# Dialect



Newsmagazine of the Saskatchewan Association for Community Living

**Spring 2008** 



Sharon Pollard and Carol Borys of Weyburn spend some cherished time together working on a knitting project. The pair has known each other for 11 years and are, says Borys, "like family." Sharon just marked her milestone 65th birthday but is "still as sharp as ever. Even just a few years ago, she could dance for over two hours without ever sitting down. She used to be able to walk all over and keep up, but now we bought her a wheelchair last year because she got just too sore. Now, in the summer, she comes along. Sharon loves parties and dancing and waits all year for her birthday. She says it's always coming soon." See story page 5. (Photo by Jill Gervais)

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52nd Annual General Meeting & Conference Hilton Gardens Hotel, Saskatoon June 11 – 15

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# Saskatchewan Association for Community Living 2007-2008

# Dialect

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Our Mission

To ensure that those citizens of Saskatchewan who have intellectual disabilities are full, active and valued members of society and that they have worthwhile opportunities and choices in all aspects of daily life.

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# Keeping connected part of a good life in the community

Each year as I sit down to send my season's greetings the old fashioned way with pen in hand and boxes of cards beside me, I become frustrated. Many people whom I met and became friends with during my time at Valley View Centre have disappeared from my life.

Why, you ask? Because I am unable to stay in touch. I've not got their addresses on file anymore. When I have moved, and it's only been three times in the past 30 years, I have sent change of address cards to my friends or phoned them to let them know where I'm now living. No such thing has happened when my friends from VVC have moved to live in the community.

When I have contacted the Department of Community Resources (once Social Services), I've been told, "No, we can't give out addresses. It's confidential." My question then is, can I send these cards to your office and you address and mail them to my friends. Of course, we know the answer to that question.

Community living for people can be great, however I think that some of the smaller, practical and important things have to be considered. A card or a phone call is very important. Just ask me. I spent 368 days in the Fort San TB sanitarium way back in 1959-60. The letters and cards I received were most important. The people I've worked with and come to know while at Valley View Centre were informed of my new address and responded with mail, so important to my well being. I don't understand why old friends can't keep in touch. Why, when someone has a disability, it all becomes confidential and my friends are cut off from contact with people they knew way back when. Surely maintaining relationships and the simplest of human contact—a letter or phone call—is good for someone's emotional well being at no cost to the government! I hope if any of my old friends from Valley View days get *Dialect*, they'll get in touch with me.

Donna Fraser Box 179. Zealandia. SK SOL 3NO

# Strength lies in grassroots

As the recently elected President of CACL, I am truly honoured to be working with a national board and staff that have an unshakeable commitment to building full citizenship for all people who live with an intellectual disability.

My involvement in this movement began when my cousin was born over 50 years ago. My commitment has been reinforced and strengthened through my involvement with Community Living Associations in Alberta, Saskatchewan, Manitoba and now British Columbia, beginning in 1968. Over the years the vision and leadership of families and of individuals living with intellectual disabilities has inspired my thinking and served as a key reminder that our work, together with community advocates and



CACL President Bendina Miller

partner organizations, must be based on a foundation of moral courage.

As CACL moves into our 50th Anniversary year, we have the opportunity to celebrate the shared success of closing institutions, including children in neighborhood classrooms, individuals with intellectual disabilities being recognized in employment through appropriate wages, and through individuals being honoured and recognized as full citizens in our country. At the same time, I truly believe that we are at a critical point where we cannot take our achievements for granted. The recent public support for Robert Latimer, for instance, serves as a rallying cry reinforcing CACL's commitment to work in unison with families, individuals living with intellectual disabilities, community living associations, and all other organizations that share a respect for diversity and a commitment to inclusion and full citizenship for all.

As President, I look forward to continuing the legacy of national and international

leadership, which was obvious in the accomplishments of past boards and clearly exemplified by the work of our Past President Zuhy Sayeed. The power of the Community Living movement lies in engaging the grassroots of our communities in this important work. Together we can achieve our ultimate goal of full citizenship for all individuals. I look forward to working with each of you on this shared journey.

Bendina Miller, Invermere. British Columbia

(Bendina Miller is the Superintendent of Schools in School District No. 006 (Rocky Mountain), Invermere, BC. She has been a teacher and special education director in addition to other roles in the education system in Saskatchewan, Alberta and BC. She has also been a committed member of the Community Living movement. She was elected president of CACL in November 2007.)

# Latimer case a symptom of much bigger issue: CACL

The recent decision by the National Parole Board Appeal Division to grant day parole to Robert Latimer brings to an end one chapter in the story of how Canadian society addresses the vulnerability of citizens with disabilities. The Canadian Association for Community Living (CACL) strongly believes that the next chapter has to be about the place and worth of Canadians with disabilities who remain so vulnerable in their communities, says Michael Bach, Executive Vice-President.

The bigger issue is the vulnerability of people with significant disabilities and those who live with unremitting pain who may be perceived by others as 'suffering.' This isn't just a debate about Robert Latimer and his daughter Tracy. While this case has been a very public example of that vulnerability, it is now the time to have the broader discussion about the right of all people to live in safe and inclusive communities and the roles and responsibilities of individuals, communities and systems in ensuring respect for the equal integrity, value and worth of the lives of people with disabilities.

The Latimer case has provided a spotlight on public

opinion about this issue. The overwhelming public support for lenience and clemency for Latimer because of his daughter's disabilities and experience of pain begs many questions. Do Canadians place less value on the lives of people with disabilities and those who live with pain? Or is it that the majority can empathize more directly with those who support people with disabilities, rather than those who live with a disability and pain? While we continue to be disappointed that Mr. Latimer has not expressed remorse for the murder of his daughter, we see this as being symptomatic of the broader issue. We believe Tracy Latimer's life should pose a challenge to the apparent moral consensus among the majority of Canadians about whose lives should be counted as equally deserving of recognition and protection. It is time Canadians consider whether this majority consensus is justified, and think through its consequences in a society whose demographics are rapidly changing with the aging of the population and the growing proportion of those with disabilities and of those living with pain.

CACL hopes that as we go into the next chapter of this story, those who bring expertise and a strong voice to the

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#### Study finds population in nursing homes 'sizable' and younger

Dr. Lilian Thorpe, a psychiatrist and professor of clinical psychiatry at the University of Saskatchewan, says some attention must be paid to the findings of a recent study she did in Saskatoon Health Regional special care (nursing) homes. Thorpe has had a long interest in issues faced by people with intellectual disabilities as they age.

"Our objective was to assess the proportion, characteristics, and reasons for admission of people with childhood onset intellectual disabilities residing in special care homes in this region," explains Thorpe, who is also Chair, Section on Geriatric Psychiatry, Canadian Psychiatric Association. "We got ethics approvals, and nursing directors of all Saskatoon nursing homes identified residents with childhood onset intellectual disabilities. Data were collected in August compared with basic administrative data (age category, sex) for the entire special care home population during this time period.

Results showed that 7.1 per cent of nursing homes residents were identified as having intellectual disabilities, and that these people were younger at a mean age of 53.7 years compared to those without intellectual disabilities where the mean age bracket was 75-79. There was a greater proportion of males at 48 per cent than the overall nursing home population of 32.7 percent.

"We received consent to see detailed chart information for 82 of 102 residents with intellectual disabilities," Thorpe says. The length of stay ranged from one month to 35.7 years, with a mean of 10.6 years. The cause of intellectual disability was varied from, in order of highest incidence to lowest: unknown reasons, head injury after birth, fetal alcohol syndrome or

effects, birth/prenatal injury, and Down syndrome. In fact, Thorpe's study showed, people with Down syndrome are less likely to be admitted to nursing homes. The greatest behavioural problem was found to be refusal or resistance to care. Most residents with intellectual disability were admitted from the community because of high physical needs or situational issues, such as parents unable to care for the person, although contributing mental issues were also given.

"It's apparent that a sizable proportion of residents in special care homes have childhood onset intellectual disabilities," says Thorpe. "This group is younger and more likely to be male than the overall nursing home population. Younger ages at time of admission will likely have an impact on overall bed needs over time."

Dr. Thorpe suggested that the lack of appropriate community services to people with intellectual disabilities was directly responsible for the institutionalization of people with intellectual disabilities into nursing homes. She felt that, while deinstitutionalization of people with intellectual disabilities from institutions such as Valley View Centre is admirable, institutionalizing people with intellectual disabilities to other institutions such as nursing homes (which generally lack staff with appropriate training in working with people who have intellectual disabilities, have no developmentally appropriate programs and are more restrictive), is directly contrary to current community living philosophy and "is highly regrettable. Legal channels have been used successfully in the United States to limit this pattern, and perhaps this may become necessary in Canada as well."

# New L'Arche community first in Saskatchewan

It's been a long time in the works, but on February 15th, the first core L'Arche member, Laura, moved into her new renovated home. The next day at a small gathering, the house was named Christopher House. In the coming months a house warming will be held when other core members Brian, Cody and Lindsay and additional assistants will move in.

"It has been a long and rewarding process, with much learning to 'be with' rather than 'doing for,' and of deepening our relationships with so many really neat people with developmental disabilities and their families," says Margaret Sanche who, along with her husband Robert, are founding members. The Sanches were part of the original Led by the Spirit committee which began working over ten years ago to bring L'Arche to Saskatoon. The L'Arche name could only be used after the group was officially been accepted as a L'Arche project in 2004.

Two assistants were hired in September and, after spending the first couple of weeks in Saskatoon, they were sent to other L'Arche communities for training while house renovations were carried out. Laurie received training at L'Arche Lethbridge to become the house leader, and the other assistant, Vlad, spent time in training at L'Arche Calgary. Both moved back to

Saskatoon early in February to prepare to welcome the first core member. With the opening of its first home, Saskatoon has now applied to become a probationary community in the Federation of L'Arche, the first in Saskatchewan. The Friends of L'Arche community holds monthly Gatherings and ecumenical prayer nights. In January, the Western Canada Regional Council, consisting of the Community Leaders from L'Arche communities in Comox Valley, Greater Vancouver, Edmonton, Calgary, Lethbridge and Winnipeg plus L'Arche Saskatoon Project, with Regional Coordinator Pat Favaro and Vice-Regional Coordinator Landys Klyne, met in Saskatoon.

"It seems that L'Arche has already begun to be much more than the home and the small group of people who will live there, though that will certainly be at the heart of what we do," Sanche says. "We look forward to seeing where this will go in some new and interesting ways in our city."

(To become a volunteer, assistant or financial supporter, or part of the Friends of L'Arche community, contact Wyndham Thiessen, ph: (306) 262-7243; e-mail: wthiessen@larchesaskatoon.org or see www.larchesaskatoon.org. L'Arche Saskatoon is a registered charitable organization. See related photos page 11.)

# Weyburn senior practices positive thinking

By Jill Gervais

When I began working at the Weyburn Group Homes Society in June 2005, I assumed I'd have a decent job just until the end of summer. I didn't realize that I would love it so much, three years later I would still here. I began taking University of Regina classes by correspondence, commuting back and forth rather than moving back to Regina. I wanted to stay with the people I'd grown so attached to. The Eighth Street group home staff are genuinely compassionate and supportive of the residents who live there and the residents themselves are amazing and unique. One of those people is Sharon Pollard.

One of the originals, 65-year-old Sharon, has become a close friend. I knew when I met her that she was gentle, sweet, and good-natured. She has the kind of smile that makes it impossible not to smile back. As she tilts her head and thousands of well-worn wrinkles appear, it's obvious that she has spent her life capturing hearts with that smile. She's sweet and endearing, but unlike the stereotypes about people with Down syndrome, she knows exactly what she wants and when she wants it. She is clear about which people are 'buddies' and which she would rather avoid. She loves to please other people, but will ultimately make choices for herself. When I suggest she wear her warmer socks, she relents. However, within minutes, she has returned to her room to put on the brighter, fancier socks she started with. As I help her comb her soft white hair, she smiles and says it looks okay. She goes to her room and moments later, she has recombed it to her specifications.

The youngest of four children, Sharon was born in 1943 in southeast Saskatchewan and lived on a farm with her parents, siblings Carol, Jeanie and Dean, all of whom are much older. In 1961 when she was 18, Sharon went to Valley View Centre in Moose Jaw where she stayed for the next 14 years. In 1975, she went into the Weyburn Rehab Unit and then an approved private care home. Finally, Sharon found a place at the Weyburn Group Homes Society. Bernice Erickson, Executive Director of the Society, has known Sharon for



Sharon visits with the house budgie at the special care home where she goes for activities with other seniors once a week. The other senior ladies "respect her and look out for her."

23 years and says that, while she's starting to slow down, she "still makes the most of every day."

"I think if everyone's day could start with a hug and a smile from Sharon, we would sail through the day without a care in the world," says Bernice. "Sharon's family is a blessing to her, she loves them dearly. She's a real optimist; we should all have a little of Sharon's demeanor."

## **Sharon says**

Interview by Jill Gervais

Did you ever go to school? No, I don't go to school.

Where did you live? I live Pangman. Grow up on farm. Jeanie, Sister Mary, Brother Dean. Mommy and Daddy dead

How did you help on the farm? Sweep. Help Jeanie do dishes. Help Dean do eggs.

Did you live in Valley View? *Didn't go there. Nope.* 

What do you want to say about Carol? Best friend Borys. Take me to Regina. She's my buddy. Love Borys. I just like her too much. Miss her.

Favorite colour: Red, sometimes black.

Do you go to (Easter Seal) camp? No, I don't go to camp. No, I don't like camp.

What do you like to do? Sit in rocking chair. Knit. Vacuum, clean. Make a bed. I like vests. Christmas presents. Santa Claus. I like socks. Summertime. Spring time. I like it. Borys. it's my buddy. I like her so much. Justine, friends. Miss her, In the hospital. She's okay.

Mom and Dad are in heaven? Yes. Heaven nice.

What made you live so long? *Not too long.* 

Do you want to go to heaven? Nah. Nah... you can go.

Well, then where do you want to go? Right here. (Sharon's friend Audrey died at work, the summer before last) Audrey pass away. She fall down. Pass away. Cry. (Sharon's friend Johnny died shortly after Audrey.) Johnny died too. Felt funny. Goodbye to him.

Do you like living here? *Like it here, like group home. Get along. Like Borys.* 

What do you like about birthdays? Chocolate cake. Help Carol cake. Chicken. Party right here. Dancing. Birthday coming soon.

#### **Ask Us**

In this ongoing column, a question received from a parent, family member or person with an intellectual disability is featured in each Dialect issue. In this issue, SACL Research Advocate Dionne Miazdyck-Shield offers information on income support and the goals of the Disability Income Support Coalition (DISC). If you have a question, provide your name, contact information and whether you are willing to let your question be published. Send to the Dialect editor, c/o SACL, 3031 Louise Street, Saskatoon, SK, S7J 3L1; fax (306) 373-3070, or email: Karin.schwier@mac.com.

**Q.** It seems like a lot of people with disabilities are locked into the welfare system as their only means of financial support. They are penalized for earning any income or having assets and sometimes they are even at risk of losing assistance. Isn't there a better system than that?

**A.** Yes. Income support systems in other provinces and countries have done more to meet the unique needs of people with disabilities. In Saskatchewan, people with disabilities are forced to rely on a welfare-based system that is insufficient and degrading and was never meant to meet their needs on a long-term basis.

The SACL is a member of the Saskatchewan Disability Income Support Coalition. DISC was formed by a broad cross section of disability advocates, consumers and organizations. We have joined to speak as one voice and advocate for a distinct, person-centred and adequate income program for people with disabilities instead of welfare. DISC maintains that an adequate baseline income will eliminate many of the impacts of disability that people face, the greatest of which is often poverty.

DISC has been raising awareness, helping the public understand the sobering statistics about Saskatchewan's social assistance system. In recent radio public service spots, they're learning it's a matter of citizenship and dignity:

Seventy-seven per cent of people on the long term social assistance caseload have disabilities. It's not their fault. And what's more shocking is they often have to live without dental care, non-prescription drugs and, sometimes even food. Social assistance shouldn't be a life sentence and the Disability Income Support Coalition needs your help in creating a separate, more dignified program for people with disabilities. Make an issue out of this. Contact your candidates about this injustice. For more information, call 1-877-569-3111.

**The Issue:** Saskatchewan's current welfare system allows only for the most basic, below subsistence level of support, condemning people with disabilities to live far below the poverty line–over 50% below–some for their whole adult lives. Although social assistance was created to be a last

resort, temporary program, it in fact has become a default program and a permanent reality for many citizens who have disabilities. The majority of people with disabilities do not receive CPP disability pensions. They depend on social assistance as their only form of income. A recent Government of Saskatchewan report reviewing the long-term "static" caseload demonstrates that the



Dionne Miazdyck-Shield, SACL Research Advocate

vast majority left on welfare are people with disabilities, a fact that proves the need for real, substantive change.

The vast majority of people with disabilities whom DISC recently surveyed felt stigmatized by having to be on social assistance and not receive enough money to meet their basic needs for food, rent, medication, or transportation. What they are asking for is to have a life that is not defined by basic economic survival, a life that is free of stigma and to be valued as full citizens. As well, individual responses to DISC surveys and reports from advocates indicate the social assistance system is inconsistent and difficult to navigate.

On a large scale, the labour market has yet to learn the meaning of accommodation, leaving people with disabilities with little opportunity to be self-supporting. When people with disabilities do find work that is flexible to meet their needs, it is often insecure, poorly paid, and lack benefits that are essential. As well, there are many who legitimately cannot work in paid, competitive employment. For these reasons, a disability income program is not a handout, it is a reasonable accommodation for those whom the economy permanently keeps out.

**Our Position:** Individuals with disabilities are turning to community organizations and other agencies seeking help to deal both with the current crisis of rising costs and falling further behind, and to affect meaningful change. DISC members believe that it is time that we move this agenda along.

DISC maintains that people with disabilities have the right to adequate, respectful income support delivered with the assistance of income workers who have the mandate and discretionary power to respond quickly to individual, discreet needs. People with disabilities deserve to have an adequate income to truly meet their needs, both disability specific and economic. A new income system for people with disabilities must be user-friendly, flexible,

accommodating, respectful and must allow them to participate in the labour market without extreme penalty.

Through our own research, DISC members have gained a deeper knowledge of the complexity, and yet the simplicity, involved in creating a new income system. Yet we remain committed and determined that this is a realistic and

reasonable policy proposal. Moreover, it is the right thing to do.

We need the help of people with disabilities and families to create a separate, more dignified program. Make an issue out of this. Contact your MLA about this injustice. Call 1-877-569-3111 or the SACL (306) 955-3344.

#### Larson takes on vice role

Laurie Larson, SACL President, was elected Vice President of the Canadian Association for Community Living (CACL) at the 2007 national conference.

"CACL is honoured to congratulate Laurie Larson on her election as Vice President," says Bendina Miller, CACL President. "As a parent and President of SACL, Laurie brings a deep understanding of the critical role of families and of people with intellectual disabilities in moving forward on disability issues. We value Laurie's leadership on deinstitutionalization, inclusive education and support for families and individuals—all areas of specific focus in the national work of CACL."

"I am excited to be working for social change at a national level. It is an honour," says Larson. "The reason I chose to run for Vice President is that CACL will allow me to actively work for the day that my sons and all people with intellectual disabilities in Canada have the opportunities, accommodations and acceptance they deserve. People in Canada understand diversity, so I believe our message of full inclusion for people with intellectual disabilities resonates with Canadians."

Judy McLaughlin of Saskatoon is serving on the national board as a director; Zuhy Sayeed of Lloydminster, Alberta/ Saskatchewan is now the Past President.

CACL is a Canada-wide association of family members and others working for the benefit of persons of all ages who have an intellectual disability. Founded in 1958 by parents of children with intellectual disabilities who wanted supports and services within the community instead of in institutions, CACL has become one of Canada's ten largest charitable organizations, and has grown into a federation of 10 provincial and three territorial associations comprised of 420 local associations and over 40,000 members. The work that CACL does for people with intellectual disabilities and their families is guided by the following principles: respect, dignity, equality, diversity, human rights, justice, self-determination, mutual responsibility, inclusion, and moral courage.



During a meeting of the Grassroots Steering Committee in January, Member of Parliament Lynn Yelich (Blackstrap) had lunch with those responsible for the federal Community Inclusion Initiative in Saskatchewan. SACL President Laurie Larson, Biggar, described the Family Network; Leanne Madsen of Estevan explained the work of the Self-Advocacy Action Group. Back, left to right: SACL Executive Director Faith Bodnar, Lisa Malowany, Bluesette Campbell, Yelich, Don Gallant, Larson, Sheila Gagne, SACL Past President Judy McLaughlin. Front, left to right: Marlene Dray, Madsen and Judy Hannah, Grassroots coordinator, who said "the Association likes to take every opportunity possible both in formal meetings and less formal gatherings to provide information about community inclusion to local, provincial and national politicians and other decision-makers."

#### New PLAN coordinator named

In January, Brenda McMullen joined Planned Lifetime Advocacy Network (PLAN) in Regina. McMullen's background as a personnel manager at Zellers for 18 years and as a store manager for Rogers Video for 12 years gives her the experience for PLAN coordination. Her son Robert lives and works in Ottawa as a sous chef and "is a wonderful young man and fabulous cook." McMullen is making contact with all PLAN members and says, "I bring enthusiasm and I'm looking forward to making a difference in their lives."

## **Noteworthy**



Edna Williams

Two women dedicated to the work of the SACL and other organizations in Saskatchewan, both parents of daughters with intellectual disabilities, have died. Edna Williams became active with what was then the SAMR in the mid-50s and worked closely with Dr. John Dolan and other founding parents. She served as president from 1968-71 and served on the Board

of Directors, as well as with Cosmopolitan Industries for many years. She was very active in the development of the Prevention Institute and the Alvin Buckwold Centre. Former SACL Executive Director Charles Fox, who now lives in Las Vegas, Nevada, recalls working with Edna during his time with the Association. "While Edna never believed her daughter Melodie could have a life outside of Valley View Centre, the seeds of change were sown by her connection to Dr. Dolan and the SAMR," Fox told *Dialect*. "She definitely was a pioneer and did contribute to the philosophy of community living despite her 'but it's not for Melodie' feelings. She was also really good at reminding some of us of the struggles that parents went through in trying to cope with the lack of services for their sons and daughters in the early years. To me, her biggest contribution was her constant attempt to remind older parents of the importance of the Association and what it stood for." Edna died in November at the age of 85 years. Another parent who was involved in SACL for many years, **Agnes Bourassa**, had a houseful of children in Estevan; her youngest, Alyson, had Down syndrome and she set her mother off on a journey to improve the medical and educational systems. When Red Bourassa died, Agnes moved to Saskatoon in the hope for more opportunity for Alyson. A board member for many years, with SACL and Special Olympics, Agnes was always a quiet but determined volunteer with the Association. She died at the age of 80.

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 U of A, welcome suggestions on how to make it a better and more useful site. Visit:

http://www.ualberta.ca/~initativ/Welcome.html.

In January, the **Canadian Transportation Agency** (CTA) released a **landmark decision** concerning the right of individuals with disabilities to travel by air without having to pay for a second seat, for an attendant or other use, to accommodate their disability. In a historic decision in the "One Person, One Fare" case, the agency has recognized the right of these individuals to have access to a second seat when traveling by air in Canada without having to pay a second fare. "Canadians with disabilities are celebrating today," said Pat Danforth, Chairperson of the Council of Canadians with Disabilities Transportation Committee. For many years, Canadians with disabilities traveling by train, bus or marine service have been permitted to use a second seat without cost when one was required. But airlines such as Air Canada, Westjet, and Jazz have not been bound to obey this policy.

**Rhonda Grant** of Regina, Vice Chair and Krista Flint, Executive Director, Canadian Down Syndrome Society (CDSS) wrote a reaction to the Society of Obstetricians and Gynecologists (SOGC) 2007 guidelines which recommend all pregnant Canadian women, regardless of age, be offered prenatal screening for genetic differences. The CDSS was alarmed by the tone and language used in these broad-based and unbalanced recommendations for all women regardless of maternal age. Following dialogue between the CDSS and the SOGG and media coverage on the issue, the SOGC invited the CDSS to write a commentary on its recommendations for new guidelines. The piece focuses on the importance of the provision of current, accurate, fair and balanced information which describes not just the challenges of a life with Down syndrome but as importantly the rich and rewarding lives possible for people with developmental disabilities in Canada. The SACL and the Saskatchewan Down Syndrome Society issued a joint release expressing concerns about the SOGC guidelines.

To support the **self-advocacy movement of people with disabilities in Kosovo**, a province of Serbia, the **Kosovo Mental Disability Rights Initiative** (K-MDRI) assisted the **Ne Per Ne peer support group** members to understand and participate in Kosovo's historic winter elections. Ne Per Ne, which means We for Ourselves, is Eastern Europe's largest peer support group for persons with intellectual disabilities, started by MDRI. In preparation for Kosovo's November elections, the peer support group invited representatives of the major political parties to discuss the importance of the elections and the issues that would affect them. Participants asked questions like, "What are you going to do regarding jobs for people with disabilities?" Approximately 90 per cent of the peer support group members voted for the first time in their lives in Kosovo's elections to choose national and municipal assembly members and mayors.

At least **53 people were killed in Baghdad** in February when two women carried explosive devices into separate crowded pet markets. The day marked the worst bloodshed in the Iraqi capital in six months. **Both women had Down syndrome** and the bombs that were strapped to them were detonated by remote control, the Associated Press said, citing the Iraqi military. The U.S., blaming al-Qaeda for the bombings, said the attacks underscore "the absolute bankruptcy and brutality of the enemy of the people of Iraq who would do such a thing," U.S. Secretary of State Condoleezza Rice spoke to reporters following the incidents.

The father-son team of **Shane and Tyler Haddad** have made some local history in Regina as the **first dad and son to play floor hockey on the same team.** They proudly traveled to the Canadian Special Olympics Winter Games earlier this year in Quebec City. Shane, 45, and Tyler, 17, were profiled in a very positive feature story in the *Regina Leader-Post*. Shane is the president of People First of Canada and is Vice-President of SACL. Tyler goes to Cochrane High School where he is a peer counselor. Watching his parents Shane and Brenda, both strong self-advocates, has made Tyler go the same route. "I've seen my mom and dad help a lot of people," he told reporter Murray McCormick, "and I want to do that, too." The Haddads have two other children: Matthew and Whitney.

There have been a number of provincial **SACL and Employment Opportunities staff changes. Maureen O'Hara Jolly** is the coodinator of the SACI's Individualized Funding/Individualized Funding Supports project. For information on this project and how people with disabilities and families can benefit, check the feature in the Fall/ Winter 2007 *Dialect* issue or download at www.sacl.org, click on Information Resources, then Dialect. Jeannine **Harlton** moved into the Saskatoon Advocate position previously filled by O'Hara-Jolly. Employment Opportunities provincial coordinator James Sanheim reports that Career and Employment Services did not renew funding, so the **Kindersley EO office has closed.** "SACL will continue to provide some support to individuals in that area through our EO consultant in Saskatoon, a position to be filled this spring." **Megan Wells**, who is a support to Best Buddies, is the coordinator Kids on the Block and the youth initiative while Christine Flynne-Boyle is on maternity leave with baby Indira. **Erin Lengyel** is the new Administrative assistant while Shannon Davies is also doing at-home parent duty with new son Kieran. Congratulations to the new parents! **Lynne Harley** is heading up the Saskatchewan Self-Advocacy Action Group. Two 12-year veteran staff members have made career changes recently; the librarian of the John Dolan Resource Centre, Lalita Martfeld has moved on and will be devoting her energies to building a more independent life for her son Jesse. A mainstay of the annual car lottery campaign and other fundraising initiatives, **Laurie Whitta** will be taking on a similar role in fundraising with the Abilities Council.

**Regina and District ACL holds annual meeting** The Regina branch of the SACL will review its new strategic plan on Saturday, April 26<sup>th</sup>. For information, contact RDACL, (306) 790-5680 or email: rdacl@sasktel.net.

**Inclusion promoters honoured** Recent award winners at the RDACI's Celebration of Inclusion in the fall are: for the Real Work Award: Doug Mortin of Mortin, Glabus and Putz; Honourable Mention: Gerrand Rath Johnson; Community Builder: Chris Hamilton, Best Buddies Blues Band, Class Act Performing Studio; Service Provider: Judge Bryant School, University of Regina's Faculty of Education; Inclusive Community Media: Regina *Leader Post*; Promoting Inclusion: Saskatchewan Down Syndrome Society Sprout Film Festival; Distinguished Member Service: Lill Lareau, Don Thibault.

People First of Saskatchewan has new blog

Diane Otterbein, a support person for People First of Saskatchewan, says the members are happy to announce their blog. They invite people to have a look and offer any feedback: http://peoplefirstsk.blogspot.com/.

**Condolences** from the Association go to former **SACL President Dale Ebert** and his family upon the death of his wife Neila. The funeral was held Friday, February 15<sup>th</sup>. Ebert was the 20th president of the Association. He lives in Prince Albert.

The **Early Childhood Intervention Program** (ECIP) Saskatchewan Inc. is **celebrating 25 years.** A commemorative book, *Toy Box Angels: A Collection of ECIP Family Stories*, is available for \$14.95. Ph: (306) 789-3637 to get your copy, or visit www.saskecip.org.

# Have you signed the Declaration of Support for Community Living?



More than 10,000 people with developmental and intellectual disabilities across Canada remain excluded in large segregated institutions. Sign the Declaration of Support for Community Living and show your commitment to community living for everyone.

Visit: www.institutionwatch.ca and sign the Declaration now.

## Storefront adds personal touch to clothing donations

In a day of email, voice mail, message managers and automated everything, it's nice to be able to talk to a person who thanks you for a donation in support of people with intellectual disabilities. That's the sense that

Jackie McCaig, General Manager, Saskatchewan Institute on Community Living, is getting since the institute opened a storefront "donation station."

"People have been very pleased," says McCaig.
"I think it makes a big difference when you are handing your donation to a live person. That human touch is something I think people really appreciate in today's technological world. When you always have to deal with voice messages and automated everything, people are even

surprised when they call here and get a live person, no voice mail. When donors come in, our staff are so friendly, we know they'll be back."

The Institute, SACI's fundraising arm that collections donations of used clothing and other quality items

which are then sold to Value Village, decided to offer the storefront dropoff location as another option for donors. McCaig says the location in the Avalon Shopping Centre, 5-2605 Broadway Avenue in Saskatoon, accepts



The SICL "donation station" located in the Avalon Shopping Centre in Saskatoon now features on its walls "the faces of people we're here for." Donors who bring clothing and small household items in are welcomed by longtime SICL staff Irene, who has been with the Institute for 18 years. Michelle, a two-year veteran, is also on hand to accept donations.

clothing and small household items. If people want an actual pick up at their door, they can still call (306) 477-2171 to arrange for a date. There are still drop bins locationed in various locations in the province.

Current hours for the Avalon dropoff location are Monday to Friday, 9:00 a.m.-5:30 p.m. and Saturday, 8:00 a.m.-4:30 p.m.

McCaig says there's been a marked increase in donations for this time of

year and once spring cleaning is really underway, "who knows what will happen!" For more information about SICL, drop bin locations and how SICL supports people with intellectual disabilities, visit www.communitylivingpickup.ca

# Students proud in new North Battleford college community

"I like coming here. I like the college experience. It's a great place to meet people." Jen O'Hanlon is one of ten people with disabilities in North Batlteford for whom the idea of going to college isn't some dream that only happens to someone else. It's a life-changing reality that's making difference in community perception and in the students' view of themselves. Career Connections is the newest post-secondary opportunity that is making college life a real possibility.

"We started out with four students but it quickly filled to the capacity of ten," says Janice Henry, SACI's Employment Opportunities Consultant based in Prince Albert. Henry has been involved in the program since it began in the fall. The 38-week program runs until October 31. "The students are really loving the learning environment and have a great relationship with their instructor and coach," adds Henry. "It's great to see how proud the students are of being college students. Most



Students in Career Connections

of them wouldn't have likely had the opportunity to go to community college, so they are really excited about this."

# **Knowing someone with Down syndrome seems to make** the difference in attitudes

By Dr. Karen Lawson

Raising children is a task that brings many personal rewards and challenges. However, a lot of research has focused on the extra costs that might be involved in parenting children with a disability, and has often neglected to look at the rewards. When asked, it seems that most people without any personal familiarity with anyone with Down syndrome assume this parenting experience is not a rewarding one. It doesn't stop there.

Research is showing that these negative views give strong indications about what people would do if prenatal testing showed Down syndrome in the fetus. Specifically, people who assume that parenting a child with Down syndrome is unrewarding are more likely to consider selective abortion. Given this link, we thought it important to begin to investigate the accuracy of these societal perceptions, and our first step was to see how they correspond to the views of parents whose children have Down syndrome.

In our study we asked parents raising a child with Down syndrome to complete an on-line survey to answer detailed questions about their parenting experiences and their relationship with their child with Down syndrome. Specifically the survey measured various aspects of parenting including such experiences as happiness, pride, less leisure time, strained relationships, responsibility for care, financial, emotional and physical costs, family continuity, and perceived emotional and financial

support from friends and family. We also asked parents how their experiences compared with their expectations of parenting and satisfaction with parenting. In all, 13 parents completed the survey and I want to thank them for their participation. This is a small number, but this pilot study provides the foundation for a larger scale study in which we hope to recruit a national sample of parents. Forty-nine members of the general community with no familiarity with people who have Down syndrome also completed the majority of the survey in terms of what they expected parenting a child with this disability.

The results show parents raising a child with Down syndrome find the experience to be much more rewarding than people from the general community expect. Parents of a child with this disability say it is personally enriching and involves slightly fewer personal costs than the community participants assume. Neither group said that they would be likely to abort following a prenatal diagnosis of intellectual disability in the event of a future pregnancy. However, while the majority of the community participants stated that they were uncertain about what they'd do, the parents overwhelmingly indicated that they would probably or definitely not opt for a selective abortion. Simply put, people who believe that raising a child with Down syndrome is more personally rewarding are less likely to consider selective abortion. In line with past research, the associated

Continued on page 19

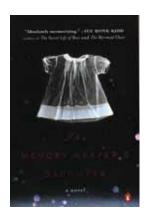


Marilyn Morrison, left, Diane Bain, and Melanie Harriman break bread at a Friends of L'Arche gathering.



Beside Doug Morrison, Charlotte Topping strikes a pose while Henry Thiessen warms Martha Crealock's lap at a recent L'Arche gathering. Henry's dad, Wyndham, is the executive director of L'Arche. The first L'Arche home in Saskatchewan opened at 503 Christopher Lane in Saskatoon in February. The local community is applying for membership in the L'Arche International Federation and if successful, this will be ratified by the International Board in Ukraine.

# On the Shelf Reviews by Karin Melberg Schwier



**The Memory Keeper's Daughter,** by Kim Edwards. New York: Penguin, 2005.

As someone concerned about inclusion and belonging for a stepson who has Down syndrome, it's hard to read fiction or see a movie that has to do with intellectual disability–especially Down syndrome–without being hyper-critical. This novel features a storyline familiar to many families of a previous era: a child is born

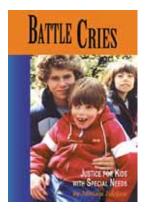
in 1964 and her father, to spare his wife the grief and with the best of intentions, makes an agonizing decision to institutionalize.

The characters and storyline ring true without maudlin sentimentality or the 'superhero' persona that sometimes plagues both fiction and non-fiction involving disability. When I read an interview with author Kim Edwards, I realized there was a good reason for that. Besides being a strong writer who can create and develop believable, rich characters and vivid scenes, this story had its beginnings in truth.

A member of Edwards' church told her about a man who'd found out that his brother, born with Down syndrome, had been put away in an institution. His existence was kept secret, even his own mother didn't know. "It was the secret at the centre of the family that intrigued me," Edwards said, but it wasn't until years later, when she was invited to do a writing workshop for adults with intellectual disabilities, that the story idea surfaced again. She thought about that abandoned baby who had grown up and died in the institution without ever knowing his family. When she finally got around to writing the first chapter, it "came swiftly, almost fully formed, that initial seed having grown tall while I wasn't really paying attention." Concerned about her own lack of experience with people who have disabilities and how that would affect the characters she created, she met with parents and people with Down syndrome, including those born in the '60s. "To create a convincing character [in Phoebe], one who was herself and not a stereotype, without being either sentimental or patronizing, seemed a daunting task," Edwards says in the meet the author' section of the book.

Readers like me need to remind themselves this story is set in a time when the idea of life in a group home and a sheltered workshop was a fantastic dream for someone with Down syndrome. I found myself wishing Edwards had written a more fully independent and involved life for Phoebe in the end. But I quibble; that was the era. More importantly, *The Memory Keeper's Daughter* is simply a very good story, with split-second decisions that change

the course of lives, with deception, family secrets, hope, redemption and how a family–even a broken one–can heal and support all its members.



**Battle Cries: Justice for Kids** with Special Needs, by Miriam Edelson. Toronto: Sumach Press, 2005

What struck me within the first few pages of Miriam Edelson's book is that her son Jake is dead. She could have just let her commitment to build a better community for her son slide. It takes a lot of emotional energy to be an advocate for social justice; without her raison d'etre, it would

be easier to go back to the "old" life she had before her son was born. For Edelson, however, the justice she sought for Jake is not any different from the society she is determined to create for other families. And so, even though it had only been a few months since her son's death just shy of his 14th birthday, she decided to finish *Battle Cries*.

This book is packed with a lot of information, observations and suggestions for families. She writes, "like so many other parents of children with disabilities, I envisage a society where children now most typically defined by their difference and discriminated against for it would instead enjoy lives characterized by comfort, dignity and childappropriate physical, cognitive and creative stimulation."

Battle Cries is a dense book. The cover is compelling and the Portraits section with accompanying photographs is more reader-friendly. The book is a hybrid of a parent's personal perspective and social observations, and an academic paper, particularly when Edelson describes her research methodology.

As a parent I kept finding myself wanting to read the personal stories about families in the "Portraits" section, wanting to meet those people first before wading into the more complex array issues examined in the first section. Edelson provides a section called "Meeting the Main Characters: A Collection of Snapshots," each of which describes the families we meet later. Perhaps it is just a personal preference, but I wanted to meet the families first and then learn about the availability of and impediments to current services and supports available to them.

Topics like strategic concerns of community living, social models of disability and inclusion, ethics of care, social policy development, funding structures, physician/parent relationships, continuity of care and so on are all important issues, but make for daunting reading. I found the "Portraits" section and the final chapters, "Reflection: Drawing Some Conclusions" and "Some Tips About

Advocacy: Finding Services and Seeking Support," much easier to digest. However, no one said advocacy was easy, so readers need to take the time necessary to pore through the issues and perspectives.

It is interesting to note a different historical perspective on how and when the "disability movement" began. Edelson suggests it "emerged in Great Britain, the United States and Canada during the 1970s to voice opposition to discriminatory treatment of disabled persons by medical personnel and the rest of society." Yet, this is nearly 20 years after some of the first Associations for Community Living (then commonly called Associations for Retarded Children) were formed by parents in Canada and elsewhere. These were formed in response to the absence of educational opportunities and because of pressure to institutionalize children with intellectual disabilities as the only option for family support.

Nonetheless, Edelson gives a thorough view of history and the development of services, supports and attitudes for and about people with disabilities, integration and segregation. Edelson says that the issues discussed in the first section of the book stem directly from the experiences of the families she profiles in the second. She is not beyond editorializing, however, and making her own personal observations: "The very spokespersons for community living who are demanding that difference be recognized and accommodated are sometimes intolerant of those who choose to make different decisions."

One of the final chapters, "Some Tips About Advocacy: Finding Services and Seeking Support" is very practical and useful for families regardless of what their philosophical foundation might be. Every parent should have this chapter to use as a guideline no matter what their circumstances or what they are lobbying for. "Celebrate your small victories together," Edelson advises families, "and then move on to the next challenge." It would seem this book is a celebration Edelson shares with the memory of her son, and in doing so has offered a great deal for other parents to think about.

(This review first appeared in the International Journal of Disability, Community and Rehabilitation, Vol. 5, No. 1. 2006, www.ijdcr.ca and is reprinted with permission. These

Inclusion is more than 9-3

Discussion Givide

books and many other resources are available from the SACL's John Dolan Resource Centre, 3031 Louise Street, Saskatoon, SK, S7J 3L1. You may also browse the holdings on line by visiting: www.sacl.org.)

# Inclusion is more than 9-3, Discussion Guide

Saskatoon, SK: SACL, 2007

The SACL Fusion Inclusion Youth Group and the Self-Advocacy

Action Group (SAAG) have joined to produce a guide to aid in the conversations around belonging and inclusion in school. The aim of the guide is to spread the message that inclusion is "more than just a buddy program."

"We believe that...inclusion is when enough space is created for everyone to participate and contribute their gifts to the community," proclaim the authors of the Guide. The booklet is a colourful and vibrant publication that includes thoughts on the Power of Words, language to consider, activities and games for awareness, facilitation tips, exercises, and personal stories by young people who have disabilities. And you'll want to read about The Donut Theory!

(For copies of the Discussion Guide, contact the SACL, 3031 Louise St., Saskatoon, SK S7J 3L1, ph: (306) 955-3344; to order the Inclusion is more than 9-3 video, contact Education Media Access and Production (EMAP), University of Saskatchewan, 28 Campus Drive, Rm 38, Education Bldg., Saskatoon, SK S7N 0X1, ph: (306) 966-4261; fax (306) 966-2412; email: media.access @usask.ca.)

School to Life Transition Handbook: 5 Steps to Successful Planning, Revised edition, 2007. Saskatoon, SK: SACL.

Kelly Cotter, a young woman with a disability, has written a personal perspective at the beginning of the SACL's revised and updated School to Life Transitions Handbook: 5 Steps to Successful Planning. "I find that participation with the [SACL] helps organize my thoughts about transitions in the future." Organizing thoughts about future plans is really what the Transitions Handbook is all about. The Handbook was designed to help students, their families and teachers plan more deliberately for the time when students leave high school and get on with building a new life as an adult. The focus is on "person-centred" planning so that at all times the student is the central and most important person in the transition process, with family members, teachers, friends and others playing supporting roles. Ready to put into a three-ring binder, the *Handbook* is meant to be an easy-to-use, easy to read individualized working document with sample stories, checklists, exercises and ideas that carry the student and the Transition team through the five steps: Starting: What Does This Transition Planning Process Mean?, Deciding Who Should Be on My Transitions Planning Team, the Transition Planning Meetings, Carrying Out My Plan, and Checking How my Transition Plan is Working.

(For a copy of the School to Life Transition Handbook, contact the SACL, ph: (306) 955-3344 or visit www.sacl.org, click on Information and Resources, and download the Handbook for free.)

#### When what seems broken is perfect By Barb Farlow

The graph is still taped to the inside of my kitchen cupboard, pencil on a string dangling down beside it. It depicts the progression of my newborn daughter's weight, most days showing a moderate increase and thus reflects a thriving child. It ends abruptly at 80 days.

How can the value and purpose of a life be determined? Can these be measured by longevity, intelligence or the productive contribution of an individual to the economic base of society? Of greater importance, who has the right or ability to make this judgment?

My husband and I were recently faced with a very difficult situation. We are in our 40's, educated and financially stable. We have five children at home and we love sports and travel. The kids do well at school, are athletic, and all are healthy as horses. Life was



Annie Farlow with her siblings.

good to us. We were pleasantly surprised when we discovered that we were expecting a new life to love and nurture.

We first heard of our unborn daughter's genetic condition long before she was diagnosed. It was considered a lethal condition, an extra 13<sup>th</sup> chromosome. Most babies don't make it to birth and those that do live a few years and are severely disabled. I thought, "Well, what is the point of that life?" When the geneticist uttered the dreaded words, "your daughter has trisomy 13" and it was a diagnosis about *my baby* and not someone else's, the reality was entirely different. With the ferocity of a lioness, I wanted to love and protect this little girl, and do all that I could for her. If her existence was only to be a few more months of kicks and flutters in utero, then I wanted her to have that life for the sake of both of us. We named her Annie.

After the diagnosis, the research began. It was frantic, and went long into the night for months. We researched medical details and personal stories. We communicated with parents all over the world who had a child with this very rare condition. We discovered that the babies can live longer, but they may need medical treatment or surgery. The most amazing discovery was that the parents continually stated that they treasured and delighted in every day of their child's life. They knew

with certainty, that the gift of that life was not theirs to keep. The children, called "survivors," were blissfully happy and progressed developmentally, albeit slowly. It became increasing clear to us, that unless the medical intervention to provide life was excessive, Annie was better off alive than dead.

We were not sure how we could do it. I was the kind of mom who usually forgot to pack a diaper bag. I would often be impatient when one of my children couldn't master the math skills in their homework. Could I ever

develop the patience for a child who may not be able to sit on her own for a year? How could we fit Annie's care and needs into our busy schedule? We had five soccer teams in the summer! We were more frightened than we had ever had been in our lives. Love

for Annie compelled us forward.

Annie was born full term, crying. She was mildly affected, as the syndrome goes. She needed a very small amount of oxygen and had hypoglycemia. Annie could not take all of her nutrition orally and so she had an NG tube (nasal gastric tube), which was a tube that went in through her nose down into her stomach. I became skilled at its reinsertion, every three days. We fed her expressed breast milk. Somehow, we dealt with all of the issues. We knew that with time, Annie would take more feedings orally and her need for oxygen would lessen, and likely be eliminated completely.

We were aware that the first year would be rough. Everyone pitched in. Our 12-year-old son took over the lawn maintenance and his older sisters took on Annie's developmental progress and bought "mind stimulating" music and ordered her a special baby seat to help develop upper torso strength. The whole family came together in ways that I never dreamed possible. We discovered how true our friends and family were by their support and encouragement. Somehow, the homework got done and the gang made it to their soccer games.

At age 75 days, Annie smiled at us for the first time. Even now, a year later, the memory of that first and only smile causes me to cry.



#### Adopting an MLA an opportunity for down-to-earth connections

By Lorri Solomon

The SACL began the Adopt-an-MLA program in April 2004 to give families dealing with disability issues an opportunity to talk personally with their Member of the Legislative Assembly. It's an important opportunity for connections that are making a difference to both the MLAs and to the families that have the opportunity to meet with them.

The aim has always been to keep the concept simple. MLAs meet with the families in their homes for about an hour to talk about issues facing these families, such as educational issues, respite issues and medical supports. This first hand glimpse into the family inside their homes offers the MLAs insight. Families report that they feel heard and connected when they've had an opportunity to meet with their MLA in such an intimate way.

"It was very good—we are known to Pat," Brenda Baker, mom of Tori said, referring to MLA Pat Atkinson's visit to their home in Saskatoon. "She has been our MLA here forever. What was nice about it was she had never actually been in our home. It was not awkward at all because we had a relationship. Pat is very aware of a lot of the issues, partly because she served in so many capacities," said Baker.

"We expressed to her what our concerns have been and what has worked for us so far. We are happy with the services we've had but we relayed to her some of the stories. There seems to be a change [in the kind of services there are] depending on how old [the child is]. We talked about that."

Families who become involved with the Adopt an MLA program understand that having "adopted" an MLA will not necessarily solve their immediate personal issues. It will however, raise political awareness of the broader issues faced by families.



MLA Greg Brkich visits Zoe at her home in Raymore

"Well, we discussed the Residential Rehabilitation Assistance Program for persons with disabilities and home adaptations, respite services. We talked about the Paraplegia Program and that

it is a wonderful program and we appreciate it although the amount covering equipment isn't sufficient," said Lesley Deutch of her family visit with MLA Greg Brkich.

"It really has proven to be a very worthwhile endeavour," says SACL President Laurie Larson, the parent who originated the initiative with her own MLA. "Families have been empowered and realize that even from their kitchen tables they can inform and influence politicians' awareness of the issues their families face. Given that this movement was born of families gathered around kitchen tables, discussing what needed to be done for their sons and daughters to remain in their communities instead of being sent to institutions," she adds, "it's fitting that we continue

to gather at kitchen tables advance our cause at this political level."

More than 15 MLAs have come forward to be adopted over the next few months, and the program has been expanded to include Members of Parliament. The most difficult part is often getting the scheduling together; MLAs are busy people, and so are family members. This program offers support to both the



MLA Pat Atkinson and Tori get comfy in Saskatoon

MLAs and the families as needed to help facilitate the visit, by making connections, and by providing support both before and after the visit.

Lesley Deutch described her experience as one of mutual respect. "He listened. He is a nice man. He listened with open ears and said that if we ever have a specific concern to call his office and it would be looked into. It was nice to share and for him to see Zoe and what her needs are."

Since the SACL initiated this method of connecting MLAs and MPs with families throughout the province, other ACLs in other provinces have followed suit.

(For more information about the Adopt-an-MLA program, contact Lorri Solomon, Coordinator, Box 1347, Carlyle, SK SOC 0R0, ph: (306) 453-2402 or email: gems@sasktel.net.)

## Childhood friends ride rapids, walk the icefields

By Shelley Elder, with contributions from Jonathan Elder and Frank Binny

Frank Binny, 23, and Jon Elder, 22, met at St Augustine School in Saskatoon when Frank was in the first grade and Jon was in kindergarten. Though Frank has moved twice since he was our neighbour back then, the two have maintained their friendship. Frank learned to swim in our pool and taught Jon how to push himself down and pick stuff up at the bottom. Talk about trust. Of course, watching them, I was amazed while I suntanned.

We've always thought of Frank as another son, as a regular part of our active family. Last summer, we loaded up the car and drove to Becker's Chalets just outside Jasper, Alberta. We had four fun-filled days seeing the Columbia Icefields and Athabasca Falls. We went up the tram, hiked in the mountains, swam in the pool and experienced the whitewater rafting.

"One of my favourite things on this trip was to have some of Frank's cooler. Frank loves orange coolers. I have to remind Frank not to eat too much." – Jon

"My favourite was walking up the mountain with Dave. I did not quite make it, so I sat on a bench and stayed there until Dave came back down. I was bushed." – Frank

Frank really showed some skill with the whitewater rafting and wanted to "dig in," just like his mom who rows competitively on the Dragon boats on the South Saskatchewan River. Jon rode up front in the bow of the raft as we did the gentle Level Two rapids.

A fan of the more reserved activities, Jon enjoyed the ride to the Icefields with Frank because they went in their own accessible van. We all boarded the big bus



The group with a guide at the rudder tackles the Athabasca River.



Frank Binny, Dave, Jonathan (seated), and Shelley Elder get set for whitewater rapid action.

with tires over six feet high. It had a lift for Jon to use. Jon was nervous about getting down onto the ice and thought he'd fall through into a crevasse.

We've always been an active family and the fact that Jon has spina bifida and hydrocephalus and Frank has Down syndrome really hasn't slowed any of us down. Frank and Jon have made lots of friends in their lives since they met at St. Augustine, but they still keep their own friendship going. Tackling rapids and icefields and talking about their adventures over a cooler is a great way to stay connected. Frank and Jon are thinking they'd like to go this summer to Niagara Falls; now that's what I call whitewater rafting!

(Shelley Elder is the Community Living Association Saskatoon representative on the provincial SACL board.)

"People in authority tend to control situations, as they are frightened of change or of what might happen if those of another social sphere are free to become themselves."

Jean Vanier, Founder of L'Arche

# There's nothing quite like a having a buddy

Students at both of Saskatchewan's universities and a few Regina high schools, and young people with disabilities are finding out that new connections can turn into budding friendships.

Best Buddies, a university-based volunteer concept designed to foster friendships between students and adults with intellectual disabilities. It was founded by Anthony Kennedy Shriver in the United States in 1989. Since, it has grown into over 1000 chapters worldwide. Since its beginnings in Canada, Best Buddies spans the country with chapters at over 70 campuses. People are matched for similar interests and make a commitment to get together a few times a month with contact at least once a week.

"It has been really neat to watch 16 friendships develop over the course of the year and see how each volunteer is making their own unique contribution," says Kim Hsu, coordinator for the University of Saskatchewan Best Buddies. Hsu is a veterinary medicine student and her own match is a young man with an intellectual disability whose father is a professor of education. "We've spent some time at Starbucks and we've played pool often enough now that Jim doesn't clobber me quite as badly in every game! I love getting updates from our Buddy pairs because virtually each one has a great story. One pair goes plane watching at the airport. Another pair of girls are practically BFFs (that's Best Friends Forever); their families even get together now!"

"I think we've had some people step out of their comfort zone and in a very short time, they've shown real growth," Hsu explains.

The U of S chapter held four group events: a Halloween Meet and Greet, a bowling party and Christmas gift exchange, and a wind-up dinner at Tomas Cook with Safeway friends. Best Buddies U of S was 'adopted' by Safeway earlier this year. 'Buddy pairs' met shoppers in the local grocery store to promote Best Buddies and help raise money for the group. Hsu said it was a good opportunity



The *U* of *S* Best Buddies gathered for a Halloween party.

to tell the public about the unique contributions everyone makes and the powerful friendships that can happen when people take a little time to get to know someone. As a bonus, \$7,000 was raised during the three promotional events.



Jaime Carter and Thomas Le

#### Regina Best Buddies enjoy range of experiences

By Amanda

Best Buddies is an extremely important part of the University of Regina and the community of Regina. It has enhanced our community through one-to-one friendships between individuals

with intellectual disabilities and students. The program is grounded in the belief that friendship is important to the development of all individuals! Our program gives people with intellectual disabilities the chance to have experiences which most people take for granted; going for coffee, out to a movie, or simply enjoying the company of a good friend. These connections give everyone an opportunity to escape from their day to day work and have fun with friends.

This has been an exciting year for the University of Regina Best Buddies. Our chapter has been growing rapidly over the last few years. In 2007-08, our chapter consists of 25 pairs. We started out with two meet and greets where the pairs met, played games, and ate pizza. We celebrated Halloween with a screamin' salsa party People dressed in costumes and learned how to dance from professional Latin dance instructors Noor Mitri and Laura Fellinger. At Christmas, we went to Globe Theatre for A Christmas Carol. We also had a potluck party and we decorated gingerbread cookies, made gingerbread houses and tree ornaments, opened gifts and stockings and had a surprise visit from Santa. We recently attended a tropical Family Fun Night hosted by Regina Association of Community Living. Upcoming events include a Steak Night Fundraiser at Brewster's, a dance night, and a tentative year-end wind up to Moose Jaw.

Best Buddies is built on developing friendships. As the name suggests, we look to facilitate the development of true bonds.

(Amanda is part of the Best Buddies Executive. To contact Best Buddies at the University of Regina, ph: (306) 596-9607; email: uofrbestbuddies@hotmail.com. At the U of S, contact HSU, email: kkh002@mail.usask.ca, or SACL's Carol Glazer, ph: (306) 955-3344.)

#### **Latimer case symptom...** continued from page 3

rights of Canadians, like the Civil Liberties Union, will turn their attention to how we bring equal protection and rights to all persons in a society where more and more the frontlines of diversity involve disability and the experience of pain. The CACL commits the resources and efforts of the Association to serving an inclusive and open dialogue.

(For the current developments, go to www.sacl.org and click on menu item Latimer News. Posted features

include a *Maclean's* article by Andrew Coyne: "Justice means having to say you're sorry: releasing Latimer now in the face of his impenitence would put public safety at risk"; an opinion by bioethicist Dr. Tom Koch in the *Canadian Medical Association Journal*, "Robert Latimer: Bait and Switch"; an interview on CBC Radio's *The Current* with Faith Bodnar, and also public statements from the SACL and CACL.)

#### **Knowing someone makes difference...** continued from page 11

parental costs are not related to attitudes toward selective abortion. It may be that parenting in general is assumed to be costly, but it is the perceived lack of personal rewards usually associated with parenting a child with a disability that may sway some people toward considering selective abortion.

Our study is showing that the societal perceptions of parenting a child with Down syndrome are more negative than those relayed by parents, most notably in terms of the anticipated rewards associated with parenting. These differing perceptions of the rewards may underlie the widespread use of prenatal diagnostic testing services.

The next steps in this research involve examining these same issues in a larger sample with parents across Canada, and documenting personal parenting stories through interviews. We also plan to examine how to best provide information about parenting a child with Down syndrome. We believe this would help in the development of balanced prenatal counseling guidelines that would lead to informed decision-making.

(For more information about this research and about the next steps outlined at the end of the article, contact Dr. Karen Lawson, Department of Psychology, University of Saskatchewan; e-mail: karen.lawson@usask.ca.)

#### When what seems... continued from page 14

Annie experienced respiratory distress at age 80 days and was transferred by ambulance to the Children's Hospital. The physicians told us she had pneumonia. Our beloved baby died less than 24 hours later.

There are two ironies to this story.

The first is that we thought we had a choice of life for Annie but the reality is that we did not. The medical records, which we instinctively felt compelled to obtain and have had reviewed, reveal no signs of pneumonia. An effective "Do not resuscitate" was ordered without our knowledge or consent. The final computerized medication report from the intensive care of an excellent hospital is inexplicably missing.

The hospital issued a letter of apology stating that sometimes "communication does not occur in as clear and consistent a fashion as we would wish. For that, we are very sorry." Recent developments in medical science can be used to diagnose and terminate certain lives but the choice to use medicine to prolong these lives doesn't

seem to be an option.

During her 80 days, our little Annie taught us our greatest lessons in life. Through her life, we experience the deepest sorrow and the most intense love. She taught us the true meaning and purpose of life and we are forever changed as a family. Our children have learned that if they are ever in need, their family will love them, protect them and do anything to support them just like we did for Annie. They developed an incredible empathy for people who are disabled and vulnerable.

The ultimate irony is that this little girl who seemed so broken, flawed and seemingly without purpose or value, was, in fact, perfect after all.

(Barb Farlow lives in Mississauga, Ontario with her family. She has been speaking to a variety of audiences, including university faculty and students, and conferences on ethics, patient-centred care and pediatrics. She plans to write a book about Annie and the Farlow family's experience. In March, the Human Rights Commission accepted their complaint.)

# Disability Studies founder sees mothers as 'accidental activists', speaks at SACL annual conference

Melanie Panitch, Director, School of Disability Studies at Ryerson Polytechnic will be in Saskatchewan for the SACIs 52nd annual conference June 11-15 as the opening keynote speaker. Her book, *Disability, Mothers and Organization:* Accidental Activists, came out of a study that explored how and why mothers with disabled children become activists. In the book, narratives of three remarkable Canadian women whose disabled children were born in the 1950s and 1960s, reveal how they learned to mother as activists, struggling in their homes and communities against the demoralizing effects of exclusion. But they came to their activism accidentally, out of an event about which they had little choice, and certainly little foreknowledge. Driven



Accidental activists: Paulette Berthiaume, Laval, Quebec; Audrey Cole, Lanark County near Smith Falls, Ontario, and Jo Dickey, New Westminster, B.C. These women were the focus of the Panitch Study.

by individual concerns for their children, they acted collectively to close institutions and secure human rights, leaving a bold imprint on their country.

Melanie Panitch, DSW, has been a founder of the School of Disability Studies at Ryerson, first as Coordinator to develop the new program proposal and since 1999 as Director of the School. She was instrumental in attracting a five-year lead campaign gift from the Royal Bank (renewed in 2006 for \$1.2 million) to establish the Ryerson/RBC Foundation Institute for Disability Studies Research and Education, which she co-directs with Catherine Frazee.

For 30 years she has been an activist, advocate, researcher and educator, and has strong roots in the community living movement. She has designed and taught courses on human rights and disability at the Universities of Guyana and the West Indies. She has lectured at international conferences in Guatemala, Mexico, Ecuador and Uruguay. Throughout the 1990's, she was Coordinator of Social Development and Public Education at The Roeher Institute; she was also part of a research team examining disability-related policies in Canada. Her work focused on child care, literacy, violence and abuse, and care-giving from which she published numerous articles, chapters, reports and books. In 2006, she received her Doctorate in Social Welfare from the Graduate Centre of the City University of New York. Her research interest lies in the disability rights movement and understanding its role in social change. For her doctoral dissertation, she conducted oral history interviews with the first wave of activist mothers with disabled children who resisted the pressure to privatise disability as their own personal trouble.

#### Association urges Canada to stay deportation of four-year-old, family

The Canadian Association for Community Living (CACL) is urging Canada to stay the deportation order of Aaron Carnales and his family. CACL joined the call by the Defence for Children International – Canada (DCIC) and many others to the Honourable Diane Finley, Minister of Citizenship and Immigration. Aaron is a four-year old boy with Down Syndrome born in Canada to Veronica and Daniel Carnales, originally of Uruguay. He also has a brother, Santiago. Aaron's brother and parents have been ordered deported by mid-March because their application for residency in Canada was not approved. The family has lived in Canada for several years, are self-sufficient and

exemplary community members.

Under the *Immigration and Refugee Protection Act*, the Minister has the power to stay the deportation order so the Carnales family can re-apply for an exemption to immigration rules on compassionate and humanitarian grounds. The family's original application was missing information relevant to a decision on their status. As a national association with a mission to advance the full citizenship and inclusion of people with intellectual disabilities and their families, CACL stands beside the Carnales family in their call on the Government of Canada to fully recognize the Canadian citizenship and best

Continued on page 24

## B.C. first to exempt savings plan assets

The B.C. government is the first provincial government to respond to the Registered Disability Savings Plan (RDSP). They have opened the door for people with disabilities and their families to use the RDSP to secure the future and improve their lives. Minister Claude Richmond and his colleagues have exempted RDSPs as assets in determining eligibility for Disability Benefits. They have also exempted all income from RDSPs, allowing people to use the plan in whatever way they see fit without any penalties.

"B.C. has set the high watermark for other provinces to reach for," says Al Etmanski, Planned Lifetime Advocacy Network. "The B.C. government's act represents a new way forward, a huge first step in a new prosperity agenda for people with disabilities. This action begins to turn disability benefits into a floor, encouraging people with disabilities to get ahead, rather than a ceiling, above which people can't expect to rise." This move represents a huge improvement on B.C.'s trust rules, he adds, which were already among the best in the country. It also sets the stage for even further improvements.

In the spring of 2007, Finance Minister James Flaherty made history when Canada became the first country to create a Registered Disability Savings Plan. The RDSP, available this year, will benefit nearly three quarters of a million Canadians with disabilities. Over time, people's RDSPs will provide billions of dollars to supplement income, enable home ownership, purchase supports, services and products and ultimately, enhance quality of life. In addition, the Disability Savings Grant and Bond will provide a federal contribution to assist families in saving for the future.

#### **Students proud in North Battleford...** continued from page 10

SACL Advocate MaryBeth Gendron worked as an employment consultant in the area at the beginning. "I was working with Vicki Machniak who was in her last year of school. She had a dream to attend college like her peers. I told them about other programs and Vicki's mom Linda went to the college president to present the idea," says Gendron. "A proposal was developed and the partners brought together."

Career Connections student Louis Johnson says the commitment is well worth it. "What I like is the activities that go on. Be prepared to stay for the whole term. You don't want to miss out on things." Career Connection includes 12 weeks of in-class training that covers nine themes: Self Knowledge, Independence, Teamwork, Employer Expectations, Safety, Responsibility, Communication, and Relationships. During a 26-week job experience, students are supported through intensive job coaching and required classroom sessions to reinforce identified skills.

"I like the course," says student Aaron Gladue. "It helps me out with my reading, getting a job and staying employed. This course is good. It helps you with work!"

All ten students are currently in the job placement segment of their training. While employment is an ultimate goal, the sheer pleasure of the college experience to many students is equally as important. "I

love this course. I enjoy learning new things that I didn't know before such as computers," says Kristen Hancock. "Going to this college program has been great. You should join, it's lots of fun!"

The partners include Northwest Regional College, SACL, North Battleford Comp High School, two departments of Advanced Education and Employment, Living Sky School Division, Light of Christ Roman Catholic School Division, Service Canada, and family representation from the BCIA [Battleford Community Inclusion Association.

(Janice Henry is the SACL, Employment Opportunities Consultant, #2–3041 Sherman Dr., Prince Albert, SK S6V 7B7 Ph: (306) 763-5606; fax: (306) 763-5613, email: janice.henry@sacl.org.)

#### **Weyburn senior...** continued from page 5

Sharon is more than a few inches short of five feet tall, with fine white hair and striking blue eyes. She loves bright, fancy, and patterned clothing, particularly vests and socks. Most of all, she needs pockets. Sharon has a collection of items that go everywhere with her, including a keychain with the word 'Qtpie' on it and several keys which have long since lost their locks. She also carries one of several pairs of glasses or sunglasses in her pocket and a small furry purple change purse in which carries the remnant coins of birthday money she has saved for years. She wears at least three pieces of jewelry at a time and has a deep appreciation for anything shiny, sparkly, or neon. She wears her bracelets over her sleeves and her necklaces under all the layers of clothing.

Carol Borys has worked at Weyburn Group Homes Society since 1996. She started as a support worker and became Group Home Operator. She has worked in several WGHS homes. Consistent staff is very important in order to create lasting relationships, she says.

"I understand what Sharon says almost all the time. She can be kind of hard to hear or understand, but we've been together so long, I understand her," says Carol. "Her words are limited, but she can usually get her point across. There are times when I say 'Sharon, I just can't figure out what you want.' But we've become so close and we trust each other. That's another reason why it's good to have consistent staff so we're all comfortable with each other."

What's great about Sharon is that she doesn't take it personally at all if someone can't understand her difficult speech. Instead she seems to kind of pity the person who can't understand her. She sometimes rolls her eyes or gives up because the other person is struggling and never perceives the fault is hers.

Sharon always tends to believe the best in people and situations. All winter, she insists, "Snow. Spring coming..." as if to convince us that something better is just around the corner. She is the first to exclaim "Sidewalk!" as the snow melts outside. Only Sharon can see pavement so positively. She also keeps her optimism high about special events and birthdays. It was only a week after her 65th that she began to comment, "Birthday soon..." One day, I tried to convince her it was a long way off, thinking she would be disappointed by having to wait so long. I tried hard to convince her that she would have to wait until spring, then summer, and even into fall. She insisted, "But that's soon!"

Until this winter, Sharon spent workdays at the WorKin Shop; now she has taken a partial retirement. She attends the Weyburn Special Care Home for seniors for a day respite program on Wednesdays. She was very hesitant at first, but came to enjoy the spa activities, games, and activities she does with other seniors her age. She still helps with exercises, activities and games at the WorKin Shop. She used to "do paper" and sorted newspapers and magazines, a job I think that made her feel important. She used to take snippets from the magazines, something she technically wasn't supposed to do. Her armoire is adorned with clippings of things she loves: kittens, rabbits, and chocolate cakes.

No other staff has ever bonded with Sharon in the same way that Carol has. While she still gets along with the other staff, Sharon is clearly best friends with "Borys." It's not surprising that the two women have become close friends as Carol has literally spent 50 per cent of the last 11 years with Sharon. Recently, Carol is off on medical leave and it has been very hard on Sharon. Sharon talks to Carol (who is not there) as she sits in the living room, saying "I love you, Carol. I love you, sweetie." A firm believer in the power of positive thinking, Sharon swears that Carol can hear her, all the way out at her farm. For her part, Carol agrees that "we're like family."

(Gervais is a University of Regina social work student who lives in Weyburn.)



Sharon Pollard of Weyburn

#### **Training Bulletin**

**SACL Annual General Meeting & Conference**, June 11–15/08, Saskatoon, SK

June 11 Public Dialogue on Deinstitutionalization; June 12 conference opens, continues June 13. Evening pre-AGM board meeting. June 14 annual meeting; evening family barbecue. June 15 Part 2 AGM, post-AGM board meeting. Visit www.sacl.org for more details soon!

# Planning for the Middle/High School Years and Beyond: workshop series on working with students with Autism Spectrum Disorder. March–May, SK.

Check listing for your location:

March 7, Estevan; April 4, Lloydminster; April 25, Yorkton; May 2, Swift Current; May 16, Moose Jaw; May 23, Rosetown; May 30, Saskatoon. Workshops run Friday from 8:30 a.m. to 4:30 p.m. Lunch not provided. Features Dr. Rupal Bonli, clinical psychologist and Bonnie Quiring Gallen, speech and language pathologist. Registration is free; space is limited. To register or for more information, ph: (306) 655-2345 or email:

Allison.Gagnon@saskatoonhealthregion.ca. Sponsored by the Saskatchewan Ministries of Education and Health.

# **Health and Wellbeing in Persons with Intellectual/ Developmental Disabilities**: *Children, Youth, and Adults*. Sept. 25–26. Vancouver, B.C.

This conference will provide education and informative updates on psychiatric, behavioural and complex health components specific to individuals with developmental disabilities, and showcase best practices in the field. For further information or a downloadable flyer, visit www.interprofessional.ubc.ca, or contact Yolande Chang, Marketing and Advertising Assistant, University of British Columbia, Interprofessional Continuing Education, ph: (604) 822-7524 or e-mail ipad@interchange.ubc.ca.

#### **Diversity Includes: CACL's 50<sup>th</sup> Anniversary conference**, Nov. 19–21, Ottawa, ON

For 50 years, the CACL has been striving for the full inclusion of people with intellectual disabilities, and we're inviting you to be included in our 50th Anniversary Celebration! We're celebrating 50 years of showing Canadians what it means to be more inclusive. To think bigger when the think "diversity." Opening minds so people with intellectual disabilities are included in every facet of daily life. Championing diversity that truly includes. Include yourself in the celebration. Participate in an international forum on the UN Convention on the Rights of Persons with Disabilities. Join people with intellectual disabilities, families and our allies from across Canada in advancing our agenda for inclusion. For details, www.cacl. ca or ph: (416) 661-9611.

**Global Forum for Inclusion 2008**, Nov. 18–26, Ottawa, ON

CACL is co-hosting, with Inclusion International this forum at the Westin Hotel in Ottawa prior to the 50th Anniversary Conference. With the recent adoption of the UN Convention on the Rights of Persons with Disabilities, people with intellectual disabilities, their families and organizations are looking to transform our rights into action. Join self-advocates, families, supporters and professionals from around the world to help make local-to-global inclusion a reality. Global Forum events will include:

- General Assembly of Inclusion International, Nov. 18
- International Conference on UN Convention on the Rights of Persons with Disabilities, Nov. 18–19
- **Spotlight on Canada**, 50th Anniversary Conference of CACL, Nov. 19-21
- Inclusion in Practice: Study Tours in Canada and the U.S. on Inclusive Policies and Practices, hosted by Provincial/Territorial Associations for Community Living in Canada, and Chapters of The Arc in the U.S., Nov. 23-26.

Watch the website for updates and registration: www.cacl.ca.

**Upcoming forum: Human Rights and the Inclusion** of Students with Disabilities: A Dialogue on the **Way Forward**. In partnership, the CACL/SACL and the Saskatchewan Human Rights Commission will present this dialogue on May 23, 7–9 p.m.; May 24, 9–4 p.m. in Saskatoon. SACL President Laurie Larson says, "This event gives us an opportunity to stress that access to inclusive education for students with intellectual disabilities is indeed a matter of human rights. All too often in our province, students rights are being blatantly denied. We can and must do better." SHRC Chief Commissioner Marilou McPhedran adds. "When we look at the source for the most human rights complaints in Saskatchewan, people-adults and children-living with disabilities top the list. But the Commission is about more than complaints. We have a mandate to work proactively, so we are delighted to partner with SACL to look at solutions that will strengthen our whole society through inclusion." For details, contact the SACL, ph: (306) 955-3344.

#### **Stay deportation...** continued from page 20

interests of their son, Aaron.

The Immigration and Refugee Protection Act (IRPA) requires that it comply "with international human rights instruments to which Canada is signatory." One such international human rights instrument is the Convention on the Rights of the Child (CRC). Article 3 of the CRC requires that "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration." Article 23 of the CRC provides that a disabled child has the right to "enjoy a full and decent life, in conditions which ensure dignity, promote selfreliance and facilitate the child's active participation in the community," and provides that a disabled child has a right to special care provided by the government. Moreover, Article 9 of the CRC provides that a child has the right to "not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child."

CACL urges the Minister to demonstrate full recognition and respect for these rights for Aaron and indeed all children in Canada. For Aaron's family these rights will only be fully respected if his family is not put in an impossible position: leaving their son in a country where, by virtue of his citizenship rights, he can access the health care and other supports he needs, or leaving the country with their son to an environment where he does not stand assured of what is his due as a Canadian citizen. Both of these options would undermine the best interests of Aaron and his family. For more information on this case, contact Michael Bach, Executive Vice-President, CACL, ph: (416) 209-7942.

# Crowds on Parliament Hill call for end of exclusion

In November 2006 over 300 people gathered in Ottawa to celebrate the accomplishments of Canadians with disabilities over the past 25 years. Over 100 organizations stood together in partnership and solidarity, signing the Declaration of Principle and joining in the discussions that focused on Building an Inclusive and Accessible Canada.

On November 22, 2007, Canadians with disabilities gathered once again during an Ottawa blizzard to call for an end to the exclusion of people with disabilities. Using the 2006 Declaration as the foundation, initiative partners finalized a National Action Plan focusing on Building an Inclusive and Accessible Canada.

"There are no insurmountable obstacles to prevent Canada from taking a World Leadership Role in providing disabled persons with the practical means for greater independence." – Obstacles, 1981



CACL's Past President Zuhy Sayeed of Lloydminster, Alberta/ Saskatchewan and Marie White, Chair, Council of Canadians with Disabilities hardly notice the weather during the rally. Other SACL marchers included Laurie Larson, Faith Bodnar, Judy Hannah and Shane Haddad



Shane Haddad of Regina, President of People First of Canada and Vice President of SACL, took the microphone on Parliament Hill. (Photos by Kier Martin).

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