OPADD BACKGROUND PAPER:

ENGAGING THE NEW HEALTHCARE PLANNING PARADIGM: OPADD AND LHINs

INTRODUCTION

The Ontario Partnership believes that older adults with a developmental disability have the right to access services available to all Ontario seniors. Accordingly, the partnership is focused on building cross sector capacity to ensure access to seniors programs for older adults with a developmental disability. This goal not only upholds the rights of older citizens it also serves to support quality of life.

One of the crucial services concomitant with quality of life during the aging process is healthcare. However, there is evidence that people with developmental disabilities do not enjoy equitable access to this universally available service. The creation of a new healthcare planning framework in Ontario offers fresh opportunity to build accessible healthcare for older adults with a developmental disability. However, because older adults with a developmental disability will be receiving community and residential support services from both the developmental service and long term care systems through individualized planning processes there may be some systemic obstacles to realizing this vision. Factors that mitigate against an easy solution to the need for accessible healthcare by older adults with a developmental disability include:

1. Developmental service providers do not have a history of experience with aging and staff generally lack education in gerontology; this extends to healthcare issues of older adults.

2. Long term care services do not have a history of experience with developmental disabilities.

3. Older adults with a developmental disability may not always be able to articulate their symptoms to healthcare practitioners.

4. Some healthcare practitioners do not see a role for themselves that includes serving older adults with a developmental disability.

5. The developmental services system is currently engaged in a transformation process, which requires the attention of service providers, planners and policy-makers.

6. The long term care system is occupied with system renewal and continuing regulation.

7. There is not a strong tradition of developmental service providers being engaged in healthcare planning initiatives.

8. While some long term care providers have been involved in healthcare planning through the former District Health Council model, there are many that lack prior healthcare planning experience.

SCOPE OF THIS PAPER

This paper has been prepared to:

1. Acknowledge the challenges and opportunities for accessible healthcare

2. Stimulate thinking about how to form a working relationship with LHINs.

3. Provide information helpful to positioning developmental services, long term care, healthcare providers, planners and policy-makers in an ongoing dialogue within the new healthcare planning paradigm.

4. Support regional committees on aging and developmental disabilities in getting to know their respective LHINs and establishing a sustained process of engagement between the DS and LTC sectors and LHINs.

5. Begin moving forward on solving healthcare planning issues related to older adults with a developmental disability.

The LHIN planning paradigm has been made explicit in legislation. It now must be operationalized with the participation of many stakeholders, including OPADD members, to ensure the needs of consumers are addressed.

Since the vast majority of healthcare planning issues related to older adults with a developmental disability are currently experienced by the DS sector and to a lesser extent by the LTC sector, this paper focuses on the current experiences of the developmental services system. However, the experiences will become those of the LTC sector as more older adults with a developmental disability become acquainted with the resources available to Ontario seniors. The challenges and proposals to address them are presented in two broad categories:

1. The working relationship between the developmental services sector and the health care system.

2. Accessibility to healthcare for older adults with a developmental disability.

It is important to keep in mind that the dialogue with LHINs is an ongoing process. As we learn during the conversation we will move to solutions that we may not be aware of today. We must allow for the continuation of dialogue and remain open as the relationship matures and our understanding evolves.

LOCAL HEALTH INTEGRATION NETWORKS

LHINs are the vehicle for shaping the Ontario healthcare system. If OPADD is to work effectively with LHINs then we must understand their role and the pathways available to us to engage with them in healthcare planning.

The mandate of LHINs encompasses:

a. Local Health System Planning:

- Developing a local Integrated Health Services Plan in accordance with MOHLTC strategic directions.

b. Local Health System Integration and Service Coordination:

- Working with health care providers to adapt and customize services to address local health needs.
- Collaborating and integrating with other Local Health Integration Networks and the ministry to develop and implement provincial strategies.

c. Accountability and Performance Management

- Developing local area accountability and performance frameworks and agreements with health service providers that would be funded by Local Health Integration Networks.
- Setting performance baselines, priorities and improvement targets in accordance with provincial framework with health service providers.

d. Local Community Engagement

- Developing and carrying out community engagement strategies.
- Developing mechanisms and channels for community dialogue.
- Responding directly to unique local concerns and requirements.

e. Evaluation and Reporting

- Evaluating and reporting on local system performance to ministry and/or Local Health Integration Network community.
- Contributing to provincial system-level evaluation and reporting activities.
- Evaluating and reporting on best practices in service integration and coordination.

f. Funding

- Providing funds to health service providers within the scope of Local Health Integration Networks and within the available Local Health Integration Network funding envelope.
- Providing advice on capital needs to the MOHLTC.

This is an important mandate and has profound implications for the future of healthcare. It also offers significant decentralized opportunity for consumers, including older adults with a developmental disability and caregivers, to shape access to healthcare services. The opportunity will be missed without the active and informed engagement of the developmental services and long term care systems with LHINs. However, the LHIN model expressly opens the door to our participation.

The goals of LHINs are:

a. Manage health system planning, coordination and funding at the local level.

b. Engage the community in local health system planning and setting of priorities, including establishing formal channels for citizen input and community consultation.

c. Through greater integration of services, improve the accessibility of health services to allow people to move more easily through the health system.

d. Bring economic efficiencies to delivery of health services, promoting service innovation, improving quality of care, and making the health care system more sustainable and accountable.

THE WORKING RELATIONSHIP WITH HEALTHCARE

The current working relationship of the DS sector with healthcare is marked by a number of characteristics and circumstances:

- The DS sector provides a caregiver role for people with a developmental disability, which includes responsibility to ensure their health care requirements are met.

- The DS sector was not generally involved in healthcare planning under the District Health Council model.

- Health has established a new system for planning and resource allocation.

- The historical lack of involvement between DS and health at the system planning level contributes to insufficient understanding and knowledge of how to access one another's systems, coordinate services and provide adequate support to mutual clientele. This is evidenced in the inequitable access to healthcare among older adults with a developmental disability and lower participation rates of older adults with a developmental disability in seniors community programs and seniors residential services.

- Developmental service providers continue to identify persisting systemic problems in working with the healthcare system. For example, hospitals continue to focus on communication with family to the exclusion of DS providers who also have a care role. The consequent lack of information-sharing about the patient hinders effective follow-up after discharge. These persisting problems cannot continue to go unresolved if older adults are to be properly served.

- The DS sector is generally not well involved in the new LHIN structure at this time. A survey of five LHINS revealed DS involvement in only two. Comments of some DS providers at OPADD regional workshops indicate a reluctance to engage with the LHIN structure.

- LHIN planning documents tend to be focused in integration of healthcare for the general population with little evidence of attention to the unique needs of older adults with a developmental disability.

ACCESSIBILITY TO HEALTHCARE

Research work and reports from developmental service providers indicate inequitable access to healthcare for older adults with a developmental disability based on nine barriers:

1. The healthcare needs of older adults with a developmental disability vary in important ways from those of the general population:

    - Cancer – roughly twice the rate of cancers of the oesophageal, stomach, and gall-bladder; higher risk for lymphoblastic leukaemia; lower rates of lung, prostrate, breast, and cervical cancers.

    - Coronary Heart Disease – more likely to develop hypertension, obesity and lack exercise risk factor for heart disease. Down syndrome higher risk of congenital heart.

    - Other - dental/oral hygiene, diabetes, epilepsy, gastro-intestinal, mental health, obesity, respiratory disease, sensory impairments, swallowing/feeding problems, thyroid disease.

    - Medications – reactions to some medications may vary from the general population.

    - Dual diagnosis – the interplay of developmental disability with mental illness is complex and challenges some of the existing structures and processes within the healthcare and mental health systems.

2. There are self-assessment and communication challenges faced by older adults with a developmental disability:

    - They may not be able to distinguish health conditions related to aging from other health conditions they have experienced during their lives.

    - They may be unable to make their symptoms and needs known to healthcare practitioners.

3. There are financial barriers:

    - Most older adults with a developmental disability have not enjoyed sustained employment at a competitive wage. They continue to live at or below the poverty level whether they are receiving ODSP or OAS and related benefits; the growing reliance on user fees and additional billings by hospitals and physicians mitigates against equitable access.

4. The shortage of family physicians:

- The Toronto Star reported on June 22 2006 that only 11.4 per cent of family physicians are accepting new patients into their practices, down from 38.4 per cent only five years ago.

- Adults with developmental disabilities returning to the community from the three provincial institutions that are being closed are faced with the challenge of finding a family physician before they are discharged. This is resulting in delays before they can be released.
- Many areas of the province have been identified as lacking in sufficient physicians.

5. Healthcare planners and practitioners do not generally have training related to the needs of older adults with a developmental disability and exhibit a reluctance to provide service to this population:

   - Service providers report differences among CCACs relative to obtaining needed medical supplies such as those required due to a colostomy and differences accessing allied health professionals such as speech therapists, occupational therapists, physiotherapists, and mental health workers; sometimes the challenge relates to the reluctance of a physician to prescribe the service.

   - Preventive measures may not be proposed and implemented due to assumption by healthcare providers that people with a developmental disability cannot comply with an examination. For example, breast examinations are not a part of the regular care provided to older women with a developmental disability.

   - Health promotion strategies generally rely on printed information that older adults with a developmental disability may not be able to read with inderstanding.

   - Family doctors generally lack experience of people with developmental disabilities.

   - The lack of psychiatrists and the unwillingness of many to serve people with a developmental disability.

   - Hospitals require DS agencies to provide staff while the client is in hospital.

   - The unique medication challenges faced by people with a developmental disability, such as the different reactions to medications and the interplay of multiple medications, are not generally well understood by healthcare practitioners. For example, Dilantin leads to loss of capacity among people with Down Syndrome and Alheimer Disease; the side effects can evidently also lead to death; this is not generally known among DS caregivers and healthcare practitioners.

   - Medication reviews for people with a developmental disability are difficult to arrange and require experiences physicians.

- Consulting physicians often require DS providers to pay a retainer in addition to the normal OHIP fee for in-home visits.

- Hospitals often require that patients with a developmental disability are supported with 24-hour staffing by the DS provider; agencies must stretch budgets to provide coverage.

- Access to rehabilitation varies resulting in severe deterioration in quality of life for some older adults with a developmental disability; for example an individual who required a tracheotomy received no post discharge support to live with the new situation and consequently withdrew from all community and social contact.

- Discharge planning is often inadequate and generally does not include coordination with the DS provider. There are instances where illegible writing on discharge documents cannot be deciphered by DS staff and pharmacists.

6. The DS sector is experiencing difficulties in attracting and retaining staff trained in developmental disabilities. Factors that contribute to this include:

   - Lower wages paid in the DS sector compared to the education and healthcare systems.
   - Increasing reliance on part-time positions that makes it harder for someone to remain employed within a DS agency while supporting a family.

   Inexperienced and inadequately trained workers may lack knowledge and insight into the healthcare needs of older adults with a developmental disability. The challenge in attracting people with a Developmental Services Worker (DSW) Diploma may also be due to declining enrollments within some DSW programs. There is a danger that declining enrollments may lead to some DSW programs being closed, contributing to a further shortage of trained workers.

7. The aging of people with a developmental disability is a new phenomenon and the DS sector lacks experience and information related to the healthcare needs of older adults.

8. The growing reliance on competitive bidding processes to select healthcare providers supports volume services at predictable and controllable costs and mitigates against complex services to more challenging patients as well as time required for service coordination.

MEETING THE CHALLENGES

The opportunity to meet the many challenges is here now. OPADD is poised to address them through:

- The dialogue initiated by OPADD with the Central LHIN.

- The cross sector partnership between long term care and developmental services, Which offers a platform for exchanging knowledge about challenges and solutions.

- The existing OPADD regional committees that provide a structure for engaging with local LHINs.

- The OPADD provincial table, which provides a vehicle for synthesizing multiple local issues, communicating these at the provincial level and building effective coordinated strategies across the regions.

LHINs are in a state of openness and flexibility to shape healthcare planning in consultation with stakeholders:

- The LHIN mandate to coordinate, integrate and strengthen healthcare must rely on collection and synthesis of various perspectives.

- LHINs are mandated responsibility to engage with stakeholders.

- LHINs have and continue to issue invitations to stakeholders to join the dialogue; this in turn opens opportunities for representation from stakeholder groups in LHIN planning processes and structures.

BUILDING AN EFFECTIVE WORKING RELATIONSHIP

The issues are known and have been documented. The DS and LTC Sectors have the information on which to build strategies to realize an effective working relationship with healthcare. The doors are open to service providers in the development of the LHIN planning process. Some possible next steps that OPADD can pursue to further the relationship with healthcare planning include:

1. Continuing communication to OPADD members and regional committees on the importance of developing close working relationships with their respective LHINs.
2. Organize reciprocal presentations between OPADD regional committees and their respective LHINs that describe the current state of affairs, provide information on the DS and LTC service systems and propose strategies for moving forward.

3. Encourage DS providers to become directly engaged with the LHIN process and to establish ongoing systems of communicating between LHINs and DS providers

4. LHINs and DS providers to identify and priorize key systemic issues related to healthcare planning for older adults with a developmental disability and establish processes and structures for resolving these.

EQUITABLE ACCESS TO HEALTHCARE

Based on what is known about maintaining quality of life through maintenance of good health, access to healthcare is a cornerstone of responsible service provision by the DS sector. The partnership between the LTC and DS sectors provides a door of opportunity for older adults with a developmental disability since it provides a bridge between programs funded by the Ministry of Health and those funded by the Ministry of

Community and Social Services. The continuing exchange of knowledge between the sectors can fuel an informed approach to solving accessibility challenges.

Some possible next steps to support equitable access to healthcare include:

1. Conduct a literature review in partnership with LHINs to assemble and analyse information on the known differences and similarities between the health care needs of the general population of older adults and those with a developmental disability.

2. Identify and develop proposals for protocols between the DS sector and health care providers.

3. Examine the effects of healthcare funding mechanisms on access by older adults with low fixed income.

4. Develop and test models of supporting access to DS specialized knowledge and services within hospitals and other health delivery settings.

5. Engage medical schools in focusing on the needs of older adults with a developmental disability.

6. Identify and implement strategies for facilitating access to mental health services by older adults with a developmental disability; this will require dialogue with both hospital and community-based mental health services.

7. Explore the regulations under the Ontario Human Rights Code to identify existing mechanisms available to ensure equitable access to healthcare for older adults with a developmental disability.

QUESTIONS FOR CONSIDERATION

1. What process is needed to continue to move forward on establishing a working relationship between DS/LTC providers and LHINs relative to healthcare planning for older adults with a developmental disability?

2. What can LHINs do collectively and individually to support such a process?

3. How can the process be coordinated regionally and provincially?

4. How can funding Ministries be engaged to support service providers in engaging with their respective LHINs?

5. What process is needed to move forward on addressing healthcare access issues for older adults with a developmental disability?