CLBC Newsletter April 2011 | Volume 07 | Issue 02

The Citizen

Connecting people with their community

COMMUNITY LIVING
BRITISH COLUMBIA

Self-Advocates talk about Quality of Life interviews

Ish and Jordana were among 20 self-advocate interviewers who worked on the Quality of Life Demonstration Project.

Rick Mowles, CEO

Contents

This month, The Citizen focuses on exploring CLBC's work to strengthen quality of life and informal safeguards, the lens that is used in the work we do to help people feel safe and welcome in their communities. We also profile a recent meeting where families had the opportunity to share their experiences and stories directly with the CLBC Board.

The Quality of Life demonstration project currently underway in the Fraser Region is part of our commitment to continuous quality improvement. Developed by international expert Dr. Robert Schalock, the Quality Of Life framework includes the following eight areas that provide an indication of an individual's quality of life: well-being; interpersonal relations; material well-being; personal development; physical well-being; self-determination; social inclusion; and rights. The demonstration project will provide CLBC with a picture of how self-advocates view their own quality of life. Over time, the quality of life framework will impact our overall monitoring framework and how we measure outcomes. To find out more, I invite you to read the quality of life article in this edition.

CLBC supports informal safeguards in community that rely on the interest and goodwill of citizens and organizations and is committed to providing education, support and leadership to encourage these kinds of safeguards. CLBC's focus on informal safeguards includes the Start with Hi initiative, the Belonging and Support Network guides, and on-going work with self-advocates and families to help them build more informal networks of people in community. CLBC has created tools, like the self-advocate and family Facebook sites, to help people connect, and resources, including "Support Networks: A Guide for Self-Advocates", to help people build their own personal connections. You can find out more about support networks in the You Asked Us column, and in the article about a recent self-advocate workshop held in Victoria.

April is Autism Awareness Month in British Columbia, a time to recognize the individuals and families among us who live with a disability that may not be visible to most people and to honour the many achievements made by the autistic community. In this edition we feature the story of a young man in Langley who is using his time and effort to help support cancer research and awareness.

Enhancing quality of life and aiming to reduce vulnerability are also helping to determine the path we take with the new group of adults supported through CLBC's Personalized Supports Initiative. CLBC participated on March 2, 2011 in the 4th annual International Conference on Fetal Alcohol Spectrum Disorder (FASD) in Vancouver. At the conference, CLBC introduced its new resource, "Supporting Success for Adults with Fetal Alcohol Spectrum Disorder", to help service providers, families, communities, educators and others to better understand FASD and how to support and strengthen quality of life and safeguards for adults diagnosed with FASD.

CLBC is committed to making sure the voices and ideas of the people it supports are heard, and that they continue to have more opportunities for "good lives in welcoming communities." I hope you enjoy reading this month's edition of The Citizen, and we look forward to keeping you updated on our work. ■

THE SELF-ADVOCATE'S PERSPECTIVE

On the move in community

By James Janzen

James Janzen shares information about finances at his topic table at the Fraser Self-Advocate Conference.

My name is James Janzen and I live with my wife Bonnie in Abbotsford. Bonnie and I have been married for three years and we live in our own home.

This year has been really good. I have been working as the Self-Advocate Consultant for the Quality of Life demonstration project through CLBC.

Quality of Life is a way to survey people who get services from CLBC. What is really best about this survey is that it is self-advocates who are asking the questions and recording the answers. It is a good way to make people feel comfortable about answering questions. It is also an excellent job for self-advocates. We have learned a lot of skills in the last few months.

I am the consultant and I also do the interviews with the individuals. It's a challenging job and a great job too.

I think the most challenging part is dealing with the unknown. We never know exactly how the interview will go. I have had to learn to be flexible in this job. I have learned how to get from Abbotsford to many different communities like Burnaby, Langley, and Chilliwack. Thank goodness for my GPS. It gets me where I need to go.

I work a lot. I also work at Home Depot as a Lot Associate. I help customers load things into their cars. It is hard work. I had to work out at the gym to get stronger so I could do this job. I have worked for Home Depot for eight years. I also have my own business repairing computers. Really my dream is to have one full-time job.

I am the president of the Abbotsford Self-Advocate Group. The group meets once a month and we have two advisors, Gregg Schiller and Arlene Schouten. There are around 30 members and we do some fundraising and advocacy. The group was really small when I joined and I had an idea to create an agenda for meetings to help it be more organized. Now it is a big group and I have been the president longer than I can remember. We meet at the offices of Communitas and new members are always welcome.

I have lived a lot of places in BC but now call Abbotsford home. My parents live in Abbotsford as well. I have two sisters, one lives in Calgary and one in Chilliwack.

My wife and I live in a condo with our cat Tigress. We love being homeowners but it is challenging at the same time.

You can learn more about the Quality of Life demonstration project on page 12. ■

Inside Voice is published in each issue of ***The Citizen***. If you are interested in writing for this column, please call Chris Rae at 1-877-660-2522, or email editor@communitylivingbc.ca

Resource for transitioning youth

TRANSITIONING TO ADULT LIFE is important and often challenging for youth and their families. Nobody knows this better than parents like Colleen Denman whose son Riley is now in grade 10. "Transition is one of those things that's been in my head since he was little," says Colleen, "The thought of adulthood always looms in the back of your mind. It can be daunting to always be the one solely responsible for someone's future happiness, security and safety."

Colleen Denman's son Riley is a student at Carson Graham Secondary School in North Vancouver and he will be turning 17 in June. He plays an important role on his school's basketball team by supporting players, assisting with practice drills and working the score clock. Along with older brother Curtis who is in grade 12, he attends every game.

It can be daunting for families to navigate the transition to adult life. When youth have special needs, transition planning is needed. There are many opportunities, supports and services that youth and their families will learn about which may be appropriate or needed for adult life.

In October of 2009, the Cross Ministry Transition Planning Protocol for Youth with Special Needs was introduced. The Protocol describes how youth and their families and the nine government organizations work together. The Protocol promotes a cross-ministry commitment to collaborative transition planning process for individual youth and their families. Community Living BC (CLBC) is one of the organizations that work in collaboration with youth and their families and other government organizations and ministries to support youth transitioning to adulthood.

The Family Support Institute (FSI) is one of the community partners who provided input and guidance during the development of the protocol. Other community partners were PLEA Community Services Society, Bridges to the Future, and Caring for First Nations Children Society.

"Our role at the table was to bring the family perspective," says Angela Clancy, Executive Director of FSI. "Families really need to see that there's an invested interest in collaboration. Their family member is touching on a number of different supports and it's important for them to know that government groups are speaking to each other."

Another desire that families expressed was for clear, understandable information about the transition process, says Angela. There is an appendix to the Protocol, called the Youth with Special Needs: Roles and Tasks for Transition Planning Team Members which is an important resource that outlines the roles of team members including youth, family, and staff from school, youth services and adult services in a clear chart.

"It shows who you go to and who you talk to. It's clearly laid out and it's in plain language," says Angela.

The chart begins at age 14 and includes information for each step in the process to age 19 and beyond. Even for families who have not started the planning process at age 14, the chart can be a valuable tool.

For Colleen and Riley, the Youth with Special Needs: Roles and Tasks for Transition Planning Team Members chart has provided a well laid-out map of the transition process which has relieved a lot of pressure.

"It's timely. It's sequential. I'm just thankful to have something that really tells me what to do and who to see," says Colleen. "It's a great resource."

Riley's story was recently featured on CTV News and can be viewed online at www.ctvbc.ctv.ca by searching for "Carson Graham's team spirit".

For more information on Youth Transition to adults services, including a link to the Youth with Special Needs: Roles and Tasks for Transition Planning Team Members chart, please visit the CLBC website under Individuals & Families > Youth in Transition. ■

Participating Ministries and Agencies

- Community Living BC
- Ministry of Social Development
- Ministry of Children and Family Development
- Ministry of Advanced Education
- Ministry of Health Services
- Ministry of Education
- Ministry of Public Safety and Solicitor General
- BC Housing
- Public Guardian and Trustee

Riding for a cause

For 27-year-old Langley resident Matt Forster, the days are busy with training and preparation. Matt is cycling in the Ride to Conquer Cancer on June 18 and 19. The route starts in Vancouver and ends in Seattle, a distance of around 200 kilometres.

He's riding for a very personal reason. His Aunt Linda, a teacher at Uplands Elementary School for 24 years, passed away late last year of esophageal cancer, 18 months after being diagnosed.

Matt, who has autism, decided to participate in the annual bike ride to raise money and awareness for cancer research in memory of his aunt. Joining him in his fundraising effort and on the ride is his support worker Joey Emanuels from the Langley Association for Community Living. Both are aiming to raise $2,500 for their participation in the event.

While Matt is using his love of physical activity to help others, it has also benefitted him personally. Over the last couple of years, he has lost 115 pounds through daily exercise and healthy eating.

The Ride to Conquer Cancer won't be Matt's first effort to support a good cause. He also raised $300 to run in the White Rock Terry Fox Run, where his parents Judy and Brad help out.

To learn more about Matt, please visit the Langley ACL website at langleyacl.com and find a link to his story, including information about his fundraising efforts, on the front page. ■

Matt Forster prepares to take part in the Ride to Conquer Cancer.

Learning and connecting

On March 17, 2011, the first Fraser Self-Advocate Conference took place at Surrey's Newton Cultural Centre. The conference was organized and hosted by the Fraser Self-Advocates to educate each other and gather information in areas such as employment, housing, transportation, finances and creating community connections.

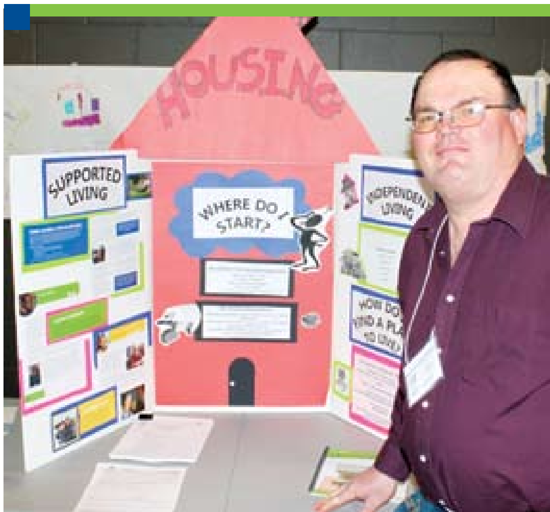
Tricia Lins, who works in CLBC's Langley office, worked with 11 other self-advocates on the steering committee to help coordinate the event. In the morning, Tricia, who also served as the MC for the event, welcomed close to 100 attendees from across the Fraser Region.

Following Tricia's introduction, Shelley Nessman, CLBC's Self-Advocate Advisor, facilitated a story telling workshop to help people learn how to share their experiences.

In the afternoon, a series of "topic tables" were set up. Each table featured a self-advocate leader who was also supported by a CLBC staff member. Discussion topics included Housing, Independence, Community Connections, Recreation, Disaster Planning, Finances, Employment, Transportation, Families, Lifeskills and Learning.

To ensure that information was presented in a clean manner, there were symbols corresponding to the topic of each workshop to help self-advocates with their selection. Each table hosted about nine or ten guests and participants had a chance to sign up to sit at three different tables over the course of the afternoon.

"We wanted self-advocates to get something out of the events. Everyone learned in their own different ways," says Tricia. "I really loved the experience, and was happy to see that the people who attended did as well. I hope to do it again in the future." ■



Jerry Laidlaw shares information about housing.

Carving out the perfect job

By Dave Pernarowski, Supported Employment Coordinator, PNGI

> "Getting this job is good for me as a carver because it will give me exposure and will let me work on my art." - James Weget-McNeil

SUPPORTED EMPLOYMENT FOR people with developmental disabilities is so much more than just helping people apply for a job. The process from the beginning to job placement is designed to ensure maximum success for the job seekers. We take the time to find out each person's skills, hobbies, interests, and dreams. Completing the discovery process gives us the ability to find just the right job for people and gives us the confidence to let a business owner know exactly what skills our job seeker brings to the table. At The Provincial Networking Group Inc. (PNGI) in Terrace, our discovery stage with job seekers is set up over a 4 to 6 week period that includes numerous meetings with the job seeker, their support people and PNGI management to map out a career planning strategy.

James Weget-McNeil is involved in the PNGI supported employment program. He is 25 years old, and is diagnosed with FASD. James grew up in the village of Gitwinksihlkw (Greenville) in the beautiful Nass Valley in northwest British Columbia, and is a member of the Frog clan (Ganada). After high school, James was accepted into the Freda Diesing School of North Coast Art at Northwest Community College and completed that program in 2009. This Art School is the only one of its kind in Canada. James was taught by master carvers Stan Bevan, Ken McNeil, and Dempsey Bob. James worked closely with Ken McNeil who is not only a master carver and mentor, but his uncle. He taught James about carving, painting and the unique culture and the history of the First Nations people.

As part of our supported employment program, we worked through a "Guiding Circles" process of discovery. Guiding Circles is a program that uses an interactive, flexible, holistic career development model designed to guide individuals toward career paths. This model combines a traditional Aboriginal worldview with contemporary career development concepts (www.ergoncommunications.com). Using the Guiding Circles process we outlined his top twelve interests and then narrowed those down to the top three, one of which was traditional wood carving.

About a week later, James stopped by my office with one of his completed carvings. The moon mask carving that James brought to the office was very impressive. I wanted to find out more about this artistic talent and follow up on how we might develop a job that matched this interest and unique skill.

James developed an artist profile and photo catalogue of the recent carvings he had done. I then helped James negotiate a consignment deal with a local First Nations gallery and boutique where his mask was sold to a large corporation that wants to display his art in their new offices.

This success developed into an idea to approach another well known retailer in our community that also features First Nations art, with a job proposal. This proposal would have James working in the retail store doing carving at a carving table on a regular basis. This would allow tourists and visitors to see first-hand the work that goes into this beautiful art and have a personal connection with the artist. The business owner could see that the benefits to his business would be numerous. He accepted the proposal and work is now underway to get everything set up and ready for a busy summer season.

The benefits for James are immeasurable as he gets to do what he loves and is paid a salary for doing the work. He will also have an arrangement to sell his finished carvings through the retail shop on consignment which will generate additional income.

Spending the time to really discover the skills, talents, personal likes and dislikes for James led us to a very unique job opportunity.■

Art brings community together

On Saturday March 5, 2011 L'Arche Greater Vancouver held its second annual Art of Being Together - an exhibition of art which brought together emerging artists, respected art judges, sponsors, and the general public. The event celebrated community and inclusivity where everyone, regardless of ability, education, gender, race or religion, is valued for their gifts.

Emerging artists were invited to submit a piece using the theme "The Art of Being Together" as their inspiration. There were 200 people in attendance, including sponsors, musicians, community leaders and volunteers.

The art works on display included 9 Finalists, 8 Honorable Mentions and 16 pieces from the Art Together project. The judges announced their top choice from the finalists' pieces and the general public was also invited to vote on the People's Choice Award. The Judge's Choice Winner was Sophia Bartholomew for her piece "Together: Transformation, Study no. 3" and the People's Choice Winner was Carrine De Ridder for her painting "The Game".

Attendees were invited to participate in a Community Art projects, in which they could help create a piece of art that was presented to South Slope Elementary School, BC Provincial School for the Deaf which is in Burnaby.

Sponsors for the Art of Being Together chose one piece of art from the Finalist or Art Together galleries. CLBC chose Diversi-tea, a painting which incorporated tea bags as part of the image.

Amanda Wong, Jen Kazda, Conrad Der and Melisa Jugdeo of L'Arche Greater Vancouver present the Art Together Gallery.

Proceeds of the Art of Being Together benefitted L'Arche Greater Vancouver, an organization where adults with developmental disabilities share life together in home and day programs. L'Arche supports people to realize their potential through meaningful work, on-going learning and companionship.■

Supporting Success for Adults with FASD

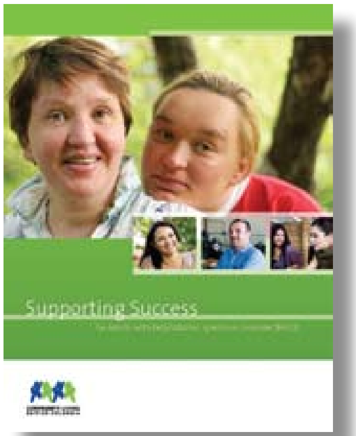
CLBC's new Fetal Alcohol Spectrum Disorder (FASD) Resource "Supporting Success for Adults with FASD" is designed to be used by CLBC staff, service providers, community members, family members and others who work with adults with FASD.

The ideas offered in the booklet are based on the assumption that each person with FASD is an individual with a unique history and situation, and that actions and supports must reflect this. Successful support recognizes these individual differences and adapts in response.

This resource serves as a starting point in gaining an understanding of individuals with FASD, and as a tool to help develop knowledge and support success.

The booklet also contains a list of other resources and websites that may be helpful along that journey.

"Supporting Success for Adults with FASD" is available on the CLBC website under Individuals & Families > Personalized Supports Initiative. Printed copies can be requested by contacting info@communitylivingbc.ca. ■



Families share their stories

On Tuesday, March 29, six parents of individuals with developmental disabilities gathered in Vancouver to share their individual stories of lived experience with CLBC Board Chair Denise Turner and CLBC Board Members Mark Duncan, Don Rowlatt and Arn Van Iersel. This meeting provided an opportunity for members of the CLBC Board to hear about these family members' different and ongoing life journeys with their adult sons and daughters with developmental disabilities.

Board Chair Denise Turner welcomed family members Vidyut Aklujkar from Vancouver, Carol Antoine from Vancouver Island, Maria Glaze from Powell River, Russ Keil from Courtenay, Annette Pope from Rosedale, and Arlene Zuckernick from Victoria. Also joining the meeting were Sylvie Zebroff, CLBC's Family Partnership Advisor, and Carol Goozh, Vice-President of Policy and Program Development for CLBC.

"We're really delighted to be meeting with you, to listen and learn and hear about your first hand experiences. No one knows what it takes to realize CLBC's vision of good lives in welcoming communities better than you and the individuals that we serve. We're here to really listen and learn about the challenges you face, and the opportunities you see to improve, and the cherished moments you have," said Denise.

Sylvie Zebroff (CLBC Family Partnership Advisor), Carol Antoine (Family Member) and Don Rowlatt (CLBC Board Member) take part in the dialogue between families and CLBC Board members.

Each of the parents was invited to share accounts of their family experiences with each other and with the CLBC Board Members. What followed was a lively and heartfelt discussion, with questions and answers amongst all the participants about the wide variety of challenges, successes, concerns and opportunities shared.

Parent Maria Glaze began the discussion by speaking about her 27-year-old daughter Rebecca and her daughter's needs in the context of the whole family. As a married mother of two adult daughters, family advocate, community activist, and longstanding member of the Family Support Institute (FSI), Maria shared how accessing individualized funding through a Microboard has had a huge, positive impact on her family's life over the past nine years and also shared some of her thoughts about the future.

Arlene Zuckernick, mother of recently transitioned adult son, Jared is a co-founder of Second Wave, a parent-based transition group and also co-founder of InclusionWorks!, both based in Victoria. She spoke about her hopes and dreams for her son Jared and the formation of InclusionWorks! with other likeminded families in her community. She also spoke about the family governance model, the diverse and often surprising community partnerships that have formed, and the challenges of long-term funding and planning.

Russ Keil, father of Ashley, who recently transitioned to adult services, is a member of the CLBC Central and Upper Island Community Council, and a member of the Provincial Advisory Committee to the CLBC Board. He expressed his strong interest in "the possibilities and options of proactive planning across the lifespan."

Speaking about Ashley, who just turned 21 and recently came through the transition of youth to adult services, Russ says, "Transition to adult services is important but it is just one part of it." As the father of three children, he also addressed how differently family members can react to a developmental disability diagnosis within a family and how reactions can change over time, from grieving lost expectations to seeing tremendous possibility.

CLBC Board Chair Denise Turner listens as Vidyut Aklujkar shares her experiences of raising her daughter Rasika.

Carol Antoine from Vancouver Island, is the mother of adult son Iggy, and a member of the CLBC South Island Community Council. Carol, who is of aboriginal heritage, spoke movingly about her son Iggy's story and their experiences with getting services, school graduation, and now the transition to adulthood.

Annette Pope is a senior parent and long-time advocate, whose adult daughter Marianne is in her late 30s. The Pope family is based in Rosedale. Annette provided a summary of the evolution of services and supports for persons with developmental disabilities in BC, by reviewing her daughter's own history. Annette vividly described time spent in the institutional setting of Glendale, the challenges of finding schooling, life in two group homes, and now, a shared home and happiness for Margaret. Annette also spoke about "lessons I learned as a parent and as a person," and concluded, "Our lives, now in the present, reflect contentment."

The final presenter of this meeting session was Vidyut Aklujkar, mother of self-advocate, CLBC employee and classic Indian dancer, Rasika Aklujkar. Vidyut is an academic of Indo-Canadian heritage, with a long history of advocacy for her daughter's educational inclusion and full social citizenship. She spoke about "my specific hopes and concerns regarding Rasika's future, taking into consideration her performing arts abilities and other office skills," and also about the changes in the level of parental involvement as adult children with developmental disabilities may themselves move into roles of self-advocacy.

Board Chair Denise Turner and fellow members of the CLBC Board listened intently as the family members shared their stories and experiences. The presentations were followed by a question and answer period which allowed for the Board members to gain greater insight into the triumphs and challenges these families have experienced. All in attendance voiced their mutual appreciation of the opportunity to share and learn through open dialogue.

If you are interested in learning more about this meeting, video clips of the family members' presentations will soon be appearing on the CLBC website under What's New > Media Room and will be shared through CLBC's Youtube, Facebook and Twitter pages. ■

Russ Keil speaks about his daughter Ashley's transition to adult services.

Supporting independence

For Denis and Kathie Bell of Comox, the Family Independence Fund has helped them to create a separate suite on the lower level of their house, building greater independence for their 24-year-old daughter Jocelyn.

The Family Independence Fund helps families throughout the province who have family members with developmental disabilities living at home. The Fund was established with financial assistance from Community Living British Columbia (CLBC) and is administered by Vancouver Foundation's Giving in Action Society to help with the care of the relative by providing one time grants to support projects such as home renovations — including lifts, elevators, ramps, flooring, door widening or vehicle modifications — that enable the individual with the developmental disability to live in the family home and access their community.

"She has a wonderful spirit," says Denis of his daughter Jocelyn, "We wanted to take the next step of creating more independence for her."

Denis and Kathie first learned about the Family Independence Fund at a workshop on homes for individuals with disabilities hosted by the Planned Lifetime Advocacy Network (PLAN).

To begin the process, the Bells submitted a letter of inquiry. Once their letter was accepted, they were invited to submit a proposal of the changes they planned for their house.

Their full proposal included design drawings for the proposed changes to their house which would give Jocelyn a more independent living space in her own separate suite downstairs.

"It is something that has to be well planned from start to finish. There is a lot of prep work involved and it is definitely a learning experience but we were always supported throughout the process," says Kathie of the application process.

In June 2010, the Bells received a $50,000 grant and began working with a contractor and Giving in Action Society to complete the renovations to their home.

As the renovation to their house would create a separate suite, the Bells needed to apply to have their property rezoned. The municipality was very supportive through the rezoning process. "Knowing that the community you live in supports your goals, it clearly demonstrates their interest in you and your family. It's a good feeling," says Kathie.

Now completed, the suite is fully contained, with its own entrance. Denis and Kathie have access from upstairs. As well as her own bedroom, and living room, Jocelyn has her own kitchen including a restaurant style booth, which is more accessible. The suite is painted in various shades of her favourite colour, blue.

"There's a level of maturity that comes with having your own place," says Kathie.

Jocelyn has also begun to express her own likes and interests more readily, talking about inviting guests over to her home and shopping for the types of foods she likes.

Although the transition process from her parents' home to her own suite has had a few minor challenges for Jocelyn, she is now comfortably settled and happy in her own place.

"She was eager to move down there. She loves it. The suite has really afforded her a greater sense of independence," says Kathie.

To learn more about the Family Independence Fund, including information about submitting an application, please visit www.givinginaction.ca and go to Our Programs > Family Independence Fund. ■

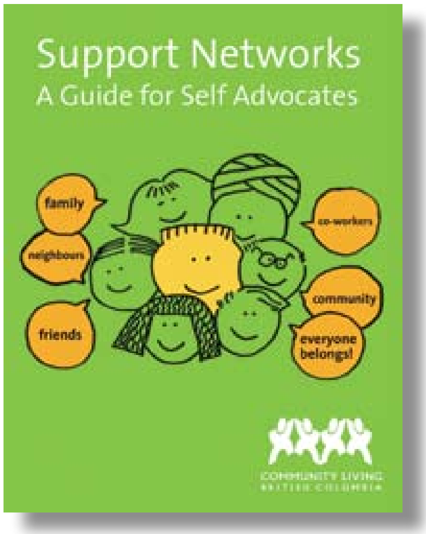
Jocelyn and her cousin Jessica celebrate as she moves in to her own suite.

Developing leaders and networks

On March 30, over 40 self-advocates, caregivers and staff participated in a personal support networks workshop sponsored by the South Island Community Council and Self-Advocates for a Brighter Future in Saanich. The workshop introduced the "Support Networks: A Guide for Self Advocates" publication, and gave people a chance to talk about what networks are, who is part of them, and how stronger personal networks can be built.

"Self-advocates work very hard to break down preconceived notions of people with disabilities," said David Steeves, Chair of the South Island Community Council. "To get out there helps break down the barriers and the fears. It takes huge determination and huge courage. Self-advocates deserve all the respect, time, support and effort that CLBC Councils can provide."

The workshop was lead by Aaron Johannes and Susan Stanfield of Spectrum Society for Community Living. Self-advocates Mary Emmond, Michael Langridge, Ava Williams and Candace Williams helped organize the venue, pizza lunch, and provided introductions, took registrations and set up the sound system. Michael's nickname is "Mike-A-Lot" and he often DJs at events.



Aaron started the workshop with an introduction exercise to help the group meet others they didn't already know, and to see who has common interests, a good place to start when thinking about new friendships. Susan and Aaron then asked the group to identify people that are in their support networks. For the group, this included friends, family, caregivers, church, recreation centres, transit staff, teams, and neighbours.

"When we do this exercise with people, even those people who feel they don't have a support network realized they are connected," said Susan. "Once they've done this workshop, or have read the guide, they also know different ways they can help make their network grow."

Four self-advocates also joined Aaron to do role playing on the dos and don'ts of meeting new people. The don'ts included not frowning, not being rude, not leaving people out and not calling people names. The dos included making eye contact, smiling, giving someone a compliment, being polite and showing respect.

"Nasty equals nastier, and happy equals happier," said Bridget, a self-advocate participant, "That means you get back what you give out."

Aaron and Susan helped to develop the Support Networks guide, and have done extensive work with self-advocates to develop other tools to help them build relationships, such as the book, "101 Ways to Make Friends" (www.101friends.ca). Currently, they are working on a new project to collect self-advocates' stories about their lives. If you would like to submit a story to this anthology, contact Aaron or Susan at aaron@spectrumsociety.org or susan@spectrumsociety.org.

The Support Network guide can be requested through your local CLBC Office and is also available on the CLBC website under Policies and Publications > Publications > Safeguards. ■

Self-Advocates talk about Quality of Life interviews

Do you do things in your community like shopping, going to movies, or eating out?

This is an example of one of the fifty questions in the "My Life – Personal Outcomes Index", a survey tool being used in the Fraser Region.

For the past several months, self-advocates from the Lower Mainland have been actively engaged in a Quality of Life demonstration project. The project has employed 20 self-advocates to conduct 300 interviews with adults receiving CLBC funded supports and services from seven service providers in the Fraser Region.

The self-advocate interviewers used a survey tool called "My Life - Personal Outcomes Index" which was developed by Persons with Developmental Disabilities (PDD) Edmonton Region Community Board. The survey is valid and reliable. "My Life" measures eight domains in the Quality of Life framework that was developed by Dr. Robert Schalock. The eight domains are: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well being, physical well being and material well being.

All the surveys have been sent to Howard Research in Alberta to be analyzed. They will write a report for CLBC and for each participating service provider. The reports will provide information about how individuals feel about their lives, and will help service providers improve the overall quality of their services by focusing on what is truly important to those they support.

The self-advocate interviewers were hired after successfully completing three days of training. They learned about how to conduct a successful interview, being prepared, teamwork, recording, invoicing and professionalism. After these three days, interview teams were contacted through e-mail about their upcoming weekly interview schedule. Interview teams also received on-the-job coaching during their first weeks of interviewing.

The teams have independently conducted interviews at different locations from the North Shore to Abbotsford. Interviewers have characterized their work as "going outside my world". It has put them in the position of working with new people and different work styles. They have also learned how to use email and a cell phone; and figured out many new transportation routes.

Self-advocates have reported they like meeting new people, proving to themselves that they can do new and challenging work, and feeling important because they are doing work that can make a difference to people lives. When asked what makes a successful interview they stated:

- Patience
- Giving people thinking time
- Being silent while people think
- Not to rush people
- Understand that some people need to think out loud
- Making people feel comfortable
- Staying professional
- Being considerate of an individual's feelings

When asked about the challenges of being an interviewer they listed the following:

- Last minute changes to a schedule
- People who do don't show up for their interview
- Meeting different kinds of people and not knowing what's going to happen in the interviews
- Getting attached to the person being interviewed and knowing I can't get involved in their life
- Dealing with all the unknowns: people, schedules, new places, people's feelings about being interviewed, questions about the project

(left) Alecia Emery and Gerry Juzenas surveyed self-advocates using the "My Life - Personal Outcomes Index"

(right) Self-advocates and trainers who worked on the Quality of Life Demonstration Project.

Having successfully met these challenges they now talk about how important it is to be professional, to go with the flow, to think on their feet and to always be prepared for change.

Interviewers came together every six to eight weeks for a work meeting to discuss how things were working for them, tricky situations, transportation supports, team work and correct procedures for using the "My Life" survey. At a recent work meeting they were asked "How has being a Quality of Life interviewer changed you?" Some responses were:

"Being an interviewer has given me more confidence. I am shy to talk to people I don't know, but now I feel comfortable with small talk."

"It has changed me by giving me the realization that everyone has problems and has difficult challenges in their life and even so keeps a smile on their face."

"I look at the whole world different."

"I am more aware of what I am doing in my life now."

"What I am doing is important and I feel like a valued member of the community."

"Being an interviewer means that I can be a leader, and be a professional; that people, like my co-workers, friends and my family, admire me for what I am doing."

"I always wanted to work with self-advocates. This is my dream job!". ■

You asked us:
Support Networks, An Informal Safeguard

Welcome to CLBC's "You Asked Us" feature where CLBC staff answer your questions about CLBC supports and services.

This month, Jule Hopkins, Manager of Service Accountability and Safeguards, answers your questions about support networks, which are an informal safeguard. Jule leads CLBC's informal safeguards project, which has a major focus on building support networks, as an important informal safeguard. The goal of this work is to address the need to reduce vulnerability and help create safe, welcoming communities for everyone.

1. What is a support network?

Support Networks are an informal safeguard that can enhance and enrich people's lives. Support Networks are made of many different kinds of people who come into your family members' life and who know and care about them. This can include family, friends, people who see them in the community like the bus driver, hairdresser and the cashier at the local grocery store. They can also be co-workers, team mates and fellow students, as well as acquaintances that may see your family member regularly at the coffee shop or at the hockey game. A support network can connect people to the community, reduce their vulnerability and help keep people safe.

2. Why is a support network important?

People in your family member's life that know and care about them is one of the most important ways to ensure your family member feels safe and valued.

A support network can help your family member feel welcome in a community setting, can help them have fun, and ensure that they can have people in their life who will be there in case of an emergency. A support network can ensure that your family member has people they trust in their life who will notice when they are unhappy or hurt or when they need some extra help or someone to talk to.

3. My family member receives funded supports and services, why do they need a support network?

People may have great services, like housing, employment and day activities but still want to feel closer to family and friends. Some individuals with developmental disabilities may struggle with isolation and loneliness. They may want people who are not paid to support them, to be in their lives, so that they can have meaningful relationships with people who are interested in getting to know them.

There is a difference between being 'in' community and being part of community. Living in community does not always mean that people have a full life. Support networks give people a chance to engage in reciprocal experiences where they have a chance to share their own gifts and strengths with others.

4. Why is it important to have unpaid people in my life?

Individuals with disabilities may have formed positive, long lasting relationships with their paid support staff. However, these relationships do not always extend to the level of real friendship and if a paid staff member leaves, these connections can be hard to maintain. Having a larger circle of friends, acquaintances and other informal connections helps to ensure that people have fuller lives that are not solely dependent on paid supports.

5. Does it matter if my family member has significant challenges and needs?

The ability to form friendships or social connections has nothing to do with a person's intellectual abilities, economic contribution or education. Forming a connection is a result of the ease and comfort building over time and growing into a meaningful relationship.

Relationships are as unique as the individuals participating in them. All people, regardless of their abilities, can engage in meaningful relationships. There are many examples of people making long lasting and caring connections to each other where the individual with a disability has multiple or complex challenges, in fact these have often been the best support networks formed.

6. ARE PERSONAL SUPPORT NETWORKS AND INFORMAL SAFEGUARDS REALLY JUST A WAY OF REDUCING FUNDED SERVICES?

Funded services and supports are integral in meeting people's disability-related needs. Just as important are friendships and social acquaintances which fulfill a deep human need and longing for connection. Support Networks that include unpaid people can augment and enhance the funded services, add dimension and create opportunities for people.

Connections support our sense of belonging and offer ways to be included in various aspects of community, such as work, social and recreational environments, school, clubs or associations.

7. WHAT IF MY FAMILY MEMBER WANTS TO DO SOMETHING THAT I THINK HAS SOME RISK OF REJECTION?

Risk and rejection are part of making connections in the world. It is important for your family member to gain confidence, take risks and explore opportunities.

There is dignity in risk taking and great potential in learning from experiences. People that support and care for an individual need to make sure that the way we address risks does not restrict the individual from reaching their goals. It is important to make sure that you are not holding back someone's right to live their own life by trying to protect them too much, express your concerns and seek help from others in the support network.

All of us have experienced this at some time and it is important to have the confidence to continue to take risks and explore opportunities. Risk can be handled by planning and implementing good safeguards.

8. HOW DO WE START TO BUILD A SUPPORT NETWORK?

You can start to build a support network by talking to your family member about who they would like in their support network. They may already have a group of informal connections that they have not thought of as an intentional support network, but people who are in some way part of their regular routine. Your family member can talk to staff that they interact with daily, tell people what's important to them and keep in touch with people by meeting up for activities or through social media, email or phone.

There are a number of resources that can help get you started on CLBC's website under Policies & Publications > Publications > Safeguards. ■

Cathy Anthony and her son Joshua are featured in a new publication "The Power of Knowing Each Other: Stories about Informal Safeguards told by BC Families" developed by CLBC and the Family Support Institute (FSI).

Tune in online

Dave and Lori Sherritt speak about being married for 26 years.

CLBC's Board Chair and Board Committee Chairs met with six self-advocates to hear their stories and learn about their challenges, concerns and successes.

At the meeting, each of the self-advocates was given time to speak about their experiences and share important information.

Video clips of the self-advocates' presentations, can now be viewed on CLBC's Youtube page by visiting www.youtube.com/user/communitylivingbc.

Links to each of the video clips are also available on the CLBC website under What's New > Media Room. ■

CONTACT US

Submit

Send story submissions and feedback to: editor@communitylivingbc.ca.

Subscribe

To receive the electronic or paper version of *The Citizen*, please visit www.communitylivingbc.ca and go to What's New > Newsletter > Subscribe.

Questions

Please e-mail info@communitylivingbc.ca

Social Media

Join us on Facebook at:

facebook.com/StartwithHi
facebook.com/CLBC.SelfAdvocates
facebook.com/CLBC.Families

Follow us on Twitter:

@CLBC_Connect

Watch us on Youtube:

youtube.com/user/communitylivingbc

The Citizen is published every two months by CLBC's Communications department. It is your information source for news that's relevant to the individuals and families CLBC supports. The views and opinions expressed in *The Citizen* are not necessarily those held by CLBC. We are always on the lookout for inspirational stories about people in the community. If you know of an event that others might like to know about, an issue that invites debate, or news worth reporting, let us know. While we appreciate story ideas and submission, *The Citizen* reserves the right to edit content for accuracy, grammar and space, but strives to maintain the integrity and voice of the author.

COMMUNITY LIVING
BRITISH COLUMBIA

7th Floor – Airport Square
1200 West 73rd Ave
Vancouver, British Columbia
Canada V6P6G5
Phone: 604 664 0101
Fax 604 664 0765
Toll Free:1 877 660 2522

CLBC is a Crown agency of the government of British Columbia and is committed to being carbon neutral by 2010.

FSC
Mixed Sources
Product group from well-managed forests, controlled sources and recycled wood or fiber
www.fsc.org XX-XXX-XXXX
© 1996 Forest Stewardship Council
25%

This newsletter has been printed on FSC certified paper.