

Respite Care: Who cares for the caregivers?

Information
is Power
Workshops
Presentations
Page Two...

In a small town in southern Alberta, a young woman is advised to “quit her job and go on welfare” so she can stay home and care for her ailing, elderly mother.

A high school student with a severe disability will soon celebrate his eighteenth birthday. For most of the boy’s life, his family has received funding for a caregiver through Family Support for Children with Disabilities. But as soon as he turns eighteen, he is no longer eligible for funding. His parents do not know where to turn and they can’t go on without a break. How will they be able to ensure the same quality of life for their son?

A young married couple’s lives change when they are in an accident while driving home from a ski trip at Lake Louise. After six months of intensive physiotherapy, the wife has returned home. Her husband is her primary caregiver. He has been taught how to address his wife’s physical needs, but is overwhelmed by and does not know how to cope with the emotional and mental trauma they are both experiencing.

An aging widowed mother has been caring for her adult son with a severe developmental disability. She needs surgery, but there is no short term service to care for him while she recuperates, and she has to choose between institutionalizing her son and risking her own health.

In Alberta, many families are willing and generous caregivers for their loved



ones with disabilities. However, as the above stories show, caregiving isn’t easy. The mental, physical, and financial toll of providing care can be immense. Currently, family caregivers in Alberta receive a limited amount of respite from their duties. But is it enough?

For the past few years, the Continuing Care Working Group of the Alberta Disabilities Forum (ADF) has been meeting with provincial authorities to educate them about family caregiver issues and to advocate for a more advanced provincial respite care program. In the fall of 2007, Alberta Health and Wellness invited ADF to propose the steps that would need to be taken to address the situation. After carefully researching the issue, the ADF submitted a project proposal that outlined the need

Continued on Page Four...

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Please send comments and letters to:
Bev Matthiessen
Editor, Action News
707, 10339-124 St NW
Edmonton, AB T5N 3W1
Phone: (780) 488-9088
1-800-387-2514
TTY: (780) 488-9090
Fax: (780) 488-3757
www.accd.net
accd@accd.net

Information is Power

On July 21, 2008, the Alberta Disabilities Forum began to host community meetings with family caregivers from across the province. (See lead article.) ACCD is delighted to be a part of these consultations. We are learning so much about the vital role that family caregivers play in society, and we'd like to share some of this newfound knowledge with you.

What is respite care?

Respite care is the "opportunity for the person with a disability to receive proper attention while the family member or caregiver takes a break. Rather than an unnecessary luxury, this can be a key feature in maintaining the health and well-being of the caregiver whose own health needs to be protected; not only for humane reasons but to ensure the continuance of low-cost personal care services that only family members give."

Source: Aging with a Disability by Roberta Trieschmann (1987)

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What do caregivers do?

Caregiving is a challenging and complex job. Sometimes it involves the continual supervision of an elderly relative with Alzheimer's; sometimes it involves assistance with daily toileting, eating, and bathing routines; and other times it involves trips to the doctor, dentist, and other specialists. The types of care provided are as varied and unique as the family members who are being cared for.

Why do family caregivers experience a high degree of stress?

The challenges faced by caregivers who are parents, siblings, spouses, and children can be tremendous. Here are a few examples of how circumstances may change when you become a family caregiver:

- You may have to give up or change your career so you can be at home to provide care. This means sacrificing career goals and income
- Family dynamics change as you make the transition from child or spouses to caregiver
- Stress and anxiety increase because you have less time for the activities (socializing, exercise, hobbies, etc.) you'd like to be doing
- Resentment and guilt can build up as you struggle to balance your own needs with the needs of your loved one

Thank you

*Robertson Wesley United Church
E. I. Clarke Fund for co-sponsoring the Education for Life Bursary*



Together, We Hold the Power!

Mailbox

ACCD received the following letter from Ikponwosa Ero, one of this year's Education for Life bursary recipients.

Thank you

I write to say a big thank you to . . . ACCD for granting me \$500.00 from the Education for Life Bursary Fund for 2008. Your contribution will help offset my education costs at the University of Calgary law school, which means less worrying about money on my part and more focus on my studies.

Once again, thank you for upholding a profoundly helpful mandate to assist persons with disabilities. I look forward to getting involved with the ACCD in the near future.



*Sincerely,
Ikponwosa "I.K" Ero*

Education for Life Bursary Recipients

In celebration of our 25th anniversary in 1998, ACCD awarded its first, annual Education for Life bursary. With this award, we support and encourage individuals in upgrading their education, preparing them to meet the challenges of a post-secondary education. For ten years, this bursary has assisted first-time, post-secondary learners in overcoming the financial barriers they may encounter when taking on new educational challenges.

This year, six students received the Education for Life bursary. They are:

- Peter Michael Wynnychuk, who will begin a Bachelor of Science degree in Engineering at Red Deer College
- Carl Sobolewski, who will begin a Bachelor of Science degree at the University of Alberta
- Frances Finley, who will begin a diploma in Psychiatric Nursing at Grant MacEwan Community College
- Jordan Doane, who will pursue a career in Broadcasting at Mount Royal College
- Ikponwosa Ero, who will begin a Law degree at the University of Calgary
- Derek Cebula, who will pursue a career as an Electronic Engineering Technologist at the Northern Alberta Institute of Technology

Did You Know?

Did you know that, each year, ACCD receives about twenty-five applications for its Education for Life bursary?

Inevitably, all of the applicants are worthy of the award, but ACCD is only able to support a handful of students each year. Through a careful selection process, we make our decision based on merit, motivation, goals,

and overall impression.

If you would like to find out more about the bursary or if you would like to help more students achieve their dreams of attending college or university, please contact Warren at the ACCD offices or email him at warren@accd.net.

Continued from Page One...

for an effective Provincial Respite Care Program and the steps that should be taken to establish the program.

ADF received the green light on the project in March 2008, with funds coming from both Alberta Health and Wellness and Alberta Seniors and Community Supports. The response to the consultation phase of the project, which began on July 21, has been remarkable. In meetings across the province, ADF has heard from hundreds of caregivers, persons with disabilities, health professionals, disability advocates, and administrators of interested non-profit organizations.

ACCD's executive director, Beverley Matthiessen, has attended several of the consultations; she is excited and optimistic about the project. She says, "I commend the government for consulting with and listening to family caregivers.

These caregivers are supporting their loved ones in their homes and in the community. They deserve all the support we can give them. ACCD is proud to be part of a project that will be putting forward recommendations

to government for a provincial respite care program."

Once the community consultations are complete, a demonstration project will run based on recommendations and strategies arising from the research and consultation process. If you are interested in finding out more

about this project, or about respite care in general, please contact Melita at the Edmonton offices or email her at melita@accd.net.

Community consultations are facilitated by Peter Faid, who has been working as a social policy and disability consultant since 1991.

"... ACCD is proud to be part of a project that will be putting forward recommendations to government..."

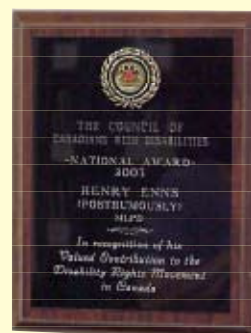
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Call for Nominations: CCD Award

Do you know an Albertan whose commitment to the disability community deserves recognition? If so, please consider nominating them for the CCD award. Once again this year, ACCD will present the Council of Canadians with Disabilities Award to an individual who is dedicated to the "pursuit of full participation in society by people with disabilities."

If you would like to nominate someone for this award, the deadline for nominations is December 30, 2008.

Nomination forms are available by calling the ACCD office at 488-9088 or toll free at 1-800-387-2514. Nomination forms are also available on the ACCD website at www.accd.net.



Meet the Board

Lindsay JoAnne Stewart, Nominating Chair

This spring, ACCD was delighted to welcome Lindsay Stewart to the board.

Lindsay was born in Saskatchewan, but has lived in Edmonton most of her adult life. She recalls that, even as a child, she was taught the importance of “helping your neighbours.” These grassroots values continue to shape her actions and attitudes, instilling in Lindsay a sense of compassion and kindness. Today, she is a determined advocate for persons with disabilities and victims of domestic violence.

Lindsay is a published writer, speaker, and educator. In 2006, she researched and produced *Too Sick to Tell*, an educational DVD that raises awareness about violence and abuse issues in the disabled community. She has 25 years experience as a consultant and public relations professional, supplemented by courses in psychology, philosophy, and crisis communication. Lindsay is also a certified Danger Assessment consultant with 60 hours of Family Violence Training Certification. Lindsay was diagnosed with Multiple



Sclerosis in the early 1990s. At the moment, though, she is learning about a different type of disability — Alzheimer’s disease. Her mother has been diagnosed with dementia and Alzheimer’s. As her mother’s primary caregiver, Lindsay sees herself as part of the “sandwich generation.” The demands of caring for her mother, while at the same time managing her own needs, have been difficult. Even facing these challenges, Lindsay keeps

a sense of humour, saying, “It’s the first time I’ve wished I wasn’t an only child!”

It would be great to have someone else around to support my mom and me.”

In her spare time, Lindsay writes magazine articles and humorous essays. She says her writing has a dark but amusing edge: “Black humour brings laughter into the lives of many individuals with disabilities.”

Lindsay is looking forward to her role as a new member of the board of directors of ACCD. She is particularly interested in the ways that awareness-raising can influence society: “I believe education is the way to translate our lives as people with disabilities and to help others better understand our needs and our desire for equality.”

“Black humour brings laughter into the lives of many individuals with disabilities”

Call for Nominations!

If you would like to nominate someone for a CCD Award, we need to hear from you by December 30, 2008

Focus on Fundraising

On the Family Day weekend each February, ACCD hosts its signature spills-and-thrills event—the All-Star Hockey Fun-Raiser. We're joined by hockey talent from the University Golden Bears and Pandas, the Edmonton Eskimo's Alumni, and the Edmonton Police Services. At this fun-filled afternoon, ACCD promotes awareness of disability issues while raising money to support our initiatives and projects.

The financial success of the Fun-Raiser relies heavily

on volunteers and sponsorship—with over 160 sponsors supporting the event last year. Sponsor contributions range from donations of items for the raffle, prize giveaway, and silent auction; to hosting the volunteer luncheon; to providing low-income families with tickets to attend the game. The money raised through ticket sales and the silent auction are used to support ACCD's many important programs and services.

Join us Family Day 2009!



Mark your calendar now and join us at the Clare Drake Arena in Edmonton on Family Day 2009! If you would like to learn more about sponsorship and volunteer opportunities for the All-Star Hockey Fun-Raiser, please contact Warren at the Edmonton office.

ACCD completes Strategic Fund Development Plan

Since 2007, ACCD's Fund Development Officer has been developing a strategic fund development plan. This initiative was made possible by a grant from the Wild Rose Foundation.

Throughout the project, ACCD produced an organizational assessment, donor recognition and volunteer policies, and focused on our main program areas of Education and Awareness, Projects and Research, Consumer Supports and

Referrals, and Awards and Bursaries.

Over the next six months, ACCD will be working on implementing action plans to carry out the strategic fund development plan. Our goal is to improve and expand upon our main program areas as we identify and attract new funding sources.

Look for more information on this important work in our upcoming ACCD newsletters.



Alberta Committee of Citizens with Disabilities

Donation Form

*I am interested in making
a donation to ACCD!*

Name: _____

Address: _____

City: _____ Postal Code: _____

Phone: _____

Fax (Optional): _____

Your E-mail: _____

Would you like us to email newsletters to you? ____

Donations are greatly appreciated:

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Please fill in all information and
mail to or drop off at

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E-mail: accd@accd.net

Help Us To Help Others!

Donate to ACCD

What We Do:

ACCD programs and activities are supported by our fundraising efforts, by private and corporate donations, and by core and project funding dollars. Our activities fall into five main categories:

Education and Awareness

- Disability Awareness Presentations
- Accessibility Assessments
- Disability Consultation
- Election Campaigns

Projects and Research

- Men with Disabilities Discussion Paper
- Raising Instructor Awareness
- Getting to Know Us
- Preventing Abuse of Persons with Disabilities
- Blueprint for Advocacy
- Negotiating for the Future:
Accessing Workplace Accommodations
- Accessible Women's Shelters

Consumer Support and Referrals

- Individual Support
- Group Support
- Referrals

Partnerships and Collaborations

- Board/committee Participation
- Project Partnerships

Bursaries and Awards

- Education for Life bursary
- CCD Award

Donation Form on Reverse