 per cent of type 2 diabetes cases in Ontario are associated with obesity. The government is improving access to bariatric surgery – a procedure that modifies the gastrointestinal tract to reduce food intake. This \$75 million initiative will increase Ontario's capacity for bariatric surgery several-fold within two years and it will continue to increase thereafter. In 2006/07, 169 procedures were performed in Ontario and 485 patients were funded for surgery out of country. Ontario will enhance capacity for bariatric surgery in the province by:

- Providing bariatric education and training to health care providers,
- Expanding bariatric surgical capacity, and
- Establishing pre and post bariatric surgery programs that will be linked to surgical programs.

For more information, contact:

Alan Findlay, Minister's Office, 416-327-4320
Mark Nesbitt, Ministry of Health and Long-Term Care, 416-314-6197
Andrew Campbell, Minister's Office, 416-326-8500
Gary Wheeler, Ministry of Health Promotion, 416-326-4806
ontario.ca/health-news
ontario.ca/health-promotion-news

First Community Joint Annual Bar B Que

By Sandra Carpenter

On Saturday August 9th, CILT joined forces with the Ethno-Racial Coalition for People with Disabilities in Ontario (ERDCO), Canadian South Asians Supporting Independent Living (CSASIL), and Wholenet Technologies for our first ever joint Bar B Que in High Park, Toronto. Because we have so many members in common, we thought we'd give it a try.

But things did not go as planned. The reason? Rain! Well, that is an understatement. At one point we had a major thunderstorm. We kept waiting for the rain to die down enough for us to go to the assigned picnic area, but it did not. Instead we huddled around the concession stand, which was the only shelter in the vicinity.

First of all, the turnout was great in spite of the weather. There were at least 80 people there.

Eventually, a curious thing began to happen. People were actually enjoying themselves. Maybe some pioneer spirit kicked in. Us against the elements or something like that. Jokes were flying around and there was lots of chatter and laughter. Some of it the way you laugh when you hit your elbow, but it was laughter!

People were fed sort of in reverse. Someone showed up with a contribution to the Bar B Que of Danishes, which were passed around to tide people over until we figured out what to do. It seemed like everyone who wanted one, got one! Then later, samosas arrived. Finally the Bar B Que was ready, but only after we moved the Bar B Que closer to us, and we successfully negotiated with the man who ran the concession stand to let us stay put for the duration.

I'd like to thank all the staff, volunteers, members and board members who showed up. I'd also like to express appreciation to the attendants who worked in spite of very adverse circumstances – Tammy, JR, Chris and Rovelene. I would also like to thank the mystery couple who showed up with the Danishes so we could feed people and stop them from getting too grumpy! Thank you to the man who ran the concession stand for allowing us all to stay put, but whose name I did not get. Thank you also to the Bar B Que guys who were responsible for preparing great food. I'd also like to extend a special thank you to Robin Simmons who agreed, on very short notice, to provide child care at the event and a very special thank-you to Rabia Kedhr whose idea the Bar B Que was in the first place.

Hopefully we'll do it again next year, it won't rain, and in general, we'll be a lot more organized!

Pedestrian Safety Tips for the Sighted: A Side Note

By Sandra Carpenter

When you walk or roll, always face the traffic if you can, even when on the sidewalk. That way you can see cars making right hand turns; a top pedestrian hazard. Avoid one way streets when possible and try to make eye contact with the driver. If you don't make eye contact, don't assume they can see you.

"Insights" Fall Film Forums

Three evenings of award-winning films celebrating
disability and diversity

FILM FORUM 1: September 20, 2008 - Al Green Theatre - 6:00 to 10:00pm

"TABOOS, DANCE AND BODY DIVERSITY": an evening of captivating films each telling a unique story while challenging traditional notions of dance, the concepts of beauty, movement, body image and one's place in society.

PHOENIX DANCE (OC)

Directed By: Karina Epperlein

22 minutes, 2006, USA

Oscar-nominated Phoenix Dance is a tribute to renowned American dancer Homer Avila. It celebrates his sublime talent and resilience while transcending formula films about transformation. After losing a leg and half of his hip to cancer, Avila relearned all his best moves and returns to the stage with Andrea Flores, to perform a duet choreographed by Alonzo King. We witness determination, skill and courage as Homer collaborates in his now "imperfect" body, and his "one-leggedness" turns into magnificent beauty. Phoenix Dance focuses on dance, movement, grace, the perfectly imperfect magnificent form. It shows a unique vision of seven powerful limbs – four of a woman and three of a man – all moving towards an artistic and powerful conclusion.

COST OF LIVING (OC)

Directed By: Lloyd Newson

35 minutes, 2004, UK

Cost of Living is Lloyd Newson's film adaptation of the dazzling and rave reviewed show by DV8 Physical Theatre Company. It is about perfection, pretence and how society measures individuals and how we in turn value ourselves. Set in a faded seaside town, street performers David and Eddie

struggle to find work and romance. Eddie is tough, confrontational and not afraid to defend his belief in justice, respect and honesty. David is a dancer who has no legs. Watching him makes you reconsider accepted notions of grace and perfection. He is quietly determined not to let his disabilities or society's prejudices get in his way. Inter-linked scenes show Eddie and David's encounters with others: some incredibly hard-hitting - others exhilarating because of their sheer physicality. The Cost of Living hurls provocations and scalding humor at notions of how the fit and unfit are supposed to act.

INVITATION TO THE DANCE (English Sub-Titles)

Directed By: Gerhard Schick

89 minutes, 2006, Germany

Award-winning, "Invitation to the Dance" exemplifies how art can create bridges between people with and without disabilities; between continents, races and cultures. It shows the artistic genesis of the dance piece "Counter circles". German dancer and choreographer Gerda Koenig, travels to Nairobi in order to collaborate on a performance with residents living with post-polio. In the process of creating the stage production, unusual insights into eastern African culture and ways of living are exposed. Ultimately creativity and the ways that five people with disabilities experience their lives on the impoverished outskirts of a bustling international metropolis are revealed. This documentary is a moving example of how dance can heal and how dancers can contribute to social change.

Oscar-nominated filmmaker Karina Epperlein, director of "Phoenix Dance", and award-winning Gerhard Schick, director of "Invitation to the Dance" will be in attendance for the post screening Question and Answer session and post screening reception where all can meet, mingle and chat.

FILM FORUM 2: September 27, 2008 - Al Green Theatre - 6:00 to 10:00pm

"JOURNEY'S TO SELF DEFINITION": an evening of entertaining and thought-provoking film and discussion that focuses on individual journeys and the forces of change that affect self-identity and society's views of who we are and where we fit.

HEAR AND NOW (OC)

Directed By: Irene Taylor Brodsky

86 minutes, 2006, USA

Hear and Now, a multi award-winning film by Irene Taylor Brodsky is a deeply personal memoir about her deaf parents' complex decision to undergo cochlear implant surgery, a risky and controversial procedure —one that can actually

restore a sense. After 65 years of silence, Paul and Sally Taylor decide to explore a totally unfamiliar world – the realm of sound. Paul and Sally met as children, fell in love, married, and raised a family. They shared a rich life together and have been active and accomplished members of the deaf community. Yet, they decided they wanted to hear their first symphonies, to hear their children's voices; they wanted simply--to hear. This is a magical and deeply moving love story of two people who embark on an extraordinary journey from silence to sound. The question is, what will they make of it? And what might they gain, or lose, forever?

AS SLOW AS POSSIBLE

Directed By: Scott Smith
60 minutes, 2008, Canada

As Slow as Possible, which premiered at Hot Docs 2008 is about a journey, the complexities that shape self-identity and the inevitability of transformation. On his 18th birthday, Ryan Knighton was told he would slowly go blind. It's taken fifteen years, and as Ryan prepares to let go of his last sliver of sight, he sets out to Germany to hear one note give way to another in the notorious 639 year long organ performance of the John Cage composition, 'As Slow as Possible'. Caning his way through the uncertainty of a road trip, Ryan navigates a series of 'note changes' in the form of airports, the unfamiliar hubbub of foreign cities, and people - some of whom don't believe he's blind at all, and one who offers him something profound. The experience unfolds like a Cage piece itself – a series of chance encounters through a labyrinth of questions, as Ryan contemplates letting go of his old identity, and waits for the new one to emerge.

Emmy award-winning filmmaker Irene Taylor Brodsky, and Paul and Sally Taylor the subjects of the film "Hear and Now", plus Robin Cass, Producer and well-known Canadian writer "Ryan Knighton" from "As Slow As Possible" will be in attendance for the post screening Question and Answer session and post screening reception where all can meet, mingle and chat with our outstanding guests.

FILM FORUM 3: October 4, 2008 - Al Green Theatre - 6:00 to 10:00pm

"THE RIGHT TO CHOOSE YOUR OWN PATH": an outstanding and thought-provoking evening of film that focuses on distinctive and compelling stories about life choices and broad-based human rights issues.

LIVING RIGHTS YOSHI

(English Sub titles)

Directed By: Duco Tellegen

28 minutes, 2004, Netherlands

Living Rights: Yoshi tells the story of a sixteen-year-old who has Asperger's Syndrome - a form of autism. In the process, award-winning filmmaker Duco Tellegen examines the contemporary relevance and divergence between the 1989 UN Convention on the Rights of the Child, and the reality of the lives of the children the charter seeks to protect.

Yoshi has been placed in a school for children with special needs and learning disabilities, but dreams of attending a regular Japanese high school. With humour, wit, and creativity Yoshi makes a strong case for all of us to believe he should. Yoshi's candid and direct address to the camera combined with every day episodes culled from his personal life makes an insightful and poignant story, as well as a compelling argument on inclusion and otherness, and in the process, challenges society's own preconceived ideas of what it truly means to be "normal".

BODY AND SOUL: DIANA & KATHY (OC)

Directed By: Alice Elliott

40 minutes, 2007, USA

Body & Soul: Diana & Kathy by Academy Award nominee Alice Elliott, is a rare look at a crisis in an unusual relationship between two people with disabilities. Diana, who has Down Syndrome, and Kathy, who has Cerebral Palsy, met at a sheltered workshop in Illinois three decades ago and vowed to fight to live independent lives. Fearful of being shut away in a nursing home or forced into a state run institution, they broke the rules and escaped the system. Body & Soul chronicles their ongoing struggle to live independently outside of institutions, Diana's desperate search to reconnect with her abusive mother, and the lawbreaking journey they take to Washington, D.C. to advocate for the rights of people with disabilities. When aging and medical crises threaten their freedom, they attempt to meet the challenge. This story moves beyond disability and activism to acceptance of a profound, symbiotic friendship.

HER NAME IS SABINE
(English Sub titles)
Directed By: Sandrine Bonnaire
85 minutes, 2007, France

Her Name is Sabine is a moving portrait of Sabine Bonnaire filmed by her sister, acclaimed French actress Sandrine Bonnaire. The film combines intimate home movies of Sabine as a vivacious, young woman taken by the actress over 25 years, with recent footage. It powerfully shows the effects of a journey through a French psychiatric institution on Sabine's personality and lust for life. This very poignant film now finds Sabine at 38, living in an adult care facility, after finally having been diagnosed as having autism. An exposé on the ignorance about autism, and an urgent plea to acknowledge value, support and involve all individuals in society, the film is even more centrally about the relationship between Sandrine and Sabine - the care, closeness, feelings of guilt and the frustration as one sister feels helpless to stop the other's decline.

Oscar-nominated filmmaker Alice Elliott will be in attendance for the thought-provoking post screening Question and Answer session and informal post-screening reception where all can meet, mingle and chat.

A fully accessible venue, open captioned/sub-titled films, ASL Interpretation, Real-time Captioning and on-site attendant services will help ensure full participation and enjoyment by Film Forum audiences.

For more information and to purchase tickets, go to
<http://www.abilitiesartsfestival.org/schedule/2008filmforum.html>

COMMUNITY NEWS UPDATES

Legal Rights for People Who Use Service Animals

People who use service animals may be denied access that others take for granted such as being able to eat at a restaurant, go grocery shopping or live in the apartment of their choice. As a result, ARCH receives inquiries from people who use service animals about their legal rights. Read more at <http://www.cwdo.org/cwdo/resources/resources.php?resources=495>.

New System For Making Human Rights Complaints In Ontario Now in Effect

The Human Rights Code Amendment Act, 2006, came into effect on June 30, 2008 and changed the way in which complaints of discrimination under the Ontario Human Rights Code are handled. The Ontario Human Rights Commission will no longer accept complaints of discrimination. All new

applications alleging discrimination are to be filed with the Human Rights Tribunal of Ontario.

Are You Interested in Being on ARCH's Board?

The ARCH Nominations Committee is now preparing its Nominations Report, to be presented at ARCH's Annual General Meeting. We would like you to consider volunteering on the ARCH Board or suggest others who could make a valuable contribution to it.

CILT NEWS

CILT's Annual General Meeting

This year's Annual General Meeting has been scheduled for Thursday September 25, 2008 5:00 to 8:00 p.m. at 39 Parliament Street (Front & Parliament) on the 11th floor. Notices will be posted in the lobby to show people where to go. Volunteers are welcome and encouraged to attend.

The AGM is a good opportunity to meet the Board of Directors and members of CILT, and to learn more about what CILT has accomplished over the past year. We are looking forward to seeing you there!

PEER SUPPORT PROGRAM UPDATE

BY NANCY BARRY

Peer Support Network Now On Facebook

A friend just recently showed me how to use Facebook. It was one of those things that I always wanted to find out about, but just never got around to it. Then one day, it hit me! What a terrific vehicle for peer support! So, I created a page entitled, "CILT's Peer Support Network". It's just one more opportunity for people with disabilities to connect and discuss issues around peer support, and also to find out about upcoming peer support events at CILT.

In order to access the Network, you must be a registered member on Facebook. It's easy! All you need is a computer and access to the Internet. Just log on at www.facebook.com, click in the box entitled "Sign up for Facebook" and follow the prompts. Once you're registered, you're good to go. You can set up a profile of yourself, and connect with family and friends who you haven't seen in a long time. As long as they are registered members on Facebook, you should be able to find them. To find CILT's Peer Support Network, click on the search box under

'Groups' and type in CILT's Peer Support Network.

We just started, so you haven't missed much. Check for upcoming community events, CILT workshops and peer activities, and participate in group discussions on various topics related to peer support.

The True Meaning of Independence: A Workshop Series for Youth with Disabilities

Facilitated by Rena Nikou

The Centre for Independent Living in Toronto and Just Believe proudly present a two-part workshop series to help Youth and Young Adults with Disabilities understand the true meaning of Independence.

Workshop #1 "Understanding Independence" explores the meaning of independence, different ways of becoming independent and ways of coping with systemic and attitudinal barriers. Workshop #1 takes place on Saturday **September 13, 2008 from 1 to 3 pm.**

Workshop #2 "Attendant Services: Increasing Independence" explores the concept of Attendant Services and how they can increase your level of independence, and offers suggestions in handling conflict in your relationships with your attendants. Workshop #2 takes place on Saturday **September 13, 2008 from 1 to 3 pm.**

Both workshops take place at the Centre for Independent Living in Toronto (CILT) Inc., 205 Richmond Street West, Suite 605 (Richmond and Duncan Street). To register for one or both workshops, call Nancy at (416) 599-2458, extension 27, by TTY at (416) 599-5077 or by email to peervolunteer@cilt.ca. Please register for one or both workshops by September 2, 2008.

For more information on Rena's workshops, check out her website at www.justbelieve.ca.

BOOK REVIEW

By Susan DeLaurier

A Brief Introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services - by Wolf Wolfensberger

This small book, with a rather clunky title, will prove to be valuable not only for people involved in designing social programs, but for anyone who wants to improve the quality of life for marginalized people. The theory of social role valorization (SRV) grew out of the principle of normalization which defined the

criteria against which the quality of any specific service project could be assessed. Normalization was not always clearly understood and SRV takes the theory further and better describes it.

Although not a popularization of SRV, this book is nevertheless clearly, if somewhat redundantly, written and is suitable for human service workers, governing board members of organizations, personal advocates, families, and people at risk of social devaluation.

Social devaluation is universal, and the only thing that varies is the 'who' that is being devalued. People become devalued if they possess certain characteristics such as poverty, poor health, disability, and low intelligence, which are devalued in many societies.

Everyone has some person or group they devalue for various reasons, while some may, in fact, be well-respected by many individuals. An example is a celebrity who is devalued as shallow, irresponsible, greedy, etc. Devaluation can also occur on a level of social collectivity and even an entire society where classes of people are judged negatively by the majority. This second type of devaluation is worse because it creates and maintains classes of people who regularly receive poor treatment. The devalued person is given a role identity that confirms and justifies society's ascription of low value or worth of a person.

Social roles, in turn, determine people's behaviours and place in society. Everyone needs to have roles in society such as parent, spouse, student, accountant, nurse, etc. These roles may change from time to time, and some of those changes may be minor. But devalued people, however, may only have a couple of very minor roles. A consequence might be trying to enlarge a small positive role into something so much larger than what is normative for that culture. For example, being a good story teller is positive, but not when you do it all the time. People interpret themselves to others on the basis of their social roles.

Wolfensberger gives many ideas for designing programs for devalued people that may seem simplistic at first glance, but they are basic things that others simply take for granted. An example is being well-groomed. Often, marginalized people, for whatever reason, are not well-groomed, and this further isolates them from the rest of society. He further suggests that by attaching the label "therapies" to service activities such as gardening, recreation, art, or work, we are presenting a negative image about the individuals who engage in these activities.

Another example is the common use of institutions being referred to as a "House" or a "treatment centre", which presents those who live there as incompetent. Normally, people simply require a street name and number to signify where they live. The usual fund raising activities which these institutions engage in tend to be

detrimental to the stereotypical images as they denote pity and hopelessness. Imagery may sound superficial but is most important because it determines these stereotypes that are deeply embedded into the minds of observers which is where value will be accorded to or withheld.

Guidelines for applying SRV measures include becoming familiar with the specific barriers faced by a group or person and know their risk factors. For example, this may include health issues among seniors and emotionally less mature attitudes among people with developmental disabilities. When valued roles are lost, it is important that others take their place. An example might be a student with a physical disability who graduates but is then unable to find a job. A possible positive solution might be to continue in the role as a student at a higher level, but working in a “sheltered workshop” would not be positive in this case.

Human service technologies now tend to use drugs, large and impersonal institutions with detailed task-analyzed individual programs to teach something outside of natural contexts. Quite often, there is no discernable change in a person’s life and the author argues that using the concepts of SRV will have a better outcome.

CLASSIFIEDS

FOR SALE:

“Estate Sale”

2007 NEW Dodge Caravan, Red Crystal
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