



## Report on a Series of Four Workshops

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## Introduction

Ontario has achieved notable success in supporting people with developmental disability. Today, these individuals live longer, fuller lives. And, while the focus of community advocates has largely been centred on the inclusion of children and adults in the community, there is a critical need to begin directing attention to the transition between adult and senior care for these individuals to ensure that there is capacity to address their needs in the future.

The “Developmental Services Results from the Survey of People Receiving Residential Supports” revealed that of the 15,256 people with developmental disabilities, who are receiving MCSS funded residential supports in Ontario, 59% are aged 40-64 years and 4% are over the age of 70. Because people with developmental disabilities typically age earlier than the general population, the need to make plans for the care of this emerging population becomes even more urgent.

This trend has created a natural intersection between the seniors and developmental disabilities service sectors. Aging adults with developmental disabilities require access to the full range of programs, services and supports for seniors. Senior service providers now must be familiar with the needs of individuals with developmental disability, and, conversely, developmental disabilities support service providers need to understand issues related to aging and the services that are available to seniors.

To address this need Reena, in partnership with four local OPADD committees (Ontario Partnership on Aging and Developmental Disabilities) sought support from the Ministry of Community and Social Services Fiscal Innovation Fund. The funding would be used to develop and host a daylong workshop in four southern Ontario locations to enhance knowledge and bolster collaboration among service providers in the seniors and developmental disabilities sectors.

## Background on OPADD

Reena is a non-profit social service agency dedicated to helping children, adults and senior citizens with developmental disabilities to realize their full potential and to become integrated into the mainstream of society. Reena, like many other agencies, began to feel the impact of an aging population in the late 1990s.

Through a partnership with Health Canada in 1999, Reena brought together leaders from the developmental services and seniors sectors to participate in a symposium, which became the

catalyst for the formation of the Ontario Partnership on Aging and Developmental Disabilities (OPADD). Health Canada then requested that Reena support similar events in four other areas of the Province. These were developed by new networks or committees and were called OPADD Regional Committees.

The purpose of OPADD is to bring together two sectors (developmental disability and seniors) in a collaborative partnership to provide seniors with developmental disabilities with the same access to services that are available to all Ontarians. The OPADD Regional Committees are overseen by the OPADD Collaborative, which includes MCSS, MOH-LTC, Senior Secretariat, OANHSS (Ontario Association of Non Profit Homes and Services for Seniors), OLTCA (Ontario Long Term Care Association) and OASIS. The Collaborative provides strategic leadership and ensures that the committees are working systemically.

In 2009, OPADD completed a successful, five- year Trillium project, which was overseen by the Collaborative. The project created a number of innovative, cross-sector programs and initiatives across the province, many of which have evolved over the years and still exist today. In 2008, OPADD applied and became an Aging and Developmental disabilities Community of Practice (CoP) through SHRTN (Seniors Health Research Transfer Network). SHRTN is now referred as SHKN (Seniors Health Knowledge Network) and is funded by the MOH-LTC. This network provides a virtual way to share information and encourage and sustain connections and networks.

The OPADD Aging and Developmental Disabilities CoP has over 700 participants, representing many different sectors, disciplines and levels within organizations, including participants from the research community, which helps to ensure our work is linked to national and international studies and is evidence-based.

In the last decade, there have been significant changes in the way that the developmental disabilities and seniors sectors work together and some excellent partnerships and relationships are emerging. However, through the OPADD Committees and various other planning tables, feedback indicates that there are challenges that need to be addressed and that more work needs to be done toward enhancing collaboration.

Many agencies have a difficult time with the transition process experienced by aging clients and have failed to reach out to the seniors sector for supports, perhaps feeling that they are experts on developmental disabilities and shouldn't have to reach out to others for supports. This often means that they only reach out to the seniors sector when they are in crisis and when there is an emergency.

Providers in senior's services have limited experience in supporting individuals with developmental disabilities, as they have rarely or never come into contact with them. As a result, they may have reservations about inclusion in programs and, possibly, admission into Long Term Care Homes, which presents significant risks and safety issues for individuals requiring senior support.

Similarly, many providers in the developmental disabilities sector are unaware of the continuum of senior's care that exists for all citizens of Ontario, and the fact that these services and supports enable individuals to remain in the community longer and prevent crisis and emergencies.

This lack of understanding and awareness in both sectors creates unnecessary barriers to service delivery, duplication of effort, fiscal strain, and considerable stress for staff. These negative outcomes could be circumvented through increased interaction and collaboration between the sectors.

## Conference Design

The overall objective of the workshops was to have equal numbers of leaders from the seniors and developmental disabilities systems together where they would have an opportunity to hear new information regarding dementia and developmental disabilities from experts in the field and engage in a structured process for discussion, learning and problem solving.

More specifically it was expected that participants would:

- have a greater understanding of the best practices of supporting and planning for individuals with dementia and developmental disabilities;
- receive practical guidelines on dementia care that can be shared with their staff;
- make contacts in the "other" sector;
- commit to meet with one partner in the "other" sector to talk about a specific project (large or smaller in scale);
- know who to connect with from the "other" sector when they have an issue or need information;
- gain insight on how to connect and join an OPADD Committee in their area; and,
- receive information on how to join SHKN Aging and Developmental Disabilities Community of Practice and how their staff can link into learning events and receive resources.

Three experts were recruited to provide the content and structure for the day:

Dr. Nancy Jokinen: Nancy co-chairs the local Prince George Group on Aging and Developmental disabilities, serves on the BC Psychogeriatric Association Board of Directors, and is a member of Community Living BC's Advisory Committee on Aging. Nancy is also

President of AAIDD's Gerontology Division and on the executive committee of IASSID's Aging & Intellectual Disabilities Special Interest Research Group. She is actively involved with the U.S. National Task Group on Intellectual Disabilities and Dementia Practices.

Dr. Seth Keller: Seth is board certified in neurology and in May 2010 became the first neurologist elected president of the American Academy of Developmental Medicine and Dentistry (AADMD), a national organization dedicated to advancing education, training, and policy for adults with developmental disabilities (DD). He specializes in Neurodegenerative Disorders, Neurodevelopmental disabilities, Seizure Disorders, and Movement Disorders, including Spasticity. A consulting neurologist for New Jersey Developmental Centers, Dr. Keller also serves on The Arc of New Jersey's Mainstreaming Medical Care Board. He is a member of the American Association on Intellectual and Developmental disabilities (AAIDD).

Rae Roebuck: Rae's career focus has been on supporting individuals with special needs as a clinical practitioner, a policy director in the provincial government and as a consultant. Over the last ten years her consulting services have been in demand in both provincial and municipal governments and broader public sector organizations where her extensive expertise in social policy and program design, implementation and review have been valued. In addition Rae has designed and facilitated many large group engagement processes around issues of particular interest to the provincial government and broader public sector agencies.

The day was structured as follows (see Agenda at Appendix 1):

- Introductions to the day from Rae Roebuck and Sandy Stemp, Executive Director of Reena.
- A presentation from Dr. Keller on assessment and health care practices for adults with developmental disabilities and dementia including review of the new National Task Group Early Detection Screen for Dementia tool.
- A presentation from Dr. Jokinen on the newly published Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia (Journal of Policy and Practice in Intellectual Disabilities Vol 10 Number 1 March 2013).
- These presentations were followed by an opportunity for questions and answers with Dr's Keller and Jokinen.
- In the afternoon, two structured discussion processes were facilitated by Rae Roebuck: the first focussed on high points in effective collaboration and the second used a case study as a focal point for information sharing, problem solving and joint planning.
- Feedback from the first discussion was obtained through a group "dotmocracy" process where all participants were invited to vote for the themes and items that were most meaningful to them.

- Feedback from the second discussion was obtained through a brief report back from each breakout group with a summary of issues.
- In addition to these formal sessions participants received greetings from the Minister of Community and Social Services and learned about both the provincial OPADD Collaborative and the regional OPADD committees.

Effort was made in the design of the workshop to have comparable numbers of individuals from both sectors at each table and to create groups for discussion purposes that shared similar geography and service base to support potential for future collaboration.

Participation from each regional workshop was as follows:

Region	Total Participants	Developmental Services	Seniors Services
Toronto	73	51	22
Central East	75	46	29
South Central	55	36	19
South East	77	48	29

The instructions for the two structured discussions held in the afternoon are provided below:

### **Group Activity I: High Points of Collaboration**

Participants began in paired interviews (with someone from the “other” sector) and discussed the following questions:

1. Tell the story of a highpoint experience in working collaboratively with someone from another system – if it can be DS/Seniors collaboration great, if not – go to another experience. Describe what made that experience a highpoint.
2. When thinking of the work you do with/for clients of your system, what are the things that you value the most in your work experience? Identify 3-4 things.
3. If you could have 3 wishes for the future collaboration of two systems – developmental and seniors’ services – what would they be?

Then moving to table groups participants shared and integrated the information from interviews under the following headings: Promising Practices, Shared Values and Wishes for the future. Groups posted their summaries for all to review and participants were able to “vote” for their favorite items amongst the recorded information from all groups.

## **Group Activity II: Building a Vision of Collaboration**

In this activity participants discussed a prepared case study with the intention of determining how the two service systems could collaborate to support the person. After this more clinically-focused discussion participants were asked to record the lessons learned from this experience in response to the following questions:

1. What new information have you learned about processes and/or resources that can inform future actions and decisions, as a result of this discussion?
2. This case study has provided you with an opportunity to think about cross sectoral collaborations. Reflecting on your discussions:
  - a. What helps or supports effective collaborations?
  - b. What gets in the way or needs to be changed to support effective collaborations?
3. As a result of this conversation, what are you prepared to do differently to continue to build upon the dialogue with the partner sector?

## **Summary of Feedback**

This section provides a summary of the feedback received from the afternoon discussion activities for each of the four communities where a session was held.

The detail for each of the discussions in the first activity can be found at Appendix 2. The following is an effort to weave that detail in major inter-related themes which are listed below in order of the number of votes they received by participants.

### **1. Systems Collaborating Effectively To Address Client Needs**

This was the major theme echoed most consistently throughout the four day-long meetings with a total of over 300 votes. Participants identified a number of recommendations for strategies that could be expected to improve both the quality and quantity of collaboration between the two sectors.

- Participants felt strongly that the sectors would be more “in synch” with each other if there were a shared basis for assessing the client needs. This would lead to the creation of common goals that are well understood by the client and those that provide sector supports. Currently there are different tools with different orientations and language being used to assess the same clients which often contributes to divergent rather than convergent thinking about the individual.
- Case conferences with the right people around the table which includes both champions or advocates and decision makers would help build understanding and lead to better quality supports and decisions for the individual.
- Case management services were mentioned in a number of different contexts as they are seen as a highly valued support to clients. Participants noted that when one sector

gets involved the other sector usually drops out whereas complex clients might need supports from both systems. Related to this was the need for more effective relationships between the DSOs and CCACs.

- Participants noted the value of an outreach model that could address many different kinds of client needs (finances, housing, and medical) with a focus on keeping the person in their current living situation. This was identified both in relation to case management services as well mobile medical services such as x-ray, ultrasound, and laboratory service.
- The need for appropriate housing was seen as critical with specialized LTC beds recognized as a highly valuable resource. Participants expressed the need for more of these resources with greater usage by the developmental services sector.
- Behaviour Supports Ontario was also identified as a valuable resource that should be available to the DD population with dementia. The program could serve as a vehicle for collaboration across the systems.
- Both systems noted the need to go beyond their sectors in building collaboration to include police, emergency services and others in the community that may need to be part of the response system for people with dementia.
- Participants suggested that good collaboration requires that there be agreement on the issues, assigned responsibilities and clarity of roles and respect for all participants involved. Further, collaboration is working effectively when sectors are acting proactively rather than having individuals needing services as a result of being in crisis.

## **2. Breaking Down Silos Between The Systems**

The previous theme, which could also be characterized as breaking down silos, had a very definite service-level focus. As expressed by participants, this theme with over 280 votes was more focussed on systemic structural and political issues

Participants felt strongly that Ministers need to have a greater understanding of who these individuals are and how their needs change over time shifting from relying on the basket of services of one Ministry to another. If this deeper understanding was achieved at the political level Ministers could be expected to provide greater leadership to the bureaucracy regarding broad systems change such as inclusive all-encompassing legislation, policy frameworks and joint funding that support collaborative, connected care.

## **3. Greater Flexibility In Decision-Making Regarding Access To Services And Resources**

Rather than being more future-focussed, this theme with over 200 votes was an expression of trying to work within the current reality of the two systems which are both bound by rules and regulations that in part are attempting to manage the access to and use of very limited resources. All participants acknowledged that these rules and criteria don't work



well with an individual who needs support from both systems. Rather it requires the professionals from both sectors to be willing to be flexible, bend the rules and think outside of the box in finding ways to get access to and/or re-align resources to meet unaddressed needs. One specific example referred to in these discussions was the “Patient Exchange” category within the Long Term Care legislation which could potentially be used to switch inappropriately placed clients from one residential system to another. <sup>1</sup> Again, the need for DSO and CCACs to be better linked and coordinated was mentioned in this discussion.

#### **4. A Better Values Orientation Toward Clients And Staff**

With 200 votes, the clear expression of the need for a strong value base emerged both in reference to clients of the systems and between the staff that work within each of the systems.

Regarding clients, participants indicated that a person-centred rather than system-centred perspective needs to drive decision-making. To support this there needs to be a holistic view of the individual and open engagement of the individual and those who are part of the individual’s circle of care. This includes having a good life history of the individual to enable understanding of who that person has been in the past, their wishes and desires as well as who they have become more recently as a result of dementia. This will help lead to a better understanding of what might constitute a “good life” for the individual at this stage in their existence. In general it was acknowledged that strategies should be focussed on maintaining the individual in their home as long as possible from a quality of life perspective.

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<sup>1</sup> Long-Term Care Homes Act, 2007 Exchange category

Regulation 176. (1) Despite sections 171 to 174, an applicant shall be placed in the exchange category on the waiting list for a long-term care home if,

(a) the applicant,

(i) occupies a bed in a hospital under the Public Hospitals Act or a private hospital licensed under the Private Hospitals Act,

(ii) occupies a bed in a facility that is a psychiatric facility within the meaning of the Mental Health Act and that is required to provide in-patient services in accordance with that Act,

(iii) occupies a bed in a group home under Regulation 272 of the Revised Regulations of Ontario, 1990 (General) made under the Developmental Services Act,

(iv) is a long-stay resident of another long-term care home;

(b) the applicant is the subject of an agreement between the long-term care home to which the applicant seeks admission, at least one hospital, facility, group home or program mentioned in sub clauses (a) (i) to (iv) and possibly one or more other hospitals, facilities, group homes, programs or long-term care homes, to exchange identified resident or patients, in order to meet the specialized requirements of any of the exchanged residents or patients; and

(c) the result of the exchange will be that the applicant will become a resident of the long-term care home to which the applicant seeks admission and a resident of the long-term care home will be discharged.

From a professional perspective participants noted that staff need to acknowledge and respect the input from everyone on the team and in the individual's environment including administrative, janitorial and professional staff. Work needs to be done across the two sectors to remove biases and pre-conceived notions which are a result of the shift away from the medical model in developmental services. Professionals from both systems need to understand, respect and value each other's expertise and ability to contribute to the care of the individual.

## **5. Improved Opportunities For Learning**

With over 150 votes participants pointed to the need for a range of on-going, readily available training and knowledge transfer strategies to support the professionals in both systems. This particular OPADD event was cited as evidence of the need for training and the benefits that accrue when it is done on a cross-sectoral basis. Some specific strategies were noted:

- Nursing students who will eventually work in the CCAC or LTC/Seniors systems would benefit from placement with the DS system so that they have first-hand opportunity to understand the population.
- Given the increasing occurrence of dementia in the aging in DS population more joint system training on evidence-base or emerging strategies needs to be provided.
- Post-secondary programs that educate and train front-line workers for both systems should create a joint specialized curriculum to provide training specific to the aging DS population.
- Both systems need to actively create opportunities for staff exchanges which would promote better understanding of the client groups, the providers and the service systems.

## **6. Improving Understanding Of The Systems And How To Support Effective Transitions**

Effective transition processes from one sector to another that are supported by a team focussed on understanding the individual and preserving continuity of care along with key relationships was identified as critical objective and received 80 votes from participants.

To enable this staff need to:

- Engage in advance care planning on a more regular basis.
- Have a better understanding of the legislation, regulations and policies that shape each system.
- Have a good understanding of the range of services that might be available from each of the sectors that is supported with access to on-line, updated resource information.
- Have a better understanding of how to navigate each sector including knowledge of service entry points and access to better navigational services ideally from the CCAC and DSO.

Two other discrete items that received larger number of votes were the request for higher staffing ratios within LTC programs and the needs for a national vision for this population that has strong links with the Alzheimer's Society.

The second activity focused on new learnings, commitment to action and clarification of what helps and hinders in effective collaborations. The following is a summary of the feedback generated in those conversations.

## 7. New Learning:

- Making referrals to Behaviour Supports Ontario Psycho-geriatric Resource Consultant for teaching strategies: <http://www.hnhblhin.on.ca/Page.aspx?id=13450>
- Referral to CCAC to determine eligibility for LTC, ADP, or PSW Respite
- Role of the CCAC regarding navigation
- Respite care available through DSO or LTC
- Role of DSO in change of status of individual
- Portability of passport funding
- Get information on funding options in both sectors i.e. passport and aging at home
- Volunteer friends from Community Centres that help with a sense of belonging
- First Link program from the Alzheimer's Society ( Ottawa)  
<http://www.champlainedmentianetwork.org/en-provider-detail.aspx?id=519&prg=223&ret=&tc=2&sc=35&area=2>
- Safely Home from the Alzheimer's Society  
<http://champlainhealthline.ca/displayService.aspx?id=20779>
- Geriatric psychiatry available for people with dementia regardless of age
- Day program options for people with dementia at the Hildegarde Centre (SE)  
[http://www.providencecare.ca/cms/sitem.cfm/clinical\\_services/long\\_term\\_care/hildegarde\\_centre\\_and\\_day\\_away\\_program/](http://www.providencecare.ca/cms/sitem.cfm/clinical_services/long_term_care/hildegarde_centre_and_day_away_program/)
- Availability of discretionary funds through P&P in DS Sector in the SE
- Smile program – CCAC  
[http://www.southeastlhin.on.ca/newsroom\\_display.aspx?id=1302](http://www.southeastlhin.on.ca/newsroom_display.aspx?id=1302)
- Meals on wheels
- Access to OT services through CCAC for environmental adaptations
- Dual Diagnosis Consultation Outreach Team (SE)  
[http://www.providencecare.ca/cms/sitem.cfm/clinical\\_services/geriatric\\_psychiatry/dual\\_diagnosis\\_consultation\\_outreach\\_team/](http://www.providencecare.ca/cms/sitem.cfm/clinical_services/geriatric_psychiatry/dual_diagnosis_consultation_outreach_team/)
- Project Lifesaver <http://www.projectlifesaver.org/>
- Medic Alert Safely Home <http://www.alzheimer.ca/en/Living-with-dementia/Day-to-day-living/Safety/Safely-Home>

- Regional Support Associates <http://regionalsupport.on.ca/eng/>
- Twin Lakes Clinical Services at Bethesda (Niagara) [http://www.bethesdaservices.com/adult\\_services/twin\\_lakes/](http://www.bethesdaservices.com/adult_services/twin_lakes/)
- Work of John Lord in building support in the community <http://www.johnlord.net/>
- Recognizing how complicated it is to navigate new system – acronyms don't help
- The potential value of multi-agency/sector case conferences
- LTC has more limitations – less flexibility
- Need for advance planning – both short and long term
- Seniors programs are under-utilized by DS sector
- Need to try different day programs as all are different
- People need information regarding how to access day programs and the ancillary services
- Supportive housing through municipalities may be an option in some instances
- Need to be sensitive to cultural/religious issues in relation to services and supports
- Cultural-specific resources
- Understanding the importance of meaningful and purposeful day time activity
- Importance of having a staff support strategy (respite)
- Importance of having access to baseline level of functioning information regarding the individual which require involvement of knowledgeable informants
- Innovative psycho-pharmacological interventions

## **8. What helps collaboration**

- Open mindedness and respect which includes listening and being listened to. This will lead to open and honest communications with no hidden agendas and can be better supported by meeting face to face. The need to be sensitive to cultural and religious differences amongst the client population and understanding their impact.
- Open dialogue that supports awareness and understanding of both the available resources and the limitations on resources from both ministries leading to a realistic understanding of possibilities. Keeping the person as the focus and centre of the discussion and respecting their decisions in the process.
- Case conferences that bring the right people to the table including those who understand and can champion change. It is important to involve policy makers in the process to increase their understanding of the needs. Case conferences need to define a common goal to guide and drive collaboration and should be supported with a plan of action, clarity of roles and responsibilities and division of responsibilities in a reasonable way.
- Access to good assessment and diagnostic information (including medical and behavioural) is essential and would be improved by the creation of shared

documentation that is supported with common tools, a shared language and education for staff so that tools are used and understood effectively.

- Assistance with system navigation from the DSO and having a lead case manager that has a good knowledge of all services in the systems to support convergence of strategies.
- Sharing resources such as finances, staffing and transportation.
- Building partnerships, even informal ones and creating local networks where staff are empowered by management to find collaborative solutions.
- Pictures on business cards to help both staff and clients recognize individual professionals.

### **9. What hinders collaboration**

- Limitations imposed by ministry regulations including eligibility and funding criteria resulting in silos and system rigidity.
- Clashes of philosophy (medical versus social models, profit versus non-profit, deficit versus possibilities, dignity of risk versus duty of care). The language and culture of the systems are different resulting in a lack of valuing of each other's system because of biases and stereotypes.
- Getting people to the table.
- Lack of attention to effective short term crisis planning.
- Waiting lists for services and gaps in service.
- Limited resources and heavy case loads.
- Differentials in staffing ratios between the two systems.
- Lack of leadership.
- Dumping – one side pulling out when the other is involved.

### **10. Commitments to action:**

- Improve the understanding regarding the resources available in the community including the CCAC and DSO in the process through:
  - a concentrated education blitz
  - the creation of a user friendly list of resources and services that is readily available on-line
- Know who to call in the other sector and have leadership facilitates those contacts and relationships.
- Use case conferences effectively to problem solve and address needs across programs and make a contract with the individual/family regarding actions to be taken.
- Explore the potential of the “exchange category” in LTC legislation to enable movement across sectors for more appropriate placement.
- Extend mutual invitations to future training to create the cross-sectoral opportunities.
- Think strategically about how to engage LTC.

- Be willing to make the first call, take the risk and ask the questions that no one else is willing to ask, start with something small and celebrate successes along the way.
- Offer to become a partner agency - don't do it alone – share resources.
- Do the right thing by focussing on the needs of the individual.
- Sit on committees from other sector to begin to build relationships.
- Add partner agency links on your own web-sites.
- Learn about other sector including legislation.
- Engage CCAC for senior's services and access senior day programs.
- Advocate for on-going education.
- Be willing to take risks – move out of our comfort zone.
- Try job shadowing across sectors.

## Conclusion

During the sessions participants were asked to indicate informally how many of them were currently dealing with individuals with developmental disabilities in their systems that were showing some signs of dementia. The show of hands that remained in the air in response to the question was a clear signal that this is a significant issue for service providers from both sectors. This was further supported in the evaluation feedback (details at Appendix 3) where the majority of participants indicated that the day was both extremely relevant and useful for them in their work. The combination of formal presentations and group discussions seemed to provide participants a range of experiences and content that resulted in a successful day for all. This was echoed in the intensity and quality of dialogue that took place in the small group discussions and is reflected in the feedback summary.

Thanks to the Ministry of Community and Social Services for making this day possible and based on the feedback from participants it is hoped that this is just one of many events that will lead to better understanding and collaboration in support of individuals who need the very best that both systems can offer.