

AAAL Connections

A publication of the Alberta Association for Community Living



Payton, Brent and Danielle Hanna of Lethbridge.

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From the editor

Welcome to the return of AAACL's *Connections* magazine.

We plan to produce three issues a year as one more way to keep the Association's



members and others up-to-date on what is happening for people with developmental disabilities and their families in the province. While we'll have some regular features in each issue that focus on the major areas of family leadership, inclusive post-secondary education, employment and friendships, we'd like to have your ideas, story suggestions, photos and news. *Connections* will reflect what's going on at the provincial level, but also at the grassroots: in families, classrooms, communities and neighbourhoods.

As a writer, I've been connected to the force that is the parent and self-advocate movement since 1982 when I was hired by the Saskatchewan ACL. Though I'm based in Saskatoon, I'm proud to claim some Alberta roots. I finished high school in Fairview and worked at the weekly newspaper there before moving "down east" to Saskatchewan. My husband Richard was very involved on the local and provincial ACL board, and when we married in 1986, I inherited a family of three. Jim, the oldest, has Down syndrome. So writing about inclusion has meant something joyful and profound for over 20 years now.

I look forward to creating *Connections* with you. If you know of someone who is making inclusion and belonging a reality in the community, school, workplace and

in the way they live every day, I'd like to know about it. Please get in touch: karin.schwier@mac.com.

Karin Melberg Schwier
Editor, *Connections*
<http://homepage.mac.com/karin.schwier/copestone.html>

On the cover

Brent and Danielle Hanna and five-year-old daughter Payton of Lethbridge look forward to the annual AAACL Family Conference. Payton goes to kindergarten at a neighbourhood school and has what her mom likes to call a "healthy addiction to Sesame Street. Elmo is her favourite." Brent owns and operates a local painting company and volunteers as Vice President of the Lethbridge Association for Community Living. Danielle volunteers as the Co-chair of Family Voices South and is the Chair of an Inclusive Education Committee with the public school district. Since Payton is now in kindergarten, Danielle is also on the school council.

Disability ethics website launched

December 3, 2007 was the International Day of Disabled Persons and the launch of a new disability ethics website. "Over the next months we hope that this site will grow into a useful tool for people interested in disability ethics and to bring the site up to standards for universal access," says Dick Sobsey, Director, John Dossetor Health Ethics Centre at the University of Alberta who, along with Heidi Janz at the U of A, developed the site. "We would also appreciate suggestions on how we can make it a better and more useful site." Visit <http://ualberta.ca/~initiav/Welcome.html>

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Individualized funding: Renewal or continued decline

by Bruce Uditsky

Some years ago, I wrote about individualized funding as a means of empowering families to develop creative supports for adults with developmental disabilities and how this funding is being eroded. Individualized funds or direct funding are funds given directly to families to enable them to purchase the supports they require for their adult son or daughter. It began in Alberta about 20 years ago when families who had adult sons and daughters with developmental disabilities could not get the quality supports they required. Having direct funding from government enabled these families to be creative and individualized.

Until recently Alberta had the most extensive individualized funding program in the world. Thousands of families were able to use their funding to either contract for needed services from agencies and/or hire their own staff. Individualized funding provided Alberta families with choices that were the envy of families across Canada and most of the globe.

Initially individualized funding enabled many families to create individualized and personalized supports for their sons and daughters. Over time, however, individualized funding became more complex to administer and many families did not have the knowledge or means to apply this type of funding in the personalized and innovative ways that were possible. There were very few resources to assist families in thinking creatively or in managing the complexity of individualized funding. As a consequence, the vast majority of families simply purchased the very same agency services funded directly by government and in turn, rather than administer their individualized funding, had their funding payments go directly to an agency.

Only a minority of families hired their own staff or continued to administer their funds as a means of attempting to ensure quality and accountability. Today there are many families who do not even know if they have individualized funding and therefore don't know how to use this funding to their advantage.

In response to these developments and given the

interest of AACL, government and service providers in wanting families to have choices within a coherent funding framework, a new funding model that would enhance individualized funding and family choices was developed collaboratively and approved by Persons with Developmental Disabilities (PDD), but never fully implemented. Today Alberta stands on the cusp in either ensuring individualized funding remains a viable funding choice for many thousands of families, or one only available to a few.



Some positive steps include the support from PDD in partnering with AACL to pilot the development of new resources to assist families in better using individualized funding. Resources to help with the practical matters of recruiting and training staff to helping families with strategies for increasing community inclusion. Community inclusion, natural supports and generic community resources are becoming increasingly important given the workforce challenges in Alberta.

If you have individualized funding today it is possible in the near future you will be asked if you would like to continue with that choice. If you currently do not have individualized funding, you might want to learn if this funding option would work best for your son or daughter. If you are the parent of a child with developmental disabilities you need to become involved or there is the risk this funding option will no longer be readily available when your son or daughter becomes an adult.

If you would like more information on the potential benefits of individualized funding as well as the challenges or the new resources being developed to empower and support families, please contact AACL. It is time for families to become informed and knowledgeable about their funding options or we risk seeing the further decline of individualized funding.

(Uditsky is the Chief Executive Officer of AACL.)

Leadership series a powerful source of challenge, renewal

What a difference one weekend can make, not to mention five! During a series of five sessions between fall and spring, 25 to 30 parents, including on occasion parents with developmental disabilities, find the energy, creativity and well of rejuvenation that fuels their commitment to create an inclusive life for their sons and daughters.

For the past eight years, the AACL has hosted an annual Leadership Series for families. The Series has gained national and international recognition. For some people new to the philosophy of inclusion, it is an experience that can shake the rationale for segregated placements. For others, it reinforces their belief that all people belong. For all participants, it offers connections with other families and they leave with the knowledge there is a network of support and strength.

“I was very dissatisfied with the life our son had had up to that point: special programs, special schools, treatment, all these things that kept him separate and apart from all other children and young people,” says Marg Meisner of Calgary, a leadership participant four years ago. Her initial connection with the Calgary Community Living Society was the spark that made her want to find out more about inclusion and community living. “David was frustrated, angry. He’d been treated badly in some segregated programs. When I started hearing how other people’s children were being included, I could see their lives were better and happier.”

She quickly realized by attending the AACL Leadership Series that inclusion for David wasn’t a matter of merely changing the kind of support for her son. It meant she had to examine her son from a new perspective. And it wasn’t easy to switch gears.

“I’d always been told inclusion wouldn’t work for David. He was ‘too disabled.’ He was labeled as a ‘severe behaviour problem.’ At the Series, they challenged me to think differently. Even though I always felt that wasn’t who David was, it wasn’t easy to think differently. But they encouraged me to see him from a different perspective. I struggled, and I had lots of questions.”

“Even after the Series was over, I was skeptical but I did find the courage to take a few chances,” says Meisner. “We tried to join a hiking club, that didn’t work out so well but the next one, the Calgary Outdoor Club, turned out to be a fantastic experience that has lasted for about three and a half years.” So accustomed to years of rejection, excuses and statements like ‘wouldn’t your son be happier with his own kind?’ makes the welcome and acceptance her son receives in the community almost surreal. Now 26, he volunteers, has paying part-time jobs and a network of true (not paid) friends who like him.

And what about that ‘severe behaviour problem’ label?

“The behaviours? They just aren’t there any more,” she laughs. “He loves his life. It really was not easy, but [being challenged] made me a believer. It has made all the difference in David’s life and it’s really changed how I think and what I believe.”

Is everything perfect now? “The great thing about living in the community is that none of us is ever done. But now David is just a regular member of the community. He contributes and he’s respected for who he is and what he can do.”

Stella Yeung, an Edmonton nurse with two adult children, is a new participant in this spring’s Series. For her, too, inclusion and community living are new concepts after a history of segregation for her son Timothy, 25. Since the death of her husband and subsequent car accidents that left Stella with chronic pain, she has juggled looking after her family, returning to school, and teaching. For her, the Leadership Series (taken while on a leave of absence from the Faculty of Nursing) has given her a chance to connect with other families for the first time.

“It is so good to meet other families and talk to them about what they are doing,” says Stella. “It is my perception in the Chinese community, we might be lagging behind the general public in our attitudes about people with disabilities. Last year, in the Chinese community in Edmonton, we started a parent support group and what I have learned in the Leader-

ship Series will help other families.”

Lori Adamchick is the executive director of AACL and a facilitator in the Leadership Series. “During the Series, we have a lot of opportunities for parents to share their own stories in small groups,” she says. “We find that people come to learn but they also bring so much character and skill. Everyone comes thinking they’re not a leader; some are reluctant leaders, but because of their love for their children, they simply have had to stand up and speak. But they don’t always recognize it in themselves.”

For Stella, advocating for her son wasn’t because she saw herself as leadership material. She simply couldn’t allow his life to continue as it was.

“Because of my physical condition, I wasn’t able to look after Timothy at home. I couldn’t bear to find a group home so I built a duplex,” she explains. “So he lives there, and my mom, my daughter and I live next door. But the care provided wasn’t even safe. I tried to work to improve it, but it got worse and his behaviour regressed. He was becoming aggressive. [It did] tear at my heart. I started to do family managed support [by which families receive individualized funding and hire their own staff]. He’s getting very good care now. He’s much calmer. He’s 25 years old, he gets stubborn but he has mostly good days. Different things [happened] that I couldn’t bear to see it continue. If I had not done something, I couldn’t imagine what he would be like now.”

The Leadership Series and her connection with AACL has given her hope and strength to keep creating a good life for her son. “My eyes are open for more,” she says. “I think there are better options for Timothy.”

The Series, which features a different theme for each of the five weekends, was designed and facilitated by Bruce Uditsky, AACL Chief Executive Officer and a parent, and Dr. Anne Hughson, an associate professor from Community Rehabilitation & Disability Studies, University of Calgary. Many weekend sessions include internationally renowned guest speakers. AACL, with the support of Persons with Developmental Disabilities Provincial and Community Boards, Alberta Community Development and Alberta Children’s Services, covers all the costs including childcare.

(For more information on the Leadership Series, contact Lori Adamchick, ph: 403.717.0361; email: ladamchick@aacl.org)

Advocacy networks enhance family voices

Alberta is divided into six regions—Northwest, Northeast, Edmonton, Central, Calgary and South. AACL has developed a network of families, known as Family Voices, in each region to advocate regionally on behalf of children and adults with developmental disabilities. These networks work with school districts to improve inclusive education, with Child and Family Services Authorities to improve supports to families and with Persons with Developmental Disabilities Community Boards to improve supports to adults with developmental disabilities. Each network is supported by an AACL Family Voices Advocate; in this issue, we visit Edmonton and the Southern Region:

Edmonton Sandy Thurston, sthurston@aacl.org, Family Voices Edmonton, tel: 780.451.3055, Ext. 242; (toll free) 1.800.252.7556, Ext. 242; (fax) 780.453.5779; 11724 Kingsway Ave., Edmonton, AB T5G 0X5. Family Voices Edmonton is always looking for new families who are interested in becoming a united voice towards creating inclusive workplaces, schools and communities. We continue to work in partnership with PDD Edmonton and Region 6 Child and Family Services to improve supports for adults and children with developmental disabilities. Families representing Family Voices are also currently engaged in partnerships with Edmonton Public and Edmonton Catholic Separate School Districts. Parents meet on a regular basis with school district personnel to improve inclusive education across both school districts.

Southern Region Tina Fowler, Family Voices South Community Development Advocate, Lethbridge ACL, 527-6 Street South, Lethbridge, AB T1J 2E1, ph: 403.327.2911; fax 403.320.7054; email: tina.fowler@lethbridgeacl.ca. Our two co-chairs are Danielle Hanna, a parent in Lethbridge and Robin Miller, the family rep from Medicine Hat. On April 29, Dr. Tim Loreman presents on Inclusive Education and the Seven Pillars of Support with Colin Saby. The day-long event at Lethbridge College is presented by the Inclusive Education Parent Advisory Committee of the Lethbridge School District 51. Call the Lethbridge ACL at 403.327.2911.

Reg Peters Library

Visit www.aacl.org, search the on-line catalogue. Contact Lisa Snyder, ph: 780.451.3055 or email: library@aacl.org. Watch this column for featured resources in upcoming issues.

Employment through Rotary's 'community capacity' philosophy

"What do you doing for a living?" We've all asked and answered this question as we meet someone for the first time. Like it or not, it's a measure of our contribution to this society. Since 2000, it's a question that 75 people with developmental disabilities in Alberta can answer with confidence and pride. For nearly eight years now, a Rotary Club partnership has been a catalyst for bringing together employers and potential employees for the benefit of both.

From the first hire with one Rotary club and one employee in 2002, the Partnership now involves 23 Rotary Clubs in 10 communities and has generated 100 jobs. The Partnership has seen steady growth and has received national and international attention from other Rotarians. It was a natural fit, melding perfectly with 'the four-way test' Rotarians use when taking on an issue: 'Of the things we think, say or do, is it the truth? Is it fair to all concerned? Will it build goodwill and better friendships? Will it be beneficial to all concerned?'

Robin Acton, AACL Director of Community Initiatives and also a Rotarian, is responsible for the Rotary Partnership. But she emphasizes that this is not a

traditional job-finding program, perhaps the very reason it is working so well. It is very much a Rotary initiative and people with disabilities are seen less as 'disabled' people and more in terms of a new, untapped source of human resources.

"Rotary has an ethic of service above self and is committed to community," explains Acton. "This initiative is community capacity building, not just people getting jobs. What makes it different from employment initiatives we've seen is that it's about working with Rotary to harness the potential that exists between Rotary and the community."

Through this partnership, Rotarians seek and create employment opportunities for adults with developmental disabilities. Mentorship is provided by AACL and ongoing community support, where needed, is provided by community agencies.

Rotarian and AACL President Wendy McDonald was struck by a speech given by then Rotary International President Frank Devlyn who said the employment of people with disabilities was one of his presidential priorities.

"It was when my life as a Mom and a Rotarian 'collided,'" says McDonald. "The Partnership has turned out to be one of the most exciting projects for me. As a Rotarian it makes me proud that we are making a difference, not only in the lives of individuals with developmental disabilities, but also the positive impact it has on businesses. As a mom, it gives me hope that the employment struggle for my son won't be as difficult as it has been for others."

"The key to this partnership is that it provides access by businesspeople to a previously untapped human resource. In our current employee shortage, employers need to look at new sources of human resources," says Acton. "There are coordinators who work with the various Rotary clubs; their role is to support the club to find employment opportunities while building the capacity within Rotary so this is something they just do naturally. Some club members become employers themselves or they act as ambassadors to other business people outside Rotary to get



Employee Ryan Baehl with Glenn Fagnan, a partner in Midwest Communications and Vice President of Sales. "Participating in the Rotary Employment Partnership has had a huge positive impact on Ryan, his family and certainly on myself and all of our staff." Fagnan was the first employer in Alberta involved in the Rotary Partnership; Baehl was the first person to be hired. (Photo by Robin Acton)

them to think about potential employees in a different way.”

Acton says that Rotary members are business people who understand that people need employment. It is far better to present the concept as an employment issue, not a disability issue. “We don’t talk to Rotary Clubs as service providers. We speak to them as fellow Rotarians and parents,” Acton explains. “We talk about supporting people on the job to the same extent as other employees; we don’t use terms like ‘accommodating’ or ‘job carving.’ We don’t use that language with other employees. We try to break down the impression that people with disabilities need something different and unusual. That can set up immediate barriers when all we’re really talking about supporting an employee to do a good job.”

Partners include individual Rotary clubs and Provincial Persons with Developmental Disabilities (PDD) Community Boards and Program Branch. There are currently Rotary Partnerships in Edmonton, Lloydminster, Westlock, Athabasca, Barrhead, Whitecourt, Fort McMurray, Grande Prairie, Red Deer, and Lethbridge. Acton expects Calgary to be added during the next six months. Former Rotary International President, Frank Devlyn, has endorsed an award to be given in his name to participating clubs.

Having paid work is so important for people with developmental disabilities. We need jobs to earn a living, to pay our bills and to have a life. We need to have choices about the jobs that we do. We deserve a chance like anyone else. Getting a job is the hard part... We need people in the community to give us a chance and prove what we can do. Rotary helps to make new jobs happen.

– Jodi Reid, Edmonton

“Speaking as a parent, this Rotary initiative is changing the way employers and the community view people with disabilities,” says Acton. “As our children get older it becomes more apparent we need an open community. When our child is two, it’s easy to imagine you can provide everything they need. It gives families hope that there’s an open, nurturing and welcoming community where your son or daughter is welcomed as a person who can offer something to make the community a better place.”

(Acton, Director of Community Initiatives, lives in Lloydminster. For information, contact her at 780.808.0752; email: actonr@platinum.ca)

What’s new? Projects and partnerships

These are just a few of the projects and partnerships the AACL has underway. Watch future issues of *Connections* for more details.

Navigating an Inclusive Pathway: Utilizing Community Capacity and Natural Supports This project, in partnership with Persons with Developmental Disabilities (PDD) Program Branch and Calgary and South PDD Community Boards, will pilot the use of community-based navigators to assist families and individuals to pursue inclusive pathways into and through adulthood while capitalizing on community capacity and natural supports.

Increasing Access to Respite through Community Networking Calgary and Area Child and Family Services Authority is partnering with AACL on a project to explore innovative strategies to use community capacity and networking to generate increased access to respite for families in the broader community through community inclusion, recruitment of individuals to provide respite and the development of resources.

Multi-Cultural Leadership Development for Parents of Children with Developmental Disabilities With the support of a grant from the Edmonton Community Adult Learning Association and in partnership with the Multi-cultural Health Brokers Cooperative, AACL is including refugee and immigrant families and multi-cultural brokers from the Cooperative in its Family Leadership Series.

Family Managed Supports In partnership with the Northwest PDD Community Board and NW Family Voices, AACL will develop a regional resource centre so parents can access Family Managed Supports (where families receive funding from PDD to hire and direct their own staff in supporting their son or daughter with developmental disabilities). With the Calgary PDD Community Board, AACL is exploring the interests and needs of families in the Calgary region who are either now using Family Managed Supports or would be interested in doing so if additional resources were available to assist them.

Community Inclusion Initiative This national initiative, funded through Human Resources and Social Development Canada over the last eight years, currently funds AACL’s From Isolation to Inclusion project in partnership with the Multi-cultural Health Brokers Cooperative and our Inclusive Education Consultant who is available to consult and provide training to schools and teachers.



Ojas Joshi, music student Amira Kanji, and Akbar Kanji perform at the Student Activity Centre, King's University College. "Being a part of the Bachelor of Music program has allowed me to live the beauty I love so much: music, performance, and friendships," says Amira. "I am so thankful for this opportunity."

(Photo by Billie Chesley)

Music student shares passion, tunes, tea

Her musical gift warmed the crowd of fellow students, faculty and guests on a -40 degree day in February as Amira Kanji shared her East Indian musical traditions. The first-year King's University College student performed eight songs, explaining the language and meaning of each. She sang in three languages accompanied by her father Akbar Kanji on the harmonium and friend Ojas Joshi on the tabla, or drums. The crowd was not only invited to clap along, but also shared in the savoury samosas and chai tea provided by Amira's aunts. The "Noon Tunes" event each Friday during the lunch hour offers a venue for music students and guest performers. "One of the best things I love about being in university is that I get to study my passion. I love singing and performing and being in university has given me the opportunity to do many of these things," says Kanji. "When I am finished university, I know I will have gained not only valuable friendships, but skills that can spark my dream into reality. I hope to sing and act in Bollywood films one day. AAAC has helped

a number of people to live their dreams," she adds. "I have dreams, big dreams, and it is through the support I have received through AAAC that I am able to tap into a new reality for my life. Inclusive post-secondary education has meant the world to me." The King's University College in Edmonton, founded in 1979, has over 630 students enrolled in Bachelor of Arts, Bachelor of Science, Bachelor of Music, Bachelor of Commerce and Bachelor of Education programs. The King's attracts students of all ages from a variety of backgrounds. Potentially life-changing experiences like inclusion in post-secondary education demonstrate that relationships and life lessons are part of being fully and meaningfully included. Inclusion of students with developmental disabilities at King's University College fits with the school commitment to "academic excellence within a caring environment." For information on inclusive post-secondary opportunities, contact Trish Bowman, Director, Community Development, 1.800.272.7557, ext. 227; 780.451.3055, ext. 227; email: pbowman@aacl.org.

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