Response to the Preliminary Discussion Paper:

Transforming Services in Ontario For People who have a Developmental Disability

submitted by:
The Ontario Partnership on
Aging and Developmental Disabilities

ABOUT THE ONTARIO PARTNERSHIP ON AGING AND DEVELOPMENTAL DISABILITIES (OPADD)

OPADD is an informal voluntary group, established in 1999, with a membership drawn both from the developmental services sector and from the long term care sector. OPADD serves as a bridge and catalyst between the two sectors, promoting co-operation, information-sharing, action research, planning and program development on behalf of Ontario citizens who are aging with a developmental disability. OPADD has a varied and flexible membership of some 40+ professionals that meets bi-monthly.

OPADD has succeeded both in bringing attention to the special needs of ADD persons and in helping set in place a range of new resources and programs, based on cross-sector planning and voluntary co-operation.

Introduction:

The Ontario Partnership on Aging and Developmental Disabilities (OPADD) is pleased to have this opportunity to comment on the *Preliminary Discussion Paper*: *Transforming Services in Ontario for People who have a Disability*.

OPADD's members and member agencies represent a broad range of stakeholders[1] in Ontario's human services community. The following OPADD response is specifically focused on the needs of, and services for, Ontario citizens who are aging with a developmental disability.

OPADD's response is organized around the suggested questions set out at the conclusion of the *Preliminary Discussion Paper*.

Q1) What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?

OPADD does not propose to comment here on the particular roles, responsibilities and authorities that are specifically mandated, by legislation and policy, to government authorities and transfer payment agencies respectively.

Rather, we wish to comment on the need to return to the shared leadership approach in human services that served Ontario so well for decades. Effective shared leadership is built on mutual respect and active involvement of key stakeholders including service recipients and their families, service providers, volunteers, and government. Ongoing information-sharing, consultation, joint planning, co-operation in the provision of services and resources and mutual accountability help ensure a climate of trust and synergy that fosters excellence.

Shared leadership is also about solving problems together, including identifying differences of philosophy, sorting out administrative tangles and addressing information vacuums that have prevented progress in the past. Examples of problems that could be worked on together include:

[1] Some OPADD member agencies may also be submitting their own responses to the *Preliminary Discussion Paper*.

- legislative, policy and administrative barriers between government departments and transfer payment agencies in different sectors (e.g., Health and Long Term Care, Community and Social Services, Education, Corrections, Citizenship etc.), and
- longstanding philosophical differences (both real and imagined) among service recipients and their friends and families, service and care providers, various communities and government departments.

Greater effectiveness and accountability throughout the service system are highly desirable and can be as effectively promoted with help, recognition, resources and real partnerships as with stringent enforcement regimes. We look forward to a return to the altruism, innovation, integration, flexibility and, especially, to the enthusiastic voluntarism of years past.

For this reason OPADD welcomes the Ministry of Community and Social Services' *Transformation* agenda with the hope that the concept of "partnership with government" will reclaim its respected and traditional place. Along with restoring the shared leadership concept, specific planning concerns and initiatives need to be considered in the transformation:

- community leadership does not just happen – it needs to be built with:
  - a clear signal of change through legislative and regulatory reform
  - an explicit government statement of its commitment to innovation and to a shared leadership and collaboration model,
  - available information and clear communications,
  - direct education,
  - recognition of the many new members of Ontario's demographic who now need to be included, and
  - active outreach – especially to new or isolated communities, but also to business and other sectors – to rebuild the concept of caring communities. Outreach is needed to help these new stakeholders find respected and constructive roles in supporting their communities' vulnerable members.

- new forms of shared leadership, partnership and innovation need to be recognized, supported and

celebrated when they produce results. OPADD is proud to be an example of a human service partnership that:

- recognizes, and is now addressing energetically, a real need,
- integrates stakeholders and resources creatively,
- works constructively within existing systems and dollars,
- communicates effectively with a wide array of stakeholders, including government, care providers and care recipients,
- promotes and achieves significant practical results that impact the lives of persons with developmental disabilities, and
- brings provincial, national and international recognition to the excellence of Ontario's human services.

2) What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?

OPADD's comments here will focus on the later life-transitions of persons with a developmental disability. However, our comments may be applicable to earlier life-transitions as well.

Transition strategies need to be considered at the levels of:

- the system / regulatory environment,
- the service delivery, and
- the person / family.

OPADD's suggested transition strategies, as they apply to the systemic / regulatory level, are already addressed, in part, in our response to question 1 above, in which we call for a return to shared leadership in identifying issues, needs and resources, planning, delivering services and mutual accountability.

The following graphic summary entitled "*Facilitating the Transition of Elderly Persons with Developmental Disabilities to Appropriate Care Environments*" (see Figure 1, on the page following) looks, in particular, at the service delivery and person / family dimensions of the later-life transition process and helps illustrate the complex interplay of three key elements of the transition process.

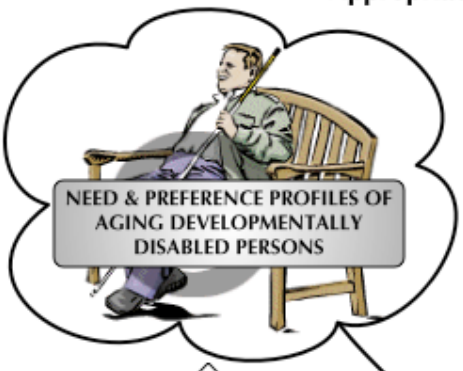
As the graphic illustrates, strategies and resources to facilitate later-life transition, at the service delivery and the person / family levels, need to be developed in three action steps:

1. identify typical care need and preference clusters
2. facilitate the transition with options
3. offer a range of care choices

The matching of a full array of care and lifestyle options to various individual needs and preferences, and the interaction of these three action steps, constitute the dynamic process of later-life transition for persons with a developmental disability .

Figure 1

Facilitating the Transition of Elderly Persons with Developmental Disabilities to Appropriate Care Environments



- **personal characteristics**, special needs
- **informal support networks** - family & friends, pets, communities
- **life history**, experiences, familiar lifestyle
- personal & family **preferences**
- **individual concerns** & worries
- **ethnocultural & religious** factors
- **environmental** & situational factors
- **present circumstances**, **urgency**
- **health**
- other unique personal circumstances

1/ identify typical care need & preference clusters

2/ facilitate the transition with options

3/ offer a range of care choices

TRANSITION CHOICES

- **design range of care & service packages** that best match various need profiles
- **help each person connect** with best model to meet needs & preferences
- **strengthen informal personal support** systems (families, friends, communities)
- **reduce barriers** to care options (personal, financial, environmental, systemic, attitudinal)
- **support the service system(s)** through communication, education, training, applied research & resource development
- **develop model policies and procedures** for care provider organizations
- **make best use of existing resources**
- consider the entire "who, when, how & where" of the transition process

Family Home settings in the community, with in-home supports / expertise available for special needs

DS - group homes (existing) with added supports
DS - group homes that evolve as residents age
DS - group homes - new settings for seniors

LTC - generic placements in LTC settings
LTC - ADD households within a LTC setting
LTC - specialized settings, e.g., dual diag., Alzh.)

Supplementary Care Options: friendship group admissions, day program supports, flexible funding models, other care / lifestyle options

The essential transition principle that OPADD wishes to emphasize is that of informed *choice*.

Transition needs to be, not a uniform process to which all must submit, but rather, a process that takes account of a wide range of individual differences and preferences and that offers options, information and choices. Transition needs to respond to differences in care needs, life circumstances, personal and family preferences, as well as to the probable future needs of the individual.

Identifying the types of care setting, lifestyle and program options that are typically the most suitable for, or preferred by, persons with particular needs and personal circumstances, will be a key task in developing the availability of the wide range of choices. The availability of good options will help ensure that the system:

- is flexible and responsive to a variety of needs and preferences,
- takes account of regional, socio-economic and cultural differences, and unique strengths, in communities across Ontario,
- respects citizenship rights and offers people real, informed choices,
- recognizes the uniqueness of aging with a developmental disability i.e.,
    - early-onset aging in some persons with developmental disabilities,
    - individual needs for preserving the continuity of particular special care routines, regimes and specific care providers (i.e., specific people), whenever possible,
    - individuals' unique life experiences and how they shape later life needs and preferences, and
    - the fundamental importance to the individual of sustaining his or her lifelong friendship (substitute family) connections.

- makes effective use of, and builds upon, existing care capacity in the service system and the broad rang of care delivery expertise within Ontario, including the services and resources of the long term care sector, and
- is ultimately sustainable.

3) What supports and services, that are currently available, work well and should be built on for the future?

The graphic illustration shown earlier in Figure 1 *(i.e., "Facilitating the Transition of Elderly Persons with Developmental Disabilities to Appropriate Care Environments")* suggests that there is a range of appropriate care choices for aging developmentally disabled individuals (see "range of choices" at the bottom left of Figure 1).

Family Home settings in the community, with in-home supports / expertise available for special needs

DS - group homes (existing) with added supports
DS - group homes that evolve as residents age
DS - group homes - new settings for seniors

LTC - generic placements in LTC settings
LTC - ADD households within a LTC setting
LTC - specialized care settings, e.g., dual diag., Alz.)

Supplementary Care Options: friendship group admissions, day program supports, flexible funding models, other care / lifestyle options

Continuity

Usually the best approach to supporting the transition of a person with a developmental disability is to help ensure that it as non-threatening and non-disruptive as possible. Familiar friendships, lifestyles and activities are highly prized and their continuity should be protected wherever possible. This suggests the need to develop additional, flexible supports that allow the individual to "age in place", with the additional expertise and resources available when needed.

Flexible Response Capability

Supportive expertise, resources and services directed to, and available in, family homes and group home settings are desirable where this is possible.

Some supports and services that are proving particularly

effective in facilitating later-life transitions for persons with a developmental disability are those that have built-in flexibility, or that complement a range of residential options, such as:

- day programs,
- special services at home, and
- supported housing with attendant care

all of which can help throughout the complex later-life transition process. These kinds of services are also invaluable in situations where a person with a developmental disability cannot remain "in place" and needs help in bridging the difficulties of moving to a new environment.

Resources of the Long Term Care Sector

Sometimes, providing supplementary support to help a person with a developmental disability "age in place" is not possible, due to the individual's complex care needs, personal preferences or other personal circumstances. Here, the resources and expertise of Ontario's long term care service system can play an essential role.

Fundamental to OPADD's mission has been the building of bridges between the developmental services sector and the health and long term care sector. Important components of the *learnings that have emerged* from this four-year relationship have been about the willingness and opportunities that exist to adapt the resources of the health and long term care sector and make them available to persons who are aging with a developmental disability.

A transition to life in a long term care home could, for example, be the most appropriate option for an elderly, developmentally disabled person where:

- their family caregiver(s) is now entering the long term care home,
- the location of the long term care home is closer to family and friends,
- the long term care home will be able to accommodate a group placement of several lifelong friends, and can keep them together,
- the individual has spent his / her lifetime living in a larger community (e.g., a provincial facility) and

may find the way of life in the LTC setting to be more familiar, and an easier adjustment than an alternative placement,

- he / she has special needs or complex health care requirements for which the in-house expertise of a LTC setting is required,
- he / she has a deteriorating condition or requires, or will soon require, palliative care.

Despite being a useful option, within the full range of care and living choices for aging developmentally disabled persons, long term care settings are seen by some as too institutional. This is unfortunate in that, in eliminating the LTC option, the person's range of choices is reduced.

OPADD believes that the Ministry of Community and Social Services needs to give a clear indication that the long term care sector will be included in planning for the later-life transitions of persons with developmental disabilities, and recognized as a valuable option, within a full range of care options. Not only is this appropriate because, depending on each person's unique needs and preferences, long term care resources may offer a superior care and living environment, it is also appropriate because developmentally disabled people, as citizens of Ontario, have as much right as anyone else to make use of these mainstream resources, if they so wish.

4) How should a reasonable level of government funding for an individual be determined?

OPADD's response to the issue of "a reasonable level of government funding" is not to focus on the calculus of an individual's financial entitlement, nor on how special needs might alter that equation, although OPADD recognizes the Ministry's need to wrestle with this complex issue, as part of the *Transformation*.

Rather, OPADD wishes, in the context of cost and sustainability, to emphasize again the importance of:

- re-establishing the shared leadership and delivery model in Ontario,
- promoting and supporting the associated, voluntary contributions in serving community needs,
- utilizing fully the extensive community wisdom and capacity,
- explicitly encouraging and supporting innovation, flexibility, and

- developing and nurturing cross-sectoral learning, planning and service partnerships.

Through these kinds of leadership initiatives, tremendous leverage can be achieved which will expand the resources and the base of knowledge available to help ensure high quality, affordable services for persons with a developmental disability.

5) Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?

6) What do you think are the priorities the government should address?

OPADD's views on to questions 5 and 6 are implicit in our responses to questions
1-4 (above) and to question 7 (below).

7) Is there anything else you would like to say about the ideas in this discussion paper or ideas not included in the paper that you feel are important?

In conclusion, OPADD would like to recommend that an emphasis be placed on three approaches in transforming services:

- **Return to the shared leadership approach, including a broad base of stakeholder inclusion** in:
  - identifying needs,
  - planning,
  - service delivery, and
  - mutual accountability, an approach that is likely to harness much good will, unique expertise, and enthusiastic volunteer involvement that will, in turn, help enrich services, build consensus and support, and leverage scarce resources.

- **Identify and try to eliminate barriers to transformation** i.e.,
  - attitudes that continue to restrict individual choice and perpetuate the segregation of persons with a developmental disability,
  - traditional divisions between care sectors that are reflected and perpetuated in legislation, policy, divisions of administrative, regulatory

and funding authority, separate service systems and long-standing antagonisms and competition,
  - defensive approaches to service planning that are driven too often by concerns over liability, money, control and turf instead of responding primarily to needs and preferred outcomes, and
  - the present lack of clear information about the new principles that will guide the transformation, limited knowledge across sectors, and the need for communication, as the transformation agenda rolls out.

- **Consider promoting and building on the specific, shared leadership model developed by OPADD**, which:
  - has been successful in bridging differences and barriers,
  - works informally and voluntarily,
  - builds community capacity using shared leadership and expertise,
  - seeks ways of improving services while working with the system's existing capacity and funds,
  - promotes innovation and the creation of practical, locally-relevant projects, and
  - measures its success, ultimately, in terms of the outcomes experienced by individuals and their families.

OPADD welcomes the openness and creativity already evident in the developmental services *Transformation* process and looks forward to seeing concrete results, and the rebuilding of a culture of shared leadership and collaboration, that will benefit persons with a developmental disability and their families, throughout Ontario.