

OPADD LETTER

February/March 2006

LONG TERM CARE AND DEVELOPMENTAL SERVICES: WORKING TOGETHER

The Ontario Partnership on Aging and Developmental Disabilities has found that collaboration between the sectors results in positive outcomes and quality of life for people with developmental disabilities who are aging. However, the pattern of partnering varies across the province. Some areas are enjoying established working relationships. Others are exploring the potential for mutual support. In some quarters there is a continuing reluctance to partner. It can help our building of partnerships to examine some of the factors that may be getting in the way.

The reluctance that is found in some places seems to be related to three factors. First, the unwillingness to partner may be fuelled by an ideological position that views the other sector as serving people who are devalued by society. Thus, partnering may be perceived as a move that will lead to

further devaluation. The idea that older adults and people with developmental disabilities are devalued by society is not without some merit. However, the basic rationale behind human service agencies is to enhance the value of all human beings in society, not to give into uniformed prejudice. The logic of keeping the two sectors apart because of the devaluation issue is based on a sense of victimization rather than social development.

Second, some believe that people with developmental disabilities should be served only within the developmental services sector. This belief is



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SUCCESSFUL WORKSHOP PLANNING TIPS

AN INTERVIEW WITH PAUL HURAS, CEO SOUTHEAST LHIN

What experience have you had planning conferences and workshops?

A lot of experience. As CEO of the Thames Valley District Health Council in London Ontario; we put on a number of conferences and forums: The District Health Conference of about 300 or 400 people and several forums of about 100 people

with guest speakers who would address a particular issue or group of issues.

What advice would you give to a committee that was planning a regional workshop on aging and developmental disabilities?

I think venue is important and meals are less important. You don't have to spend a

lot of money on meals. The number one issue is you want a good conference; to have strong speakers and at least one well known speaker; not just someone who writes well or someone who is published, but someone who really engages the audience and gets people walking away with what he or she said.

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The Newsletter of the Ontario Partnership on Aging and Developmental Disabilities

Submissions to the newsletter are invited from regions, local projects and partnering organizations

BULLETIN

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LONG TERM CARE AND DEVELOPMENTAL SERVICES: WORKING TOGETHER

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contrary to several decades of work that has focused on opening society to people with developmental disabilities. It ignores the rights of all Ontario seniors to access services they need.

Third, there is a fear that partnering will lead to reinstitutionalization of people with developmental disabilities. This fear is understandable given the work to take people out of institutions where their lives were lived in separation from society. However, the vast majority of seniors benefit from appropriate support services such as day programs, foot care, meals on wheels, visiting programs and supportive seniors apartment. Less than 5% of people over the age of 65 move to a long term care home.

The partnership is seeking equitable access to all seniors' services for older adults with developmental disabilities. Such access is of central importance to ensuring quality of life. The continuum of seniors' community programs in Ontario supports wellness, social interaction, learning and continuing independence.

The realities are: there will be no large influx of new funds to the developmental services sector; family caregivers are aging; developmental service providers do not have education and experience with the aging process; and the aging boom includes people with developmental disabilities.

Partnering offers a pivotal strategy to respond effectively to these realities. It allows for the free trade of knowledge about aging and developmental disabilities so all

caregivers are equipped to support the transition of people to older adulthood. A reasoned approach to collaboration will ensure that people with developmental disabilities have access to the richness of programs and services available to all Ontario seniors. Transition planning, informed by cross sector knowledge exchange, offers a means to support aging that has as its hallmark, by quality of life.



SUCCESSFUL WORKSHOP PLANNING TIPS

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That has always been the key. If I can walk out of there and say at least one of the speakers was really dynamic and had good content, then I have been to a really good conference. I can forget what the meal was like. I can even forget what the venue was like. A good speaker will draw people even if that person is only there for one hour. The other value of most conferences is in the participants speaking to each other. If you have a strong dynamic speaker who has a good message then the participants start talking to each other about it and find ways of saying, "We could do that here. We could do that in our area. We could make this happen."

The key is bring in a strong keynote speaker and the conference will be a success.

How would you ensure a good workshop program that offers variety and holds people's interest?

You need a strong theme. Tie your keynote speaker to a theme. Then you need people to talk about examples, what works, lessons learned, stories. You want other speakers to be people who tell stories of what is happening on the ground. Another option is to break into group sessions for discussions or offer a panel presentation with opportunity for people to explore the issue further and report back. A working conference needs people to tell stories and then opportunity for everyone to sit down and start thinking how they can do that in their jurisdiction, how they can make it happen.

What do you feel are the best ways to market a workshop?

I think paper is still best. I get a ton of e-mail. I know that is a quick and easy way to get material out, but I lose stuff on e-mail because I get so much of it. I still think that something that

catches my eye; I will remember it. The picture will be in my mind and I will search for it. It think it is important to use paper and be professional in crafting the image you want to convey for the conference.

Other planning tips?

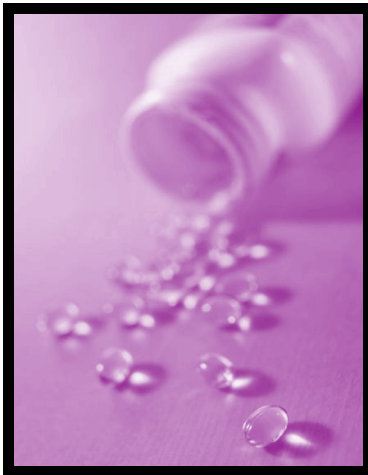
Get a well know keynote early. This is possible even in smaller communities. Once I called up Jeffrey Simpson who writes for the Globe and Mail and asked him if he would come to a conference we were planning. He normally wouldn't come to something in a small community. Anyway, we started talking about dates and he said, "My son is at University in Windsor. I'll come to your conference and then go over to see him. You can count on me I will be there." All of a sudden our conference became exciting. I was able to call other speakers, tell them we already had Jeffrey Simpson and they would say, "I'll speak too." Also, make it fun. I go to a lot of conferences and I like the ones that are fun.

INTERNATIONAL STUDY ON DOWN SYNDROME

BY MARY DRAPER, M.A. (PSYCH) BETHESDA OUTREACH SERVICES, ST. CATHARINES

An international research initiative in the field of dementia is currently underway in various locations in Ontario. Funded jointly by the National Institutes of Health and Aging in Washington D.C. the goal of this project is to determine whether administration of high doses of Vitamin E will delay or slow down the progression of cognitive/functional declines associated with Alzheimer disease in aging persons with Down syndrome. To date, 18 individuals in Ontario have been enrolled in the study, the vast majority of these recruited by staff from Bethesda's Outreach Services in Niagara.

Bethesda is proud to be working collaboratively in this initiative with the New York State Institute for Basic Research in Developmental Disabilities (IBR) in Staten Island, NY, one of the principal research sites for the study.



Individuals with Down syndrome 50 years of age or older, with or without a diagnosis of Alzheimer disease and at all levels of mental disability will be eligible for enrollment. Prospective candidates will be required to undergo a comprehensive medical screening and capacity assessment in order to determine their eligibility for admission to the study. Once selected, all participants will be followed up for a period of 3 years with medical monitoring and cognitive/functional evaluation of

dementia status, object memory, cumulative spatial memory, visual recognition, skilled movement, expressive language and adaptive life skills completed by the research team at regular 6 month intervals. Stable use of cognitive-enhancing agents like Aricept is permitted if the individual is already under treatment for dementia.

Some of the exclusion criteria are a prior history of heart failure, severe sensory impairments (blindness), current use of anticoagulants and regular use of vitamin E greater than 50 units per day. At each study site, for those individuals admitted into the study, a side-effect checklist will be administered and subjects will undergo a physical examination and laboratory testing. Additional monitoring will include detailed evaluation of signs and symptoms associated with cardiovascular disease and diabetes in order to address some recent concerns associated with vitamin E use. A vitamin E regimen of 1000 international units twice daily plus a multivitamin will be utilized in this randomized double-blind, placebo controlled investigation. All candidates will be assigned a research number in order to protect their identity with half of the participants assigned to the treatment group and the other half to placebo as is usual in research of this kind.

A signed consent, provided by those individuals who are considered capable of consent, will be obtained prior to their participation in any of the procedures. Also, a signed consent will be obtained from an appropriate surrogate for those individuals who are not deemed to have the capacity to consent. Individuals who meet the DSM IV criteria for dementia will be considered as lacking capacity to give informed consent.

The study organizers in the U.S. are aiming for a total international enrollment of 350 participants. To date, 265 individuals in the U.S.

England, Ireland, Australia, New Zealand as well as Canada have been enrolled in this project so there is currently room for substantially more participants.

If you or your colleagues are aware of or have been involved in the care of individuals with Down syndrome who meet the appropriate age and eligibility requirements, the researchers would be pleased to discuss with you the prospects for their inclusion in this important international study.

For more information contact:

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(905) 684-3160 ext. 229



This is the first large-scale treatment study of Alzheimer disease in a specialized genetically predisposed population. Should the potential benefits of the project yield positive evidence of the benefits of vitamin E, it could ultimately contribute significantly to changes in the standards of care for older persons with Down syndrome and will be a model for future efforts at implementing effective treatments developed for sporadic Alzheimer disease to the population of at-risk individuals with developmental disabilities.

SUCCESSFUL WORKSHOP PLANNING TIPS

AN INTERVIEW WITH DAVE ZAGO OF ZAGO ASSOCIATES CONSULTING

What experience have you had planning conferences and workshops?

I've planned many events ranging from 30 to 150 attendees.

What makes a workshop great?

The quality of the speakers. If you have high quality speakers and give them enough time, they will make the event a success.

What advice would you give to a committee planning a regional workshop?

Ask yourself who your key audiences are and build a program to meet their expectations. Are you after a multi-sector audience? If so, build a program that can cross several foci. Are you targeting a particular group or sector? If so, design an in-depth program for them. Are you after a "lay of the land" workshop where folks are brought up to speed on a set of topics? Are you after a "futuristic" workshop where folks are expected to think what the world might look like 10 years from now?



How would you ensure a good workshop program that offers variety and holds people's interest?

Depends on your workshop theme. Once you've settled on a theme, think about some "unusual suspects" to be key speakers or facilitators. Seeing the same faces gets boring. Look out-of-province or out-of-country for speakers if you have to. This will raise the cost

"If you have high quality speakers and give them enough time they will make the event a success."

but sometimes these folks are coming to Ontario for a gig and you can piggy-back on that. I built the Rural Aging Conference on the schedule of a guy from Saskatchewan who was a draw. He was coming to Ottawa in mid-March and I asked him to take the train to Stratford and he did. So, we did our conference at the end of March. I was then able to build other speakers around that.

The question of discussions is tricky. If it is a conference where I'm coming to hear some leading edge thinking, some strategic advice, or explanation of a complex topic, I'm not interested in hearing what people next to me have to say. In those instances I prefer no break out discussions. If I'm planning a workshop intended to generate local action or awareness, then I would build in either small group discussions or facilitated large group discussions.

What do you feel are the best ways to market a workshop?

Send out an event notice early so that folks can mark their calendars. Put event notices in association or agency newsletters. Follow up with registration packages and easy Registration instructions. Inform the media running up to the event.

Other tips?

You need good sound and audiovisual equipment. Some sites don't have good quality systems so you can run into problems if you rely on them to support your sound and A/V presentations. I found a sound guy for hire who would

bring his equipment and stay for the day to control volume and so on. When you're in a big room such as a hall or arena, the on-site speakers in the ceiling often don't work very well. Having an experienced sound technician really makes a difference to people's ability to hear what is going on.

Having a smooth registration in the morning also helps to get the day off on the right foot. If the registration is delayed, it can put attendees in a bit of a snarly mood. You need the big ideas to build the program and make it attractive but you need the little details to pull it off and make it a success.

If it is a regional workshop, think of mutually inconvenient locations to hold it where everyone has to travel a reasonable distance rather than requiring some people to travel too far. That usually means having urban attendees travel to less-urban locations. Sometimes, it's worth hosting the event in a smaller urban centre such as a Stratford. That can cause problems for speaker's travel so beware. My colleague did a conference in Owen Sound once and she had to go to Oshawa to pick up the main speaker. There's no train or plane service to Owen Sound and the guest speaker wasn't driving all that way by herself. So, the adage *location, location, location*, applies to event planning as well.



MAINTAINING QUALITY OF LIFE THROUGH CROSS SECTOR PARTNERSHIP

BY JANE POWELL AND TASNEEM KARIMJEE

Partnership between L'Arche Toronto and the Community Care East York Adult Day Program - told by each of the service providers.

The L'Arche Perspective

Patsy and Dorothy are two women with intellectual disabilities who are members of L'Arche Toronto and participate in the East York Adult Day Program. Patsy and Dorothy have been welcomed and well integrated at the program for a number of years. They both enjoy their time there immensely. There has been a kind of no fuss, no muss attitude on the part of day program staff. Whatever needs to happen for Patsy or Dorothy to have a good day and find their place, happens. We at L'Arche are happy that Patsy and Dorothy have a place to go to during the day where they are accepted and their gifts welcomed. When asked about the day program Patsy always comments, "I like going there."

Perspective of the Community Care East York Adult Day Program

Patsy Ramsay has been attending the Adult Day Program at Community Care East York since 1996. She starting coming once a week and integrated well with the clients and staff. She especially enjoyed the music programs and the various arts and crafts programs. She enjoys singing and is able to do so without the use of a

songbook. Patsy also goes on several of our day trips. Her favorite place is Windreach Farms.

Patsy currently attends three times a week and is a well loved client not only by the other members but by staff as well. The key to Patsy's success at the Adult Day Program is that she was



Dorothy Arthur and Patsy Ramsay

treated like everyone else and was expected to share her opinions and views throughout the day. She is recognized and valued for her comments. The staff ensure that Patsy has an opportunity to join programs where she is challenged & interested.

Dorothy Arthur joined the Adult Day Program in 2001 and has flourished as

well. When Dorothy first started, she isolated herself by requesting coloring, which is a solitary activity. However, over time staff have been able to integrate her into most of the programs. Despite her hearing loss, Dorothy has adapted very well and is an expert at lip reading. Over the years, she has taught us key phrases in sign and we have been grateful for further training on common Sign Language usage from Mike MacKenzie at L'Arche. The training was important not only for the staff but the clients as well as it strengthened the atmosphere of acceptance. Dorothy loves Bingo, puzzles and our own creation, "Cover Up Dice."

Dorothy also enjoys arts and crafts and social events especially birthday parties. Whenever a member has a birthday, Dorothy quickly pulls out paper and crayons and makes them one of her special and unique cards.

Patsy and Dorothy come on the same day each week. This has developed their relationship further. They save seats for each other and ask about events happening outside of the program. They look out for each other at the centre and provide evidence that the Day Program fosters friendships, caring and nurturing for clients.

REPORT FROM SPECIAL OLYMPICS IN THE UNITED STATES: MAJORITY OF HEALTH PROFESSIONALS NOT TRAINED TO TREAT HEALTH PROBLEMS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

A new report by Special Olympics in the United States shows that health professionals are not receiving adequate training to treat people with developmental disabilities. As a result, this special population is often overlooked in the health care system. The study was led by Stephen Corbin, Dean of Special Olympics University and Matthew Holder, Executive

Director of the American Academy of Developmental Medicine and Dentistry. The mounting pressures on the Canadian health care system suggests that this report can inform caregivers and advocates in Canada about possible shortcomings in health care for seniors with developmental disabilities. To view the report go to:

[Http://northamerical.specialolympics.org/research/documents/CACW_Health.pdf](http://northamerical.specialolympics.org/research/documents/CACW_Health.pdf)



OSTEOPOROSIS CANADA LAUNCHES NEW EXERCISE AND EDUCATION PROGRAM

Osteoporosis may not currently be on your radar screen, but you should know that anyone can develop osteoporosis and at any age. Certainly there are people who are at higher risk for this disease, but the fact remains that anyone can develop porous, fragile and easily broken bones. This insidious disease is dubbed “the silent thief” because there are often no symptoms until a fracture occurs. In fact, osteoporosis can weaken bones to the point that a sudden strain, bump, or fall can cause a fracture or a vertebra to collapse.

“One in four women and at least one in eight men over the age of 50 have osteoporosis.”

The reduced quality of life for those with osteoporosis is enormous. Osteoporosis can result in disfigurement, lowered self-esteem, reduction or loss of mobility and decreased independence.

Ontario is home to nearly 1.5 million seniors (people aged 65 and over). This figure represents 40 per cent of Canada’s senior population. The number of seniors in Ontario and around the world is expected to increase even more rapidly when baby boomers turn 65 beginning in 2011. One in four women and at least one in eight men over the age of 50 have osteoporosis. It therefore becomes critical for Osteoporosis Canada to educate Ontario’s senior population on the issues related to the disease.

In response to this looming epidemic, Osteoporosis Canada is now drawing on their legacy as the first national organization created to serve people who have or are risk for osteoporosis. As a result, they are proud to introduce a new education and exercise program called **Break Through**.

Funded by the Ontario Ministry of Health and Long-Term Care, **Break Through** champions a holistic approach to the diagnosis, management and treatment of osteoporosis. The program provides basic information about the disease, nutrition and exercise as well as describing resources designed to strengthen program delivery and community linkages.

The **Break Through** Program includes three essential components:

- Adult Education
- Bone Health
- The development of Bone Mineral Density testing standards and guidelines.

This new program has been designed for adults over the age of 50 and will be delivered through various organizations such as participating seniors’ and recreational facilities across Ontario. Community linkages and connectivity among service providers will be crucial to ensure effective delivery of osteoporosis care.



Participants in the **Break Through** program will receive interactive information about bone health and facts about reducing their risk of osteoporosis and osteoporotic fractures, along with an exercise program designed to maintain bone strength and prevent bone loss and falls.



Break Through champions a holistic approach to the diagnosis, management and treatment of osteoporosis.

Osteoporosis Canada is producing a new exercise DVD that stresses the importance of early education, supports improvement in the quality of Bone Mineral Density (BMD), testing and reporting of the results to physicians. Increased public awareness of the disease and its risk factors will empower Ontarians to make informed choices about their bone health.

To find out if the **Break Through** program is available in your community, visit the Break Through section of Osteoporosis Canada’s Web site at :

www.osteoporosis.ca
or call the office at 1-800-463-6842.

OPADDD REGIONAL BRIEFS

Central East has received MCSS Innovations Funding to conduct focus groups in each geographic area of the region. The groups will identify issues related to the aging of people with developmental disabilities in the LTC and DD sectors. Central East is also working on ensuring representation from First Nations and other cultural communities.

Hamilton/Peel/Brant/Halton/Niagara Falls is moving forward with the help of MCSS Innovations Funding to establish a foundation for Citizenship with Aging and Developmental Disabilities. The citizenship framework includes obtaining a clear picture of the demographics of older adults with a developmental disability and identification of opportunities for inclusion. The region's first time workshop was held September 25, 2005.

Northeast with the leadership of Sudbury Developmental Services, has been building a cross sector committee over the past few months. Partnering across the huge geography of the Northeast is a core element of planning. Northeast has scheduled their first time workshop for September 28 and 29, 2006.

Northwest established a workshop committee to plan their follow-up workshop. The committee has been meeting regularly and a follow-up workshop has been scheduled for March 30 and 31, 2006. The challenge of planning across the vast Northwest geography is being managed through teleconferencing.

Ottawa Champlain has established terms of reference and built a representative cross sector committee that also includes the University of Ottawa, Social Planning Committee of Ottawa, Council on Aging, Parent Group, Ministry representatives. Their first time workshop will be scheduled for the spring or fall of 2006.

Southeast is now developing their follow up workshop program. A two day follow-up workshop, with funding assistance from the Ministry of Health is scheduled for April 18 and 19, 2006. One full day will be devoted to building strategy for the establishment of a sustained cross sector planning process.

Southwest is holding discussions with key players in the long term care and developmental services sectors as well as with both Ministries. Discussions are focused on developing strategy to

re-establish a sustained cross sector process. Volunteers are beginning to come forward from both sectors. Southwest has yet to schedule their follow -up workshop.

Toronto has established a committee with the help of MCSS Innovations Funding, is developing a process to engage all service providers and other players in both sectors. The engagement process include strategies for supporting cross sector partnering across Toronto. Toronto's first time workshop will be scheduled for sometime in 2006.



Regional workshops are serving as the catalyst to developing cross sector planning capacity across Ontario

UPDATE ON ASSISTIVE DEVICES

Thousands of Canadians have improved their quality of life by using assistive devices to maintain their own independence and reduce dependence on family and caregivers. The evolution of assistive technologies offers new possibilities for people with disabilities. Assistive technologies are developing in many areas of human functioning: communication, cognition, personal care, personal mobility, housekeeping, recreation and adaptations to homes and premises.

As assistive device is any product that can be used to make the activities of daily life at work, home or play easier.

Depending on the assistive device and individual situation, a person may be able to obtain financial assistance from the provincial government to purchase a needed assistive device. Service clubs in some communities may offer assistance with the cost of assistive devices.

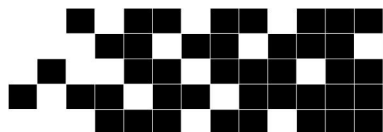
When acquiring an assistive device, it is very important to understand proper use and maintenance. Find out about any warranties, procedures to be followed in using the device, regular maintenance, cleaning and servicing of the device is the responsibility of the user.

Information about assistive devices and related Ontario Government programs can be obtained by telephone or via the web.

*Ministry of Health & LTC Info Line
(416) 327-4327 or
toll free 1-800-387-5559*

*Assistive Devices and Home Oxygen Program (416)327-8804 or
toll free 1-800-268-6021*

http://www.health.gov.on.ca/english/providers/program/adp/nletter/nl_0106.html



Ontario Partnership on Aging & Developmental Disabilities

Building Bridges Between the Long Term Care and Developmental Services Sectors

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Your gateway to information on aging and
developmental disabilities
www.opadd.on.ca

OPADD's Aging and Developmental Disabilities Project
is funded by:



Our Vision

That older adults with a developmental disability have the same rights to support and services as all older adults.

Our Principles

CHOICE
ACCESS
CREATIVE OPTIONS
INDIVIDUALIZED PLANNING

Local Solutions

OPADD believes that local community groups are key to producing tangible results by linking both sectors at the level of the local agency with participation from local planning bodies. Each organization retains its autonomy and enriches its capacity to support people with a developmental disability as they age.

THE IMPORTANCE OF ORAL HEALTH

Having healthy gums and teeth is vitally important to maintaining good health. Unhealthy gums can result in painful infections, tooth loss, difficulty eating and problems in speaking. Poor oral health puts seniors at risk for serious health problems such as heart disease, stroke, pneumonia and diabetes.

Seniors generally have less access to oral care services since dental care is not covered by the health care system. Older adults with fixed incomes are forced to pay basic bills for rent, heat and food at the expense of dental care. People with developmental disabilities are not only subject to a basic fixed income in their senior years but may be unable to articulate symptoms related to gum disease and tooth decay. This places added responsibility on caregivers to ensure a good program of monitoring, prevention and treatment of oral health is in place. Oral health problems can be prevented through good habits and regular check-ups.

These oral health care tips can help

caregivers and seniors with developmental disabilities maintain good health of teeth and gums:

Flossing: Removes bits of food and plaque from between teeth and under the gum line. Flossing keeps gums healthy.

Brushing: Maintains good health in the mouth if done correctly. Proper brushing includes:

- Brush twice a day with a soft brush with rounded bristles
- Change the brush every 3 months
- Choose a brush that lets you reach your back teeth.
- Use a toothpaste with fluoride
- Brush in gentle circles for 2-3 minutes
- Brush your tongue

False Teeth: The person with false teeth must still be concerned with oral hygiene and health:

- Clean false teeth every day; soak them overnight in denture cleaner

or warm water and vinegar.

- Take them out at night and brush them; massage gums with toothbrush or damp cloth.

Dental Implants: Implants such as crowns and bridges are much like regular teeth. Since implants are not as strong as teeth they must be handled gently when flossing or brushing.

Visit your dentist regularly!

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