THE OPADD LETTER

FALL 2007

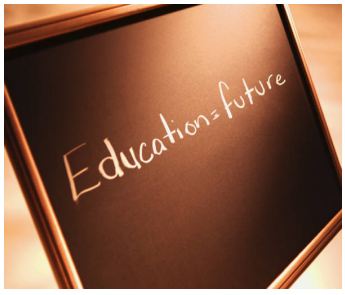
MAKING A DIFFERENCE: KNOWLEDGE CREATION

Our cross sector partnership is about making a difference for older adults with a developmental disability. A cornerstone in this process is creating new knowledge about aging with a developmental disability. Since this is the first generation of people with a developmental disability to live into old age. OPADD Regional Committees are supporting knowledge creation through innovative cross sector learning projects. Two are featured in this edition of the OPADD Letter.

Central East Identifies Educational Needs of Service Providers

One of six project committees in the Central East Region is researching the learning needs of paid caregivers. The findings will shape ongoing training programs to build cross sector knowledge about aging and developmental disabilities.

Information on learning needs was gathered through focus groups held in five geographic areas across the region: Midand, Penetanguishene, Orillia, Barrie and South Simcoe. A broad range of service providers participated.



Participants were first given information about OPADD's role as well as the accomplishments and directions of the Central East Regional Committee. They were then divided into focus groups to identify staff educational needs. The committee is now analysing the findings and will be planning new learning opportunities in the coming months. Focus group participants were offered the opportunity to help with this planning.

For more information about the Central East project contact:

Lorraine Jelly
Administrator
Coleman Care Centre
140 Cundles Road, West
Barrie, ON
L4N 9X8
Phone: 705-726-8691
Fax: 705-726-5085
lorrainejelly@rogers.com

Toronto Regional Committee Launches Exchange Program

Last year, the Toronto Committee tested the value of cross sector exchange visit as a low cost learning method. Committee members teamed up for reciprocal visits to one another's agencies. The test exchange program found that participants easily acquired new knowledge and understanding about the other sector. The results were so positive that the committee is broadening the exchange.

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LONG TERM CARE HOME ACCESS PROTOCOL FOR ADULTS WITH A DEVELOPMENTAL DISABILITY

The protocol, distributed mid 2006 provides a framework to ensure appropriate transition and ongoing support for adults with a developmental disability who move to a long term care home. Read how its working in real lives.

SEE PAGE 2

Inside this issue:

LONG TERM CARE HOME ACCESS PROTOCOL FOR ADULTS WITH A DEVELOPMENTAL DISABILITY: A CASE STORY

The Ministry of Community and Social Services and Ministry of Health and Long Term Care published their joint protocol in mid 2006. It provides a framework for planning when an adult with a developmental disability needs to move to a long term care home. This story about one adult seeking to move to a long term care home illustrates how the protocol provides for individualized planning.

A client moving to the community from Huronia Regional Centre was in need of more support than the developmental services agency could offer. The client was assessed through the CCAC to determine which long term care programs might provide the needed support. One of the factors taken into consideration in the process was that the client had a relative living in the Peel region. Malton Village, a long term care home in Peel was contacted to see if they would accept the client once the placement planning process was completed. Malton Village has experience with transition planning of older adults to a long tem care home.

A series of transition planning meetings were held involving Malton Village and MCSS to discuss the client's needs, the home's resources and the opportunity for cross sector collaboration. The client was deemed to require augmented support services. Consequently, Mary Centre was approached to explore how it might serve the client as the developmental services agency in partnership with Malton Village.

The client's sister and MCSS staff visited Malton Village to assess the suitability of the long term care home for the client. Subsequently, a staff team from Malton Village visited Huronia Regional Centre to meet with staff there and to learn more about the client's daily care routines, participation in social activities, recreation programs, dietary preferences and requirements and needed physiotherapy. The transition planning process identified the following:

- Transitional staff support from Mary Centre in the form of visits with the client to oversee the settling in period. This support was reduced as the client became oriented to the new surroundings.
- Eight hours per day of individualized support hours to assist with daily hygiene and maintain services received prior to the move. Support hours were split into two shifts of four hours each.
- Need for adaptive devices including a specialized low flow mattress, repositioning aids and a specialized commode so the client could be toileted on a regular basis.
- Private accommodation for the client.
- A reassessment to take place at the end of the first three months of the placement.

The latest report on this transition process indicates the client has adjusted very well to the new surroundings and to the staff. The family has expressed satisfaction with the care being provided.

UPDATE: MCSS FACILITY CLOSURES INITIATIVE

In Years 1 & 2 of the Facilities Initiative 443 residents have moved to community:

- 113 residents moved to the community in Year 1 (2005-2006)
- 330 residents moved to the community in Year 2 (2006-2007)

Out of all the moves, 12 individuals (3%) moved to a long term care home.

At the end of June 2007, a total of 468 individuals will have moved to the community, leaving 493 individuals at the 3 facilities.

All of them will be moving to community by March 31, 2009.

PROVINCIAL GOVERNMENT PARTICIPATION IN THE CROSS SECTOR DIALOGUE

OPADD is in continuing dialogue with the Ministry of Community and Social Services and the Ministry of Health and Long Term Care about issues surrounding aging and developmental disabilities.

OPADD's dialogue with the Ministries is based on building cross sector capacity to learn, plan and support older adults with developmental disabilities. A few highlights:

Transition Planning

A key strategy in the support paradigm is transition planning to older adulthood. OPADD believes that the geographic and social diversity of Ontario will require the identification of several different transition planning models. While there may be some variability among the models, OPADD has identified common success factors in transition planning. A formal evaluation study of the models can confirm the presence of the success factors and their impact on outcomes. The findings of the evaluation can provide a basis for decisions about transition planning models and practices. OPADD believes that a formal evaluation will equip both sectors for success in transition planning.

Protocol for Access to Long Term Care Homes

The new protocol has provided valuable guidance to planners and service providers. The protocol affirms that planning shall be based on client need. It provides for individualized staff support from the developmental services sector for people who move to long term care homes. OPADD has submitted a brief to the Ministries to provide feedback on the protocol and suggest changes to clarify its intent.

U-First! Training

U-First! Training grew out of the MOHLTC Alzheimer Strategy and provides opportunity for cross sector training that benefits all older adults with dementia. The tendency for people with Down-Syndrome to exhibit symptoms of Alzheimer Disease, makes U-First! Training a key part of any education strategy for developmental services and long term care staff. For more information on newly available U-First Training watch the opadd web-site. **www.opadd.on.ca**

MAKING A DIFFERENCE: KNOWLEDGE CREATION

Continued from page 1

The next "Walk in My Shoes" initiative has been organized to take place this fall to build bridges and bridge gaps in support of older adults with a developmental disability.

The model is simple. A letter describing the exchange program and a short registration form was sent to all Toronto agencies. They were invited to participate by completing a short registration form. There is no fee to participate. Interested agencies complete and return the form to a central address. Agencies are then matched on a cross sector basis.

Registrants of matched agencies arrange the best date and time for their reciprocal visits. Participants will have opportunity to learn about the philosophy, program models, legislative requirements and staffing patterns in one another's sectors.

Based on experience with the test of cross sector exchange visits, new working relationships will be formed. These cross sector relationships will provide a foundation for continuing cross sector training, planning and support of older adults with a developmental disability.

A Ryerson student on placement with one of the agency members of the Toronto regional Committee is providing administrative support to the venture.

For more information about the Toronto "Walk in My Shoes" initiative contact:

James Sejjengo
927 Clark Avenue W.
Thornhill, ON L4J 8G6
Tel: 905 889-2690 ext. 2045
Fax: 905 889-3827
E-mail: jsejjengo@reena.org

PLANNING YOUR REGIONAL WORKSHOP

Regional workshops are the foundation for establishing cross sector working relationships, building knowledge and facilitating local projects. Planning and delivering a workshop that can deliver on these goals requires excellent planning skills and an appropriate workshop program. One of the best planning processes incorporated into a workshop was seen in Barrie last November. The two day event was designed to allow participants to build on what they know and reach out to those who have not yet become involved in partnership activities. OPADD has developed a Guide to Planning Your Regional Workshop, based on what we know about what works. The Guide also provides a detailed explanation of how eligible regions may apply for up to $5000.00 in funding from OPADD to offset workshops costs. An excerpt from the Guide that deals with planning the process part of your regional workshop follows. For more information see the Guide on the home page quick link at www.opadd.on.ca

CLEARLY PLAN THE PROCESS

Identify the goals to be achieved by the process. Then build a process that moves the group to the desired outcome. Planning must also consider the roles of the players who will be attending, the time and space available and strategies for sustaining new working relationships following the workshop.

IDENTIFY YOUR FACILITATORS

Know who will be facilitating the plenary and small groups sessions; orient them to what is required; involve them in planning the process; ensure all facilitators are

working from the same page.

SUPPORT THE GROUP IN MOVING THROUGH THE PROCESS

Set the Stage – opening remarks about the process to be used; expectations of individual participants; outcomes to be achieved; goals to be clarified.

Explain the Task – provide clear instructions about what the group or groups are to do; where they are to do it; resources available; time limits; reporting requirements.

Guide the Groups – ensure that there is an identified facilitator and recorder within each group to provide the necessary support during group discussions.

Provide for Reporting Back – building a group plan from small group discussions and planning work gives all participants the bigger picture that is unfolding; avoid too many small group reports that are repetitive and long-winded as this is a sure way to lose the audience; implement strategies to keep reports focused and lively; ensure everyone gets the proceedings.

MAP OUT THE PROCESS

Once your process has been defined by clear objectives, map it out and dovetail it into the rest of the workshop programme. A sample process follows:

Provide Context – present information on environmental factors that impact the cross sector process; conduct a SWOT analysis; provide an update on regional achievements since the previous workshop.

Set Direction – exercises to identify the vision or outcomes desired; consolidation of ideas to identify themes and/or areas for collaboration; identification of questions that need to be answered.

Do Group Work– breakout groups to expand on designated themes and respond to focus questions.

Have Groups Report – groups provide feedback to the plenary session; identify areas of emerging consensus; clarify possible next steps to complete the process.

Plan Next Steps – identify and provide action planning principles, methods and templates; assign people to specific action groups by geography and/or topic areas; continue small group discussion to complete action plans and identify outcome indicators.

Plan for Sustainability – identify factors that can promote and prevent achievement; confirm key success factors; clarify requirements for continuing support and coordination of work, monitoring and follow-up, responsibilities and time frames.

Build in Accountability – provide written descriptions of action and sustainability plans to all participants; confirm date and time for next steps, follow-up, implementation.

DIALOGUE ON STEWARDSHIP

RON CORISTINE, PROJECT MANAGER
ONTARIO PARTNERSHIP ON AGING & DEVELOPMENTAL DISABILITIES

Should older adults with a developmental disability move to long term care homes? The dialogue around this question is pivotal to moving beyond prejudice about people with a developmental disability and walking our talk about inclusion and stewardship of public funds.

Our view of people with a developmental disability has evolved. We no longer accept the idea that they are less than fully human. Today, people with a developmental disability are protected from discrimination through legislation such as the Ontario Human Rights Code. This evolution of thought and legislation allows older adults with a developmental disability to access the full continuum of services and programs for Ontario seniors.

This guaranteed access dovetails with the philosophy of inclusion held by the developmental services system. Inclusion is part of the vision that people with a developmental disability have opportunity to be included in society to the greatest extent possible. Inclusion encompasses things such as schooling, employment, community organizations, health care and old age security. The developmental services system believes that people with developmental disability should not be separated in parallel systems such as the old provincial institutions for retarded persons.

However, the promotion of inclusion is stalling as old ideas and prejudice get in the way of clear thinking about how to plan the transition to older adulthood for people with a developmental disability. Some LTC service providers have no previous experience with developmental disability and are reluctant to accept them as clients or members. Some developmental service providers feel that older adults with a developmental disability should not use the long term care continuum of services. The logical extension of this exclusionary thinking will require the creation of a parallel system of services for older adults with a developmental disability. This is not mindful of the philosophy of inclusion and raises serious questions about responsible stewardship of public resources. In effect, young people with a developmental disability would be unable to receive support within the developmental services system as it reshapes itself into a parallel LTC system.

While it is the norm that families and caregivers strive to keep aging members at home as long as possible, the changes associated with aging can sometimes be too severe. At some point quality of life cannot be maintained despite the best efforts of everyone concerned. This is the tipping point. This is where the aging individual and care-givers must face the prospect that any mix of developmental and seniors services will not be enough. Serious consideration must be given to moving to a long term care home. However the tipping point need not be a crisis. It can be anticipated and sometimes even delayed through effective transition planning throughout older adulthood. In some cases, effective transition planning to older adulthood can avoid the need for a move to a long term care home.

The Ontario Partnership on Aging and Developmental Disabilities brings players in the long term care and developmental services systems to a dialogue on these issues. To date the partnership has developed cross sector planning capacity, knowledge exchange, models of transition planning to older adulthood and several resource guides. The partnership is also working closely with funding Ministries to develop greater capacity for cross sector collaboration such as the joint Ministry protocol for access to long term care and funding of staff dedicated to supporting older adults residing in long term care homes. The goal here is to ensure that access to long term care homes and all services for seniors is appropriate, planned and supportive of quality of life. For more information visit www.opadd.on.ca

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RESEARCH IN AGING WITH DEMENTIA

The growing prevalence of dementia is reinforcing the attention of researchers to understand its onset and progression. The research abstract presented research illustrates a creative approach to diagnosis.

THE POTENTIAL OF GAIT ANALYSIS TO CONTRIBUTE TO DIFFERENTIAL DIAGNOSIS OF EARLY STAGE DEMENTIA: CURRENT RESEARCH AND FUTURE DIRECTIONS - CANADIAN JOURNAL ON AGING - Volume 26, No. 1, 2007, Page 19

- by Debra Morgan, Melanie Funk, Margaret Crossley, Jenny Basran, Andrew Kirk and Vanina Dal Bello-Haas

The prevalence of dementia is increasing worldwide, with an increase predicted in the industrialized world from 13.5 million affected to 36.7 million in 2050. Incidence rates from CSHA translate into 60,150 new cases of dementia per year in Canada. Alzheimer's disease accounts for the majority of all cases. Early differential diagnosis becomes increasingly important as new pharmacological therapies are developed, and also provide more opportunities for patients and family members to make informed decisions to facilitate timely access to appropriate behavioural and supportive interventions designed to improve quality of life for patients and their caregivers.

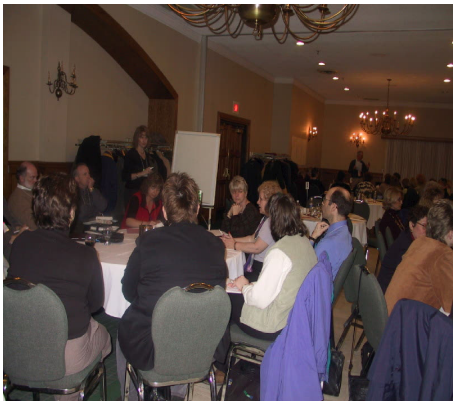
Information about gait characteristics (the pattern or manner of walking) is informative in the diagnostic process, in identifying patients at risk for falling as well as future functional and cognitive decline and may have important implications for discriminating among dementia subtypes (Alzheimer's disease, vascular dementia, dementia with Lewy Bodies, and fronto-temporal dementia).

Several factors contribute to the difficulty in interpreting existing literature examining gait patterns in persons with dementia. It has been argued that lack of precision in characterizing movement disorders in AD has been a major barrier in distinguishing AD from other degenerative disorders with cognitive, behavioural and motor symptoms. Others have observed the inconsistent use of terms in literature.

Evidence is mounting that specific types of dementia may have characteristic gait abnormalities, but more research is needed to identify further which gait patterns and abnormalities are unique and which are common across dementia types. Of special importance is information on gait changes in the early stages of dementia, when differential diagnosis is especially difficult but also critical in developing treatment and management approaches.

In conclusion, research is beginning to uncover the associations between dementia subtypes and gait characteristics. Future research, including autopsy studies, will continue to expand knowledge in this area, contribution to the efficacy of the assessment process for individuals suspected of having dementia and enhancing patient care throughout the disease process.

THANKS TO OASIS FROM OPADD REGIONAL WORKSHOPS



In 1999, the Ontario Association Supporting People with Special Needs (OASIS) made a commitment to assist with funding of eight first time cross sector regional workshops.

This funding was provided to the four first time workshops held in London, Kingston, Sudbury and Barrie in 2000/2001. The organizing committee for each workshop received $1,000.00 from OASIS at that time in addition to other seed money.

More recently, in 2006/07, the remaining four regions (Northeast, Ottawa/Champlain, South Central and Toronto Regions) received $1000.00 each from OASIS towards the cost of delivering their first time workshops.

THANK-YOU TO OASIS FOR THEIR ENDURING COMMITMENT TO SUPPORTING CROSS SECTOR LEARNING AND PLANNING CAPACITY!

Ontario Partnership on Aging & Developmental Disabilities

Building Bridges Between the Long Term Care and Developmental Services Sectors

Contact us:

Sandy Keshen, Co-Chair
Margaret Ringland, Co-Chair
Ron Coristine, Project Manager

Aging and Developmental Disabilities Project
C/o Reena
Toby and Henry Battle Centre
927 Clark Avenue West
Thornhill, ON
L4J 8G6

Telephone: 1-905-889-2690 ext.2203
Toll Free: 1-866-667-3362
Fax: 1-905-889-3827
E-mail: rcoristine@reena.org

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The Ontario Trillium Foundation
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Our Vision

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

Our Principles

QUALITY OF LIFE
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.

ADMINISTRATIVE SUPPORT FOR REGIONAL COMMITTEES: AN INTERVIEW

OPADD regional committees are central to focusing cross sector work in local communities. Some committees receive administrative support from one of their member organizations. There are advantages and "costs" associated with secondment of admin support. Maria Lagunzad provides admin support to the Toronto Region Committee (TPADD). Maria spoke to the OPADD Letter about her experience.

What are some of the tasks you perform for the committee?

I type and circulate the agenda for meetings and keep track of attendance. I attend meetings, usually once a month, and take minutes. Keep contact lists and contact information of committee members. Of course, preparing for a conference, workshop or a special project involves more to do such as sending out letters, corresponding with other committee members, preparing conference brochures, handling registration and getting supplies ready.

Approximately how much of your time do you spend on committee work?

Approximately 2 days a month are dedicated to committee work, once again unless the committee is planning a conference, workshop or special project, that would involve more time.

What support does your agency give you to provide this function?

Time.

What advice would you give to other regions who are looking for Admin. Support?

Having a background knowledge of both what the committee stands for and the organizations that are involved would help. Also basic administrative skills such as being organized and detail-oriented are helpful.

EXPAND YOUR KNOWLEDGE ABOUT AGING AND DEVELOPMENTAL DISABILITIES!
WATCH FOR NEW POSTINGS ABOUT LOCAL PROJECTS! **WWW.OPADD.ON.CA**