

ONTARIO PARTNERSHIP ON AGING AND DEVELOPMENTAL DISABILITIES
BUILDING A FUTURE WHERE AGING IS O.K.

EXECUTIVE SUMMARY

Transition to older adulthood for large numbers of people with developmental disabilities is a new phenomenon. The Ontario Partnership of the long term care and developmental services sectors was formed to address the issues that arise for older adults with developmental disabilities. The partnership's vision is that older adults with a developmental disability have the same rights to support and services as all older adults.

The partnership established a task group to examine transition planning issues, to provide a report on the current state of practice and to make recommendations for strengthening capacity to support transition planning. The task group engaged in a variety of research activities to gather information. The data was analysed and findings confirmed to reflect what we know today. Recommendations were developed to further our knowledge about transition planning. The body of knowledge assembled by the task group is contained in two documents:

1. "Building a Future Where Aging is O.K.", Final Report of the Transition Task Force.
2. Transition Planning Guide – A Guidebook for Caregivers.

The report provides a vehicle to make explicit what we know today and covers a number of important areas:

- Demographic information about older adults with developmental disabilities
- The relationship between the long term care and developmental services sectors.
- The role of family caregivers in transition planning.
- Transition planning practices within the developmental services sector.
- Transition planning practices within the long term care sector.
- Key steps in the process.
- Gaps and barriers to transition planning.

Some of the findings include:

- The developmental services sector is facing immediate pressures to support people as they age and to plan for a doubling of these numbers within 10 years; this pressure is exacerbated for both sectors by the depopulation of institutions
- Aging among some people with developmental disabilities is accompanied by earlier onset and a more complex presentation of co-morbidities.
- The willingness to enter into cross sector partnership arrangements varies among jurisdictions in Ontario.
- Access to services for senior citizens is unequal across the province suggesting there are barriers to access in some jurisdictions.
- Families, developmental service organizations and long term care providers rate involvement of families in transition planning as highly important; there is potential for service providers to involve and support families more fully in order to inform them of available services, engage them throughout the transition process and foster client ease of access to both systems as needed.

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- Almost half (45%) of the long term care programs responding to the transition survey reported that they have a transition planning process in place; a much smaller proportion of developmental service agencies are engaged in transition planning.
- The analysis of success factors as ranked by all three respondent groups indicates a high priority given to seven items:
 - a. Willingness of other agencies to work with us.
 - b. Family Involvement.
 - c. Funding (Additional funds or flexibility in allocation to cover transition costs).
 - d. Staff training.
 - e. Availability of appropriate services for older adults.
 - f. Guidance from funding Ministries.
 - g. Community Care Access Centre Assessment Tools.
- Key players in transition planning include the family or guardian, developmental services frontline staff, the Community Care Access Centre, the client, long term care front line staff and MCSS coordinated access programs.
- Extra resources are provided by a minority of DS and LTC providers during the transition process; the vast majority of these resources are realized through internal reallocations.
- All respondent groups see the need for a coordinating body to help persons with developmental disabilities access Long Term Care Services; a majority of opinion is that the body should play a major or support role.
- Few respondents are aware of, or are participants in local cross sector planning groups.
- There is a gap between the transition support provided by DS agencies and the level of support LTC providers need.

These findings indicate that much has already been achieved in various jurisdictions as service providers in both sectors work together to support the transition of people with developmental disabilities into older adulthood. However, the potential remains for much more to be accomplished. The report makes several recommendations to further the work.

Numbers of Older Adults with Developmental Disabilities

R1. That OPADD request the Ministry of Community and Social Services, and the Ministry of Health and Long Term Care in conjunction with CCAC's and MCSS coordinated access programs and with consideration of other databases such as the Intellectual Disability Database for Ireland :

- a. To prepare and maintain a provincial demographic profile of all people with developmental disabilities in order to provide planners and managers with data on which to base decisions for program adaptation and resource allocation.

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- b. To disseminate profile information at intervals to all provincial and regional associations and planning/coordinating bodies related to aging or developmental disabilities and to OPADD.

Relationship of the Long Term Care and Developmental Services Sectors

R2. That OPADD further opportunities for cross sector knowledge exchange by inviting Ontario College and University programs related to health, aging and developmental disabilities and appropriate government Ministries to a symposium on the need for curriculum reform; that such reform consider the needs of students in the medical, health and direct support programs as well as those already working in their respective disciplines

R3. That OPADD engage in dialogue with the Ministry of Health and Long Term Care and the Ministry of Community and Social Services to identify strategies for greater cross sector collaboration at the Ministerial, planning and service delivery levels.

The Role of Family Caregivers in Transition Planning

R4. That OPADD formally support the inclusion of families throughout the transition planning process and that OPADD convey this position to all partnering organizations with a request that they encourage their respective members/stakeholders to develop strategies to include families before, during and after the transition process as well as strategies for informing families about long term care services.

Transition Planning Practices Within the Developmental Services Sector

R5. That OPADD encourage the development of best practices in transition planning through:

- a. Regional cross sector planning processes.
- b. Local cross sector initiatives.
- c. Dialogue with Local Health Integrated Networks (LHIN's).
- d. Dialogue with the Ministry of Community and Social Services and the Ministry of Health and Long Term Care.
- e. Distribution of the Transition Guide (see Recommendation 11).

Transition Planning Practices Within the Long Term Care Sector

R6. That OPADD, through its partners and regional planning committees support cross sector staff exchanges during transition processes as a means to further knowledge exchange and build sound transition practices that strengthen support and minimize disruption for the client.

R7. That OPADD advise the Ministry of Health and Long Term Care and the Ministry of Community and Social Services of the need to fund cross sector staffing before, during and after the transition process to older adult services.

R8. That OPADD facilitate a dialogue between the LTC and DS sectors on the level and types of assistance required during the transition planning process; that a planning document be prepared that describes the forms and costs of this transition assistance.

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Building a Model of Transition Planning

R9. That OPADD inform the Ministries of the need for transition planning funding for both services sectors to support older adults with developmental disabilities as they access seniors' services and programs and that OPADD provide the Ministries with the transition assistance planning document.

Gaps and Barriers to Transition Planning

R10. Final Report of the Transition Task Group - That:

- a. OPADD receive and approve the Final Report of the Transition Task Group
- b. The report be posted on the OPADD website, and distributed in hard copy to all OPADD members, regional cross sector planning committees, CCAC's and key stakeholders including regional offices of funding Ministries, the Seniors Secretariat, Health Canada and Social Development Canada.

R11. Transition Guide - That:

- a. OPADD receive and approve the draft Transition Guide
- b. Direct that the guide be tested on a sample of paid and unpaid caregivers from long term care and developmental services
- c. The tested and revised guide be posted on the OPADD website and distributed in hard copy to all OPADD members, regional cross sector planning committees, CCAC's and key stakeholders
- d. OPADD arrange for the Guide to be reviewed and updated annually.

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BACKGROUND

The Transition Planning Task Group was formed by the Ontario Partnership on Aging and Developmental Disabilities (OPADD) to gather and analyse information about the current state of transition planning for people with developmental disabilities who are aging. The goal of this applied research was to identify best practices, tipping points, barriers and issues pertaining to transition planning. The knowledge gained is to be shared with the partners in long term care and developmental disabilities to strengthen their capacity to respond to the aging boom among the population with developmental disabilities.

The aging of people with a developmental disability is an emerging phenomenon. The task group sought to corroborate its findings by using data from a variety of sources (triangulation). The group's work plan included a series of tasks to gather data from several sources:

- a. Transition planning survey – design, testing and distribution of a survey across both sectors and among family caregivers.
- b. Case Studies – presentation and examination of actual cases of people in transition to older adulthood.
- c. Literature Review – review of current literature pertaining to transition planning.
- d. Review of Web Sites – gathering of web-based information on transition planning.

More information on these sources of information is presented in the Appendices.

This report presents the principle findings of the Transition Planning Task Group and makes recommendations for improving our capacity to plan for people with developmental disabilities as they age.

DEFINITIONS

There are different terms used to describe the system of services for older adults in Ontario. These services are commonly referred to as long term care or seniors programs/services or older adult programs/services. These terms are used interchangeably in this report to describe the whole system of services encompassing adult day programs; home support services such as visiting programs, security alert, meals on wheels; older adult centre programs; in home support such as homecare; supportive seniors housing; retirement homes and long term care facilities.

The term “long term care” is sometimes used to describe residential placement in a long term care home. This report uses the term “long term care home” to denote these residential services.

ACKNOWLEDGEMENTS

It must be noted that the work of the task group could not have been completed without the support and participation of the OPADD partners. Distribution and collection of the survey was facilitated by participating regional networks, provincial associations, offices of the Ministry of Health and Long Term Care, offices of the Ministry of Community and Social Services, Community Care Access Centres, Regional Psycho-geriatric Programs and local cross sector projects.

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Acknowledgement and special thanks are due to Joan Turner, volunteer extraordinaire, who tabulated the raw data. Shehenaz Manji, a member of the task group and James Sejjengo, Task Group Co-chair assisted with review and analysis of the raw data. Finally, guidance was provided by the Co-chairs of the Transition Task Group, Cindy Stephens, Director of Nursing at Cummer Lodge and James Sejjengo, Resource Manager at Reena, in the formation and implementation of the work plan and in the many meeting discussions. The membership of the task group is presented in the Appendices to the report.

FORMAT OF THE REPORT

The task group's triangulated approach to data-gathering not only served to confirm corroborating findings from more than one source but also resulted in a substantial amount of information. This report presents a summary of the most important findings arranged within the following key categories:

- A. Numbers of older adults with developmental disabilities
- B. Relationship between the long term care and developmental services sectors.
- C. The role of family caregivers in transition planning.
- D. Transition planning practices within the developmental services sector.
- E. Transition planning practices within the long term care sector.
- F. Key steps in the process.
- G. Gaps and barriers to transition planning.
- H. Conclusion

The Transition Task Group developed a survey instrument to gather current information of transition practices in Ontario. Following a pretest of the instrument it was distributed to more than 1200 long term care and developmental service providers and families. The OPADD partners were instrumental in assisting with the job of getting the survey out to their members and stakeholders. A total of 173 usable surveys were returned. The numbers of respondents from each group are:

- Long term care 101
- Developmental Services 57
- Families 15

The variance in the size of the samples weakens the reliability of the data when making cross group comparisons. Nevertheless, corroborating information from other sources does help to offset some of the risks to reliability. The qualitative data gathered also provides insight into the issues of transition planning as perceived by each respondent group. Finally it is important to note when reviewing report data obtained from the transition survey that respondents sometimes did not answer all questions. The number of responses therefore varies among items from the survey. Finally, a 10 point rating scale was also used for several questions in the transition survey. In all cases, 1 has the lowest value on the scale and 10 the highest.

A. NUMBERS OF OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES

Developmental service providers participating in the survey, reported on the age of adults they serve. One quarter (24%) of all adults currently being supported are over 50 years of age. One half (49%) are over 40 years of age. These numbers indicate that the

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developmental services sector is on the cusp of having to allocate half of its resources and knowledge to the support of adults who are aging. The complete data are presented in Table 1.

Table 1: Adults Served by Responding Developmental Service Providers

DEVELOPMENTAL SERVICES	NUMBER	CUMULATIVE NUMBER	PERCENTAGE	CUMULATIVE PERCENTAGE
Over 70	130	130	2%	2%
61 to 70	405	535	6%	8%
51 to 60	1086	1621	16%	24%
41 to 50	1736	3357	25%	49%
31 to 40	1599	4956	24%	73%%
18 to 30	1816	6772	27%	100%
Total	6772		100%	

The impact of an aging population on the developmental services sector is more significant when additional factors are considered:

- a. While people with developmental disabilities are living longer, there is evidence that symptoms of aging appear sooner than in the general population; for example, a study of aging among people with intellectual disability (Lifshitz and Merrick 2004) found that people with developmental disability, whether living at home or in a community setting, experienced deteriorating health at an earlier age than the general population particularly in terms of vision, hearing and dental integrity.
- b. The depopulation of provincial institutions will move an additional 1042 adults to the community, half of whom are over the age of 50; while some of these adults may move directly to long term care homes where this form of support can best meet their needs, the net result will be to increase the size of the older adult population in the community.
- c. The prevalence of dementia among people with Down Syndrome will continue to exert increasing pressure on developmental service providers; see Table 2 for more information.

Table 2: Reported Incidence of Alzheimer Disease among People with Down Syndrome

AGE	PERCENTAGE
40 – 49	10 – 25 %
50 – 59	20 – 50 %
Over 60	75 %

FINDINGS:

NUMBER OF OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES

- The developmental services sector is facing immediate pressures to support people as they age and to plan for a doubling of these numbers within 10 years.
- The impact of the aging boom on the developmental services sector is made more significant by the earlier onset of the aging process among people with

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developmental disabilities, the prevalence of dementia among adults with Down Syndrome and the pending influx to the community of older adults from institutions.

- The aging boom among people with developmental disabilities and the depopulation of institutions have significant implications for the long term care system.

RECOMMENDATION:

NUMBER OF OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES

R1. That OPADD request the Ministry of Community and Social Services, and the Ministry of Health and Long Term Care in conjunction with CCAC's and MCSS coordinated access programs and with consideration of other databases such as the Intellectual Disability Database for Ireland:

- c. To prepare and maintain a provincial demographic profile of all people with developmental disabilities in order to provide planners and managers with data on which to base decisions for program adaptation and resource allocation.
- d. To disseminate profile information at intervals to all provincial and regional associations and planning/coordinating bodies related to aging or developmental disabilities and to OPADD.

B. RELATIONSHIP OF THE LONG TERM CARE AND DEVELOPMENTAL SERVICES SECTORS

The Ontario Partnership on Aging and Developmental Disabilities demonstrates the potential for the two sectors to work together in responding to the aging boom. Principle areas of this collaboration are knowledge exchange and piloting of innovative service delivery models.

The potential benefit of knowledge exchange is self-evident. Developmental services have a deep understanding of the needs of people with developmental disabilities. Long term care encompasses expert knowledge of the normal aging process, pathologies of aging and dementia. Knowledge exchange can strengthen the capacity of each sector and avoid unnecessary risk as both systems deal with the aging boom because:

1. It can strengthen the capacity of the developmental services sector to provide appropriate support during the aging process and to support people with developmental disabilities who wish to access the wide range of programs and services available to Ontario seniors.
2. It can provide new intervention skills for people working in programs and services for older adults that will make it easier for the long term care sector to provide appropriate support to people with developmental disabilities.

While the potential of the partnership is clear, the two sectors have evolved under different funding Ministries and in accordance with different legislative frameworks. This serves to separate the sectors as they must deal with regulations that mitigate against new and innovative collaboration.

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The transition survey, the review of cases and reports from local cross sector projects reveal that collaboration between the sectors, where it exists, results in positive outcomes for people with developmental disabilities who are aging. However the pattern of partnering varies across the province. Some areas are enjoying long standing working relationships that support effective cross sector planning. Other areas are just beginning to explore the potential for mutual support in addressing the developmental disabilities aging boom.

In some jurisdictions the historical separation of the two sectors seems particularly strong and there is reluctance to consider the possibilities of partnering arrangements. There seem to be three motivations beyond the historical and funding barriers that reinforce the separation. First, reticence to partner is sometimes fuelled by ideological positions on both sides that view the other sector as serving people who are devalued by society. Partnering is perceived as a move that will lead to further devaluation. Second, there are views that people with developmental disabilities can only be well served by the developmental services sector. This sector-centricity results in keeping people with developmental disabilities away from services to seniors. Interestingly, this shows up in the transition survey data. Third, there is a fear that partnering will lead to institutionalization or re-institutionalization of people with developmental disabilities, particularly where there are sufficient numbers of long term care beds.

The ideological views and fears held by some people working in the sectors are important to note and to discuss since they will otherwise impede willingness to explore partnering. The idea that the two populations of older adults and people with developmental disabilities are devalued by society is not without some merit. However, this is not a prescription for retreating from the work of enhancing the value of all human beings in society. The logic of keeping the two sectors apart because of the devaluation issue is based on a sense of victimization rather than social development.

The position that only developmental services can support people with developmental disabilities is highly contradictory to the community living movement's professed philosophy of inclusion. Adherence to such a position is a setback to several decades of work to open society to people with developmental disabilities. It also places the community living movement as the gatekeeper that prevents people from enjoying what is available to them.

The fear of institutionalization of people with developmental disabilities is understandable given the work of the community living movement to take people out of institutions where their lives were lived in separation from society. However, the partnership between the two sectors is about a much bigger picture. Partnering helps caregivers become knowledgeable in their support role during the aging process. It creates new opportunities for people with developmental disabilities to live rich lives at any age. It supports an effective transition to all aspects of growing older. For those with a developmental disability where a move to a long term care home is the means to maintain or improve quality of life, partnering provides a means to incorporate appropriate supports into the transition.

While, OPADD believes that organizations should retain their autonomy and find solutions at the local level, it is concerning that some players may be missing an opportunity to solve the great challenges that lie ahead. There is no prospect of a large influx of funding to fix problems. Technology may contribute to administrative efficiency but is not going to make a significant difference in resources available to support people. New funding formulas may help to distribute resources more equitable but will not result in more resources across the

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system. The work of families to support family members with developmental disabilities will continue to be a principal factor in the equation of maintaining people in the community. However, families are also aging and unable to carry on as principal caregiver in many cases.

The size and impact of the aging boom in the immediate and long term requires a substantial response. Solutions to the aging boom must be found for the most part within the resources that are already here. Creating the means for people with developmental disabilities to grow older with grace and among their own cohort of older adults is the fundamental rationale for the partnership. The knowledge exchange between the sectors allows for the free trade of current ideas and knowledge. Shared planning processes can help to build transition bridges as people with developmental disabilities grow older. A reasoned approach to collaboration will serve to ensure that people with developmental disabilities have access to the richness of programs and services available to all Ontario seniors.

While there are many cross sector successes to celebrate, findings from the transition survey provides evidence that more work remains to be done in bringing the sectors together around the issue of aging and developmental disabilities. Data in Table 3 indicates that people with developmental disabilities are under-represented in both residential and non-residential services for seniors.

Table 3: Proportion of People with Developmental Disabilities Using Non-residential and Residential Seniors Services

	FACILITY RESIDENTIAL		COMMUNITY NON-RESIDENTIAL		RESIDENTIAL & NON RESIDENTIAL	
	#	%	#	%	#	%
Total All Adults	12,000	59%	8358	41%	20,358	100%
# w/ Dev. Disability	291	1.4%	136	.6%	427	2%

Table 3 illustrates that .6% of non-residential and 1.4% of residential participants are people with developmental disabilities. The data on prevalence of developmental disability in Canada varies with estimates that range from .5% to 3% of the population. When the national estimates are compared to the findings of prevalence of people with developmental disability in long term care, it remains unclear whether this population is under-represented or over-represented in the long term care system. However some comments received to the transition survey indicate that not all older adult programs admit people with developmental disabilities. Moreover, the reported experiences of developmental service providers in various OPADD forums indicate that programs for seniors are not equally accessible in all jurisdictions.

This is of concern since many of these programs are designed to support health and quality of life and avoid unnecessary or premature need for placement in a long term care home. In addition, some long term care homes that responded to the survey indicate that they do not serve people with developmental disabilities.

It is important to note that these services for seniors are the repository of caregiver knowledge on how to support people as they grow older and this knowledge is in critical short supply among staff of developmental services providers. The need for information and knowledge about aging among developmental services staff was documented in the

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proceedings of four regional conferences facilitated by OPADD in 2000 and 2001. This was also confirmed in a training needs study conducted in Huron County by the Huron Trillium Partnership.

The presence of barriers to accessing seniors' services becomes more disquieting when one considers some additional information on the tendency to an insular focus among care staff. In a study of living arrangements (Fothringham 1999), it was found that preoccupation with the basic tasks of caring for clientele seems to mitigate against staff exploring whether there are more suitable environments within which a client may be supported. The study found that a large number of individuals were suffering substandard care due to their needs not being met within their current environment.

The impact that aging has on the fit between the person and their environment is underlined in a review of literature on aging and intellectual disabilities (McCallion and McCarron 2004). This examination reveals that age-related co-morbidities are more complex among the population with intellectual disabilities for several reasons since their aging is often accompanied by:

1. An increase in behaviour problems and emotional instability.
2. Withdrawal.
3. Overestimation of one's own abilities.
4. A reduced timeline within which these issues arise.
5. A more pronounced rate of decline.

The net result of aging among people with developmental disabilities, as uncovered by the authors, is a more difficult set of changing conditions which require planning if the person is to be effectively supported during their transition to older adulthood. The tendency to an earlier onset of co-morbidities related to aging among the population with developmental disabilities is corroborated in a study of access to home care services (Harrington, Carillo and others 2001). The authors expressed concern that this earlier onset coupled with the growing population of older adults with developmental disabilities would place considerable pressure on the system and could result in higher levels of dependence among this population.

This pressure is reflected in the comments of a group home worker:

“Our major challenge is we lack medically trained staff in this setting. We lack front line nursing staff and our support workers are not authorized to treat any of the issues...has or will likely develop in the future.”

Other studies highlight related concerns such as a greater risk associated with accidents (Strauss, Shavelle and others 1998) and a tendency for many people with developmental disabilities to have an average of five health problems with more than half of those going undetected (Fisher 2004). The implications are that age-related support must be different than what is provided during middle age.

The Report of the National Advisory Council on Aging, “Aging with a Developmental Disability,” highlights a number of concerns related to aging and access to services for people with developmental disabilities. The report's recommendations speak to the need to end marginalization of older adults with developmental disability by ensuring their access to

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appropriate services for older adults and by equipping caregivers and organizations with the requisite skills and resources.

FINDINGS:

RELATIONSHIP OF THE LONG TERM CARE AND DEVELOPMENTAL SERVICES SECTORS

- Aging among people with developmental disabilities is accompanied by earlier onset and a more complex presentation of co-morbidities.
- The aging boom coupled with the complexity of age-related co-morbidities poses a significant stress for the developmental services system and for staff who lack training in aging.
- The willingness to enter into cross sector partnership arrangements varies among jurisdictions in Ontario.
- Access to services for senior citizens is unequal across the province suggesting there are barriers to access in some jurisdictions.

RECOMMENDATIONS:

RELATIONSHIP OF THE LONG TERM CARE AND DEVELOPMENTAL SERVICES SECTORS

R2. That OPADD further opportunities for cross sector knowledge exchange by inviting Ontario College and University programs related to health, aging and developmental disabilities and appropriate government Ministries to a symposium on the need for curriculum reform; that such reform consider the needs of students in the medical, health and direct support programs as well as those already working in their respective disciplines

R3. That OPADD engage in dialogue with the Ministry of Health and Long Term Care and the Ministry of Community and Social Services to identify strategies for greater cross sector collaboration at the Ministerial, planning and service delivery levels.

C. THE ROLE OF FAMILY CAREGIVERS IN TRANSITION PLANNING

Families are the principle caregivers for many people with developmental disabilities. While there are no Canadian data, three American studies (Fujura 1998), (Bradock 1999) and (Rietschlin 2000) report that 45% to 80% of people with developmental disabilities live with family. In some cases, families share this role with developmental service agencies. The issue of aging and developmental disabilities is one with which many families are conversant as they respond to the aging of a son, daughter or sibling. The issue takes on added significance where parent caregivers must simultaneously face their own aging. Furthermore, changes in the social context may limit the future availability of families to provide care-giving support into the senior years of their child. Increasing divorce rates, geographic dispersal, reduced birth rates, labour force participation and later child birth are contributing to further dilution in the capacity of families to provide support or to complement the support of service providers.

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While the central role of families may be changing due to social forces, the importance of family involvement for successful transition planning was rated highly by all three respondent groups participating in the transition survey, as illustrated in Table 5.

Table 5: Importance of Family Involvement in Transition Planning

AVERAGE RATING OF EACH RESPONDENT GROUP	DEVEL'MNTL SERVICES	LONG TERM CARE	FAMILIES
On a Scale of 1 to 10	8.2	8.1	8.3

The importance of family involvement was also reflected in the work of the Huron Trillium Partnership, a local cross sector project in Huron County. The Huron partnership formally recognized the importance of family involvement in its discussions of how to build cross sector planning capacity. The partnership was concerned that older adults with developmental disabilities should be able to access services for seniors and that families should continue to be active participants in the life planning process. Both long term care providers and developmental service agencies agreed that families should remain central actors in the planning role before, during and after any transition to older adulthood including transition to seniors' services. The partnership upheld this thinking in one of several principles it adopted on transition planning:

“The relationships that each person may have with members of his/her family are to be respected. Transition Planning will always allow for the inclusion of family in the Transition Planning Process.”

This principle provides the basis for service providers in both sectors to facilitate family involvement when people with developmental disabilities access services and programs for older adults. A study of transition to respite services (Townsend and Kosloski 2002) revealed that satisfying involvement for families was reflected in higher effectiveness of care.

Evidence gathered from families via the transition survey indicates that they too see themselves as key players in transition planning processes. The transition survey was directed to families where the person with a developmental disability was 40 years or older. Sixty four percent of the 15 family respondents report that they are involved in transition planning to older adulthood. Moreover, all families who are not currently involved in a transition planning process indicate that they expect to be involved in one within the next 5 years.

Families were asked if they received help from a service agency or support professional in their planning. Twelve families indicated they receive such help. Eight of 12 respondents (66%) indicated the assistance was offered by a developmental services provider or support professional. Four respondents used a variety of other sources such as a lawyer, social worker or hospital. This suggests that families tend to look to developmental service providers to assist with planning. The capacity of the developmental services sector to respond to family-initiated transition planning may be limited by a lack of resources, a lack of knowledge about the long term care system of services, staff untrained in aging and the philosophy of some providers that precludes use of long term care services.

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Long term care and developmental services providers were asked to report their experiences of family involvement in the transition planning process. DS providers indicated that families are the second most involved player, immediately behind the client. Their average rating of families as players was 9.2 on a scale of 1 to 10. Long term care providers reported that families are involved in 80% of cases. This data corroborates the reports of families as highly involved in transition planning.

Families were asked to describe the outcomes they sought through the transition planning process. Generally, families reported that their planning covered a range of non-residential and residential options. It is interesting to note that families were involved in some innovative residential options outside of the service system such as buying or building a home. Two families indicated that their plans were in the direction of placement in a long term care facility. This reflects the general population where an estimated 10% of older adults seek placement in a long term care facility. It is also worth noting that no families were seeking placement with a developmental services provider. These responses are summarized in Table 6.

Table 6: Services Sought by Families

FAMILIES	NUMBER	PERCENTAGE
Non-residential seniors services	4	37%
Supportive Seniors Housing	3	27%
Long Term Care Placement	2	18%
Buy 2 bedroom condo	1	9%
Construction in own home	1	9%
Total	11	100%

FINDINGS:

THE ROLE OF FAMILY CAREGIVERS IN TRANSITION PLANNING

- The potential for families to support aging children and siblings in the future may be diminished due to social changes.
- Families, developmental service organizations and long term care providers rate involvement of families in transition planning as highly important.
- Developmental service and long term care providers report that they involve families in transition planning most of the time.
- Family involvement by both sectors throughout the transition planning process supports ease of access to the services of both systems in the interests of providing quality of life during the aging process.
- Families often seek help with transition planning from an agency or support professional. A little more than half the time they receive this help from a developmental services provider.
- The type of support families seek for their aging member reflects a variety of non-residential and residential seniors services.

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- The large numbers of family caregivers who are aging, the current pressure on the developmental services system and the lack of preparedness among the developmental services sector to address aging issues suggests that families may be unable to find sufficient help with transition planning from the developmental services sector.
- There is potential for service providers to involve and support families more fully in order to inform them of available services, engage them throughout the transition process and foster client ease of access to both systems as needed.

RECOMMENDATION:

THE ROLE OF FAMILY CAREGIVERS IN TRANSITION PLANNING

R4. That OPADD formally support the inclusion of families throughout the transition planning process and that OPADD convey this position to all partnering organizations with a request that they encourage their respective members/stakeholders to develop strategies to include families before, during and after the transition process as well as strategies for informing families about long term care services.

D. TRANSITION PLANNING PRACTICES WITHIN THE DEVELOPMENTAL SERVICES SECTOR

While there is evidence that some service providers have begun to tackle the complexities of planning for the transition to older adulthood, there is also evidence that suggests agencies may be falling behind when it comes to preparing for the aging boom. Developmental service providers reported via the transition survey that they are involved in transition planning with 291 out of 10,200 adults they are serving. This amounts to 3% of all adults. This number is low given that 49% of all adults supported by these same respondents are over 40 years of age and 24% are over 50 years of age. The low numbers involved in transition planning are reflected in the small number of providers who have a written policy or statement on transition planning in place. Only 8% of developmental service agencies report they have a written description or policy for transition planning. In addition only 19% of developmental service respondents report plans to develop any written material or policy within the next year. While these data are not conclusive due to the difference in sample sizes between family and agency informants, they are suggestive that there is work to be done on bringing agency and family transition planning capacity into tandem.

This interpretation is supported by comments received from some survey informants. In the words of one responding developmental services provider:

“...We do not refer anyone to LTC – we have supported numerous individuals within their home through to death.”

The data suggests that some developmental service providers are adopting a practice of aging in place. These providers may have sufficient resources to provide this support in the short term and perhaps even in the long term. However based on pressures identified over the past few years many providers do not have the resources required to maintain people in place as they age. Moreover paid caregivers in the sector do not have the requisite training. Finally, these types of comments suggest that some developmental

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service providers are denying access to seniors' services through a deliberate decision or through lack of information about what is available. This is not completely surprising since many of us tend to ignore questions about our own aging and to put off making plans ahead of time. However there is an additional responsibility on service providers to move beyond human foibles in the interests of informed deliberation and planning on behalf of clientele.

When asked to provide more detailed information on the outcomes sought for transition planning, a smaller number of providers responded. These data appear in Table 7.

Table 7: Outcomes Sought Transition Planning by Developmental Services Agencies

Reported Outcomes being Sought	Number	Percent
Access to non-residential seniors programs	25	42%
Access to residential placement in supportive seniors housing	10	16%
Placement in a long term care facility	25	42%
Total	60	100%

A comparison of transition planning outcomes between developmental services providers and families appears in Table 8.

Table 8: Comparison of Transition Planning Outcomes - Families and DS Agencies

	FAMILIES		DS AGENCIES	
	#	%	#	%
Non-residential seniors services	4	37%	5	42%
Supportive Seniors Housing	3	27%	10	16%
Long Term Care Placement	2	18%	25	42%
Buy 2 bedroom condo	1	9%	0	0
Construction in own home	1	9%	0	0
Total	11	100%	60	100%

This comparison indicates that both families and developmental service agencies have a similar sized focus on transition planning to non-residential services. However DS agencies are twice as likely to plan for transition to long term care residential placement compared to families who tend to plan more towards supportive seniors housing and other residential models. The data do not directly show the reasons for the preponderance of referrals to long term care homes made by developmental service providers compared to families. However the survey findings suggest some factors.

We saw earlier in the discussion on family role in transition planning that the vast majority of DS providers (92%) do not have any written policy or statement in place pertaining to transition planning. Only 19% report on plans to develop such a written policy or statement in the next year. This data suggests DS providers are not as highly focused on transition planning as the number of older adults they are serving would suggest. Moreover it does not appear that transition planning is a high priority for a majority of providers, despite the known earlier and more complicating health effects of aging among people with developmental disabilities. It may be that developmental service providers are relying on

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internal resources and avoiding transition planning that calls upon access to resources available to seniors. Consequently, the exacerbation of health issues during the aging process may lead to a truncated transition process that moves immediately to residential placement options.

There is evidence that health conditions play a large role in the aging process among people with developmental disabilities and perhaps have more impact in more cases than the general population. Literature on health risks among people with developmental disabilities reports that certain populations of people with developmental disabilities have particular health risks. The conditions that may arise from these factors can add to the support requirements during the aging process and include:

- a. Specific syndromes (e.g. Down Syndrome, Fragile X, Prader-Willi Syndrome).
- b. Extent of central nervous system compromise that results in an associated developmental disability such as epilepsy, cerebral palsy and some forms of visual impairment.
- c. Placement within specific programs (institutional settings may pose risks of infections; community group home settings may pose risk due to lifestyle choices that result in lack of exercise, smoking, alcohol consumption, poor diet, unsafe sex, drug use).
- d. Access to basic healthcare services (lack of knowledge among care staff of the aging process and reduced ability of some people with developmental disabilities to make their health needs known pose two significant barriers to health care access).

Many of these same factors are cited in the National Advisory Council on Aging report, "Aging with a Developmental Disability - Seniors on the Margins."

The significance of monitoring and management of health conditions and functional ability among older adults with developmental disabilities is reinforced in case studies reviewed by the task group and further underlines the need for proactive transition planning guided by staff trained in aging and that includes access to support services available to Ontario seniors. These case studies also help to identify some of the strategies that were put in place to manage the transition:

"...She started manifesting signs in the summer of '99. She began to seem to withdraw from social contact...She also became self-injurious...She was having frequent falls...She developed more problematic behaviours...She became incontinent. We contacted (agency x)...to perform an assessment. They needed large amounts of data regarding her history that we were unable to provide. We never had this information in the first place before she came to us. Also their diagnostic tools were insufficient to assess someone with her level of pre-existing disability. It wasn't until the summer of 2002, she was finally diagnosed with progressive dementia."

"Situation has become very difficult for other people in the house and staff because of individual being very anxious and not sleeping...Individual's

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physical condition deteriorated. Stairs became problematic. Some supports put in place by CCAC but not enough to make the situation sustainable...Geriatric assessment done...recommended LTC...Family and circle of support involved...Power of Attorney for Personal Care put in place...Service provider intends to maintain relationship with the individual”

“Staff visited...before she moved in and felt very comfortable with everything...staff stayed overnight at the beginning...now down to 20 hours per week...met with LTC Home staff at shift change-over...good dialogue...will be involved in her plan of care and conference.”

“A man of 53 lived in a fairly independent setting...eventually needed a more accessible location...has since ended up with a G-tube and other issues. Took one year for a transition process.”

“An individual living in the community who was not involved with any service system...fell in the winter and broke hip...called on developmental services sector and health sector to see what would be best for the individual. Developmental services has a long waiting list...tremendous change in individual following surgery...individual put on waiting list for long term care bed...currently residing in a geriatric psychiatric setting, not eligible for long term care and no options in developmental services sector.”

“Behaviour of individual deteriorated, more anger and aggression, demanding more attention, daily living skills decreasing, psycho-geriatrician felt individual had some progressive dementia and maybe Alzheimer’s.”

These excerpts from several case studies illustrate the number and complexity of the support requirements that emerge while staff struggle with adapting to changes in the person. This complexity of support during the aging process is underlined in a study of aging among people with a dual diagnosis (Bongiorno 1996). The study highlighted that staff must deal not only with the onset of medical complications, but often psychological and emotional problems as well. The researcher recommends that staff receive training to equip them in appropriate intervention with aging clientele.

Psychological and emotional problems also come into play during the retirement process. The lower income among people with developmental disabilities limits their choices related to post employment. Moreover the earlier onset of age-related health problems may influence the need to consider retirement at a younger age. However studies of older workers with developmental disabilities (Factor, 1989; Heller, Factor, Sterns and Sutton, 1996; Mahon and Goatcher, 1999) found that their preference was to work as long as possible and to obtain better paying employment. Developmental service providers may not be equipped to manage the changes in client support that will accompany retirement. Moreover the tension among client aging, low income, desire to find higher paid employment and preference for later retirement may contribute to additional emotional problems among older adults.

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The transition data, case studies and findings from the literature suggest a number of features that should be built into a successful transition planning process:

1. Begin the transition planning process early – in the person's forties.
2. Gather and maintain history and background information on each client.
3. Create baseline data on each client prior to his/her entry into the years when the aging process accelerates.
4. Ensure staff acquire new skill sets related to support, intervention, health and emotional conditions associated with aging.
5. Develop capacity to engage in medical and psychological/psychiatric consultation, assessment and intervention.
6. Become aware of the full range of services available to older adults and how to access them.
7. Get to know the contact people at the CCAC and all seniors' programs/services; visit these programs to become familiar with what they offer.
8. Develop transition planning that encompasses the full range of the aging experience – physical, emotional, employment, decision-making.
9. In the transition planning process, consider the impact that aging has on all other people in the client's life (staff, roommates, friends, family) and how this may influence planning decisions.
10. Ensure the individual's plan includes clearly identified risk factors arising from family history, the presence of a syndrome, living situation and lifestyle.

FINDINGS:

TRANSITION PLANNING PRACTICES WITHIN THE DEVELOPMENTAL SERVICES SECTOR

- There is a difference between family members and developmental service agencies relative to preparedness to engage in transition planning:
 - DS provider respondents report transition planning with 291 or 3% of adults they support.
 - Sixty four percent of family respondents report that they are involved in a transition planning process.
- When asked to specify the nature of the transition planning, DS providers identify 60 individuals; this represents .6 of 1 % of all adults served by respondents.
- DS providers are more than twice as likely to focus on transition to a long term care placement compared to families.
- DS providers and families focus on transition to non-residential seniors services at about the same rate.
- Changes in health status and the emergence of dementias among some clients will disrupt support interventions of agencies unless providers develop proactive strategies for transition planning.
- Emotional and psychological issues may be present in some individuals as they age and will impact the person's adjustment to the aging process.

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- Retirement is an integral element of transition planning and will pose additional stress on the aging of clients unless service providers develop and articulate comprehensive transition planning processes.

RECOMMENDATION:

TRANSITION PLANNING PRACTICES WITHIN THE DEVELOPMENTAL SERVICES SECTOR

R5. That OPADD encourage the development of best practices in transition planning through:

- a. Regional cross sector planning processes.
- b. Local cross sector initiatives.
- c. Dialogue with Local Health Integrated Networks (LHIN's).
- d. Dialogue with the Ministry of Community and Social Services and the Ministry of Health and Long Term Care.
- e. Distribution of the Transition Guide (see Recommendation 11).

E. TRANSITION PLANNING PRACTICES WITHIN THE LONG TERM CARE SECTOR

Long term care programs were asked via the transition survey whether they had a transition planning process in place. Almost half (40 out of 88 or 45%) of those who responded to the question indicated they do have a process in place. Twelve or 14% indicated they have a written policy on transition planning. The data suggests that long term care providers are more attuned to transition planning than developmental services. This is reasonable given that people accessing long term care services are doing so to support their transition to older adulthood. However the aging of the population with developmental disabilities requires that developmental service providers gain a similar level of fluency with transition planning.

Long term care providers were asked to describe the essential features of their approach to transition planning. Of the 72 providers who responded to this question, 63 mentioned one or more identifiable features pertaining to transition planning. Analysis of these data revealed that responses fell into one of three categories: actors, processes and resources. Most frequently identified actors include families, CCAC's, other community resources and clientele. Most often identified processes included individual/case by case, assessments and home visits. Resources that were most often cited include specific programs used to facilitate the transition process (e.g. seniors day program), additional funding support and assistive devices. A summary of the analysis appears in Table 9.

Some of the features of transition planning found generally in long term care programs are echoed in the comments of a senior practitioner working in the field who was asked to describe the transition process to a long term care residential placement

“Point of access is the CCAC...assessments will be performed by all disciplines...in terms of preparation the family should already have a good level of familiarity with the environment their loved one is to be transferred to...family council is available for those who wish to join...with clients we try to accommodate their native inclinations, what they are used to in the past...to give them a chance to hold onto an identity that they value.

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Everyone gets special treatment, in that we take great pains to look at them as individuals and no two care plans are the same.”

Table 9: Transition Planning Features Reported by Long Term Care Providers

		TIMES MENTIONED	PERCENTAGE
ACTORS	Families	19	30%
	CCAC	18	28%
	Other community resources / agencies	12	19%
	Client	11	17%
	Social Worker	4	6%
	Total	64	100%
	PROCESSES	Individual / case by case basis	8
Assessment		7	22%
Tours / home visits		5	16%
Transition planning		3	9%
Adjust level of care to individual		3	9%
Counseling		3	9%
Continuity of services		2	6%
Integration with other residents		1	3%
Total		32	100%
RESOURCES	Specific program supports transition process	8	53%
	Additional funding support	2	13%
	Assistive devices / life support equipment	2	13%
	Legislation / Resident Bill of Rights	1	7%
	Internal Policy	1	7%
	Written Plan	1	7%
	Total	15	100%

Long term care providers reported that they often receive assistance from local developmental services providers when people with developmental disabilities enter day services or residential support. This support varies between direct face to face intervention with the client to indirect support such as telephone consultation. Long term care respondents were split on the suitability of this support with a slight majority assessing it as adequate. The data suggests that some developmental service providers are engaging in transition support following the client's access to a seniors program. However the support, when given, is often not enough. The data is presented in Table 10.

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Table 10: Long Term Care – Transition Assistance Received from DS Provider

	DS PROVIDES ASSISTANCE		LEVEL OF ASSISTANCE		ASSISTANCE IS ADEQUATE	
	YES	NO	DIRECT	INDIRECT	YES	NO
DAYSERVICE	17	30	16	7	16	11
	36%	63%	70%	30%	59%	41%
RESIDENTIAL SERVICE	22	11	27	24	25	22
	67%	33%	53%	47%	53%	47%
DAY AND RESIDENTIAL	39	41	43	31	41	33
	49%	51%	58%	42%	55%	45%

When asked to identify how the transition support from developmental service providers could be improved, long term care respondents most often specified an increase of support from the developmental service provider. Training, consistent use of the same staff person and access to other specialized services were also mentioned. A list of the suggestions made for improving support follows:

“Weekly visits prior to admission and for 3 to 8 weeks following transition.”

“Regular scheduled visits.”

“We have started to meet with them (ACL) in regards to some clients needing service.”

“More involvement from the beginning and to have follow through with a counsellor/worker.”

“We would like quicker response time to issues around behaviour and disease processes as well as longer involvement period following transition; more flexibility for hours of accessing resources, i.e. evenings/nights.”

“More communication and involvement from the developmental service agency.”

”In our experience the staffing within the developmental disabilities agencies changes often leaving inconsistent contacts & gaps in service for client support.”

“OT, PT, Psycho-geriatric – need more assistance.”

“More education and training to work with each individual. Help to staff in managing behaviours and help getting them settled in the program. More information on what works for the client.”

“Would like a more active approach to assisting a move from community to LTC.”

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Participating agencies in the Huron Trillium Partnership Project found that the provision of developmental services staff over a defined period of time and for specific reasons offered a key element in successful transition planning to long term care programs. Long term care staff learned about the client and about productive forms of individual intervention. Developmental services staff were able to provide needed additional support during the transition process. It is important to note that long term care staff focused their expertise on interventions related to aging while developmental services staff concentrated on support related to the person's disabilities. The partnering agencies worked hard together without additional resources to ensure quality of life for individuals as they age. The concept of "double-dipping," which has sometimes been applied to cooperative cross sector initiatives is simply inappropriate in the context of transition planning to older adulthood.

FINDINGS:

TRANSITION PLANNING PRACTICES WITHIN THE LONG TERM CARE SECTOR

- Almost half (45%) of the long term care programs responding to the transition survey reported that they have a transition planning process in place.
- A minority (14%) indicated they have a written transition planning document or policy in place.
- When asked to describe the essential features of their transition planning process, long term care providers identified a number of actors, processes and resources.
- Most frequently identified actors include families, CCAC's, other community resources and clientele.
- Most often identified processes included individual/case by case, assessments and home visits.
- Resources that were most often cited include specific programs used to facilitate the transition process (e.g. seniors day program), additional funding support and assistive devices.
- Long term care providers accept help from developmental services providers with the transition process, where such help is available. The help is often seen as inadequate.
- Suggested improvements in support from developmental service providers include more visits prior to admission, greater staff involvement, improved communication, faster response time, greater availability, more consistency in staff providing support, education, training and other specialized services.
- The provision of transitional support over a specific period of time is a pre-condition to successful transition planning that provides orientation and training to long term care support staff and benefit to the client.

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RECOMMENDATIONS:

TRANSITION PLANNING PRACTICES WITHIN THE LONG TERM CARE SECTOR

R6. That OPADD, through its partners and regional planning committees support cross sector staff exchanges during transition processes as a means to further knowledge exchange and build sound transition practices that strengthen support and minimize disruption for the client.

R7. That OPADD advise the Ministry of Health and Long Term Care and the Ministry of Community and Social Services of the need to fund cross sector staffing before, during and after the transition process to older adult services.

F. BUILDING A MODEL OF TRANSITION PLANNING

The Transition Task Group sought to begin the process of understanding best practices in transition planning and to build a model that would be helpful to caregivers and people with developmental disabilities. A number of survey questions were designed to gather this type of data, which included identification of success factors, philosophy, most important players, cross sector assistance, family involvement and cross sector coordination capacity.

Success Factors

Survey respondents were asked to rate twelve factors for their importance to the transition planning process on a scale of 1 to 10. The ratings were averaged to identify the priorities within each sample and to identify areas of agreement across groups. The full results are presented in Table 11.

Table 11: Transition Planning Success Factors – Average Ratings by Group

SUCCESS FACTORS	DS	LTC	FAM
Agency philosophy	8.2	8.6	6.0
Willingness of other agencies to work with us	8.5	8.2	9.2
Family involvement	8.2	8.1	8.3
Support circle involvement	7.4	7.4	6.1
Training of staff	7.7	8.5	8.1
Cross sector staff training	7.2	8.5	5.9
Availability of appropriate services for older adults	8.8	7.8	8.8
Involvement of coordinating / planning bodies	7.3	7.3	6.1
Flexibility in funding allocations to cover transition costs	8.2	7.1	7.5
Additional funding for transition costs	8.1	7.6	6.8
Guidance from funding Ministries	7.3	7.2	7.3
Community Care Access Centre Assessment Tools	6.9	7.3	7.5

Table 11 shows that all groups rated all twelve factors as fairly important. No factor received an average rating below 5.9 on the scale of 1 to 10. Different presentations of the

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data can help to draw out the factors that are rated a higher priority across respondent groups. Table 12 helps to focus on these priorities by showing the top six factors identified by each group.

Table 12: Top Six Ranked Factors for Each Respondent Group

	DS	LTC	FAM
1	Availability of appropriate services for older adults	Agency philosophy	Willingness of other agencies to work with us
2	Willingness of other agencies to work with us	Training of staff	Availability of appropriate services for older adults
3	Agency philosophy	Cross sector staff training	Family involvement
4	Family involvement	Willingness of other agencies to work with us	Training of staff
5	Flexibility in funding to cover transition costs	Family involvement	Flexibility in funding to cover transition costs
6	Additional funding for transition costs	Additional funding for transition costs	Community Care Access Centre Assessment Tools

Success factors that were ranked in the top six across all three respondent groups are:

1. Willingness of other agencies to work with us.
2. Family involvement.
3. Funding – additional funds or flexibility in allocation to cover transition costs.

These results indicate high acceptance of cooperative activity as a means to address transition planning issues. However, comments provided by respondents identified the presence of some speed bumps on the road to greater cooperation:

“As a long term care facility we have not dealt with these issues.”

“Have not received support from developmental service agencies.”

“We have been unable to engage more effective involvement.”

“Sometimes we need the community worker to provide additional support as needs change.”

Currently Agency Y & CCAC is decreasing services due to funding cuts.”

“Some come to us with no supports or involvement with ACL’s.”

These comments suggest that cooperative activity may be mitigated by inexperience in cross sector partnering, a lack of information on who or how to contact a provider in the other sector to consult, funding issues and the lack of connection between some people with developmental disabilities and the developmental services system. The findings provide corroboration of the need for OPADD to continue to facilitate cross sector cooperation and planning including partnering with family organizations.

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When the factors are arranged to show high agreement across respondent groups another priority ranking appears that supports cross sector partnering and teases out additional priorities. Table 13 illustrates this cross group agreement pattern.

Table 13: Factors with High Agreement across Groups (Avg. Score < 1.0 Difference)

SUCCESS FACTORS	DS	LTC	FAM
Willingness of other agencies to work with us	8.5	8.2	9.2
Family involvement	8.2	8.1	8.3
Training of staff	7.7	8.5	8.1
Availability of appropriate services for older adults	8.8	7.8	8.8
Guidance from funding Ministries	7.3	7.2	7.3
Community Care Access Centre Assessment Tools	6.9	7.3	7.5

This comparison further refines understanding of priority factors for successful transition planning as perceived by informant groups. These additional priorities include:

- Staff training.
- Availability of appropriate services for older adults.
- Guidance from Funding Ministries.
- Community Care Access Centre Assessment Tools.

The importance of staff training was identified again and again in the first round of regional cross sector workshops held in 2000 and 2001. Since then a number of groups have developed an ongoing program of cross sector training. These groups include:

- Northwest Committee on Aging and Developmental Disabilities.
- Central East Training Committee on Aging and Developmental Disabilities.
- Huron Trillium Partnership.

The continued activity of these groups relative to training indicates that training remains an important cross sector activity to equip caregivers with the information and knowledge they require to deal with the aging boom among people with developmental disabilities. The need for training on aging within the developmental services sector and for training on developmental disabilities within the long term care sector begs the question of how to duplicate these training models across the province.

The reported need for “availability of appropriate services for older adults” lends support for cross sector collaboration to help long term care services and their care-giving staff adapt to the new reality. Since there will not be a massive influx of new funds to deal with the aging of people with developmental disabilities, service providers and families must find ways to adapt current services to support transition planning. This process can be strengthened by the use of assessment tools from CCAC’s and guidance from funding Ministries.

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Table 14: Factors with Higher Ranking by Service Providers and Lower Family Ranking

SUCCESS FACTORS	DS	LTC	FAM
Agency philosophy	8.2	8.6	6.0
Support circle involvement	7.4	7.4	6.1
Cross sector staff training	7.2	8.5	5.9
Involvement of coordinating / planning bodies	7.3	7.3	6.1
Additional funding for transition costs	8.1	7.6	6.8

In this presentation it is clear that service providers are more attuned to systemic success factors than families. Agency philosophy, staff training, use of coordinating bodies and funding are familiar issues that providers deal with on a regular basis. However it seems puzzling that families do not rate support circle involvement as a higher priority since this is a factor that we expect accompanies every person with a developmental disability. This data informs transition planning thinking by alerting all players to the difference of perception and needs among service providers and families. It is not necessary to resolve all of these differences but to be aware of them and to find ways to encompass the needs of everyone at the transition planning table. The high degree of congruence between service providers on these factors offers guidance to organizations on possible priority areas in building transition planning capacity.

Philosophy

The keys to successful transition planning were also sought by asking informant groups to identify their general philosophy of support to older adults with developmental disabilities. A total of 9 family respondents, 51 developmental service respondents, and 73 long term care respondents replied to this question. General themes raised by the respondents are listed and distributed by their frequency of mention in Table 15.

Table 15: Philosophy of Support Themes Identified by Informants

THEME	DEVELOPMENTAL SERVICES		LONG TERM CARE		FAMILIES	
	#	%	#	%	#	%
Flexible living choices	17	18%	24	17%	4	21%
Seamless support	11	12%	29	21%	7	37%
Individualized service	19	20%	19	14%	5	26%
Equal treatment	0	0%	10	7%	0	0%
Age in place	22	24%	0	0%	3	16%
Collaborative planning	5	5%	20	14.5%	0	0
Education & training	8	9%	7	5%	0	0
Specified approaches	4	4%	7	5%	0	0
Holistic approach	3	3%	21	15%	0	0
No formal philosophy	5	5%	2	1.5%	0	0%
Total	94	100%	19	100%	139	100%

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There is congruence among all informant groups in the identification of three themes:

- Flexibility in choices for living for persons with developmental disabilities.
- Working toward seamless and inclusive supports that overcome access barriers.
- Providing services that are individualized to the person's needs.

Respondent comments to this question described a quality living environment as one that was designed to focus on abilities and where the person felt at home. Informants described a variety of optional models for living:

- A continuum of family home.
- Supportive adult residences.
- Community living group homes.
- Homes for persons with Alzheimer's.
- Non-congregate settings.
- Retirement/accessible home models.
- Nursing homes.
- CCAC cluster care.
- 24 hr supervised residential care.
- Specialized units in nursing homes for those with developmental disabilities.
- Designated number of beds in LTC facilities.
- Designated clustered units.
- Separate specialized facilities operating under different regulations to LTC.

Comments around seamless support indicated that quality of service was maintained through the life span. This could mean additional services with aging, continuity with community activities and social opportunities when moving to long term care settings, "opportunity to participate in a wide range of leisure, fitness, educational and support services that respond to the differences in age, abilities and lifestyles", and availability of extra funding to subsidize/pay for emerging needs (e.g. home help, hospital room, additional staff).

Informants described Individualized service as a person-centred approach based on individual needs, wants and goals. This translated into an assessment of individual strengths and care needs and the development of individual care plans. Some long term care respondents voiced the challenge of matching their existing services to individual needs of persons with developmental disabilities: "staffing patterns do not allow us to consider this type of client"; "therapeutic interventions used typically with non-developmental clients are often not successful with these individuals", "because of their behaviors developmentally challenged people can become isolated within the home and programs". This tension of trying to "fit" the person with a developmental disability in the long term care setting may be linked with an attempt to normalize all residents (7%) with "equal treatment", "equal services" and "same protocol for admission".

A distinct theme shared by the families (16%) and the developmental service sector (24%) focused on allowing a person with a developmental disability to age in place. Both these respondent groups indicated a strong preference for continuing to support in existing "homelike" environments in the community for as long as possible. Some indicated that they would commit to "support persons in the home they have known until they die" while others considered moving to a long term care setting "as a last resort" or "when medical

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needs exceed agency capacity”. This sentiment appears to be similar to the experiences of seniors in the mainstream.

Collaborative planning was mentioned by 14.5% of long term care responses and 5% of developmental service responses as part of their philosophy of care. Actors involved in planning and collaboration of resources were CCAC, LTC facility, Community Living Associations, the resident, their families, physician, nursing, dietary and recreation staff, social workers, community workers, private and public sectors.

Specific knowledge gaps identified in comments on education and training were dementia, Down syndrome/Alzheimer’s disease, care planning, and behavior management.

Key Players

Transition Planning was also measured in terms of the key players associated with the process. Family and developmental services survey respondents were asked to provide information on this variable by selecting key players from a list and rating them on a scale of 1 to 10. Replies are presented in Table 16.

Table 16: Rating of Players Involved in the Transition Planning Process

	DEVELOP SVCS (N = 57)		FAMILIES (N=15)		DS and FAMILIES
	Times Selected	Average Rating	Times Selected	Average Rating	Total of Avg. Ratings
DS Front line staff	45	8.9	8	7.3	16.2
LTC front line staff	35	5.3	4	6.9	12.2
CCAC	44	6.7	6	5.9	12.6
MCSS Coordinated Access	37	4.9	5	6.9	11.8
Pvt Support Circle Facilitator	32	2.8	3	1.0	3.8
Case Resolution Coordinator	34	3.9	3	3.3	7.2
Physician	44	6.0	3	3.3	9.3
Psychiatrist	41	5.1	3	3.7	8.8
Psychologist	40	4.8	3	3.7	8.5
Family or Guardian	43	9.2	8	8.3	17.5
Client	46	9.3	4	3.2	12.5

It is interesting to note the disparity in ranking of the client (9.3 by developmental services versus 3.2 by families). Players where there is strong agreement in rating between the two groups (a difference in average ranking of less than 1.0) include:

1. CCAC.
2. Case Resolution Coordinator.
3. Family or Guardian.

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Only one of these, the CCAC is ranked above 5. If the average ratings of the two respondent groups are added together we obtain a reasonable combined ranking of all players. This ranking extrapolated from the data in Table 16 is presented in Table 17.

These data suggest that while there are important areas of agreement, there are significant differences between developmental service providers and families in terms of who should be at the table. The disparity indicates a need for the parties to communicate during the transition planning process to ensure the players needed are present. Special note should be taken of the importance of involving appropriate representatives from the long term care program receiving the client where such is the case. Further examination of the factors behind the difference in ranking for the client is also needed.

Table 17: Ranking of Players Involved in the Transition Planning Process

	Total of Avg. Ratings
Family or Guardian	17.5
DS Front line staff	16.2
CCAC	12.6
Client	12.5
LTC front line staff	12.2
MCSS Coordinated Access	11.8
Physician	9.3
Psychiatrist	8.8
Psychologist	8.5
Case Resolution Coordinator	7.2
Private Support Circle Facilitator	3.8

Long Term Care providers were asked to identify the degree of involvement of families in transition planning. Their responses indicate a high priority given to family participation and reflect the ratings of DS providers and families. The data indicates that families are involved 80% of the time and their involvement level is “always” or “often” 60% of the time.

Table 25: LTC Reports of Family Involvement in Transition Planning

	NUMBER	PERCENTAGE
Always	26	34%
Often	20	26%
Sometimes	15	20%
Never	15	20%
Total	76	100%

Cross Sector Transition Assistance

The survey asked service providers to talk about the cross sector assistance that occurred during a transition process. Developmental service agencies reported that in the vast majority of cases they provided some level of involvement with the client. Long term care providers reported a lower level of help received from the developmental services sector.

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Both groups indicated that the level of support was inadequate. The details of these comparisons are presented in Tables 18 through 21.

Table 18: Transition to Non-Residential - Involvement Given/Received

NON-RESIDENTIAL SERVICES	Developmental Services		Long Term Care	
	Involvement Given		Involvement Received	
	#	%	#	%
Direct	39	81%	16	40%
Indirect	6	19%	24	60%
Total	48	100%	40	100%

Table 19: Transition to LTC Placement – Involvement Given/Received

LONG TERM CARE PLACEMENT	Developmental Services		Long Term Care	
	Involvement Given		Involvement Received	
	#	%	#	%
Direct	31	83%	27	53%
Indirect	6	17%	24	47%
Total	37	100%	51	100%

Table 20: Transition to Non-Residential – Adequacy of Involvement Given/Received

NON-RESIDENTIAL SERVICES	Adequacy of Involvement			
	Developmental Services		Long Term Care	
	#	%	#	%
Yes	24	72%	17	36%
No	9	28%	30	63%
Total	33	100%	47	100%

Table 21: Transition to LTC Placement – Adequacy of Involvement Given/Received

LONG TERM CARE PLACEMENT	Adequacy of Involvement			
	Developmental Services		Long Term Care	
	#	%	#	%
Yes	18	67%	25	53%
No	9	33%	22	47%
Total	27	100%	47	100%

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Developmental service providers were also asked to report on the level of involvement they provided in transition planning to supportive seniors housing. No comparative data was collected from supportive seniors housing programs. The data is presented in Tables 22 and 23.

Table 22: Placement in Supportive Housing – Involvement Given by DS Provider

PLACEMENT IN SUPPORTIVE SENIORS HOUSING	Involvement Given	
	#	%
Direct	38	88%
Indirect	5	12%
Total	43	100%

Table 23: Placement in Supportive Housing – Adequacy of Involvement by DS Provider

PLACEMENT IN SUPPORTIVE SENIORS HOUSING	Adequacy of Involvement	
	#	%
Yes	29	83%
No	6	17%
Total	35	100%

The data indicates that a majority of the 57 developmental service providers offer support during the transition process. While developmental service providers describe the majority of their support as direct (involving contact with the client), most long term care providers report that the involvement they receive from DS providers is indirect. Moreover the adequacy of the involvement provided/received is rated higher by developmental services providers than it is by long term care agencies. This disparity of perception between the two sectors underlines the need for closer communication and planning during the transition process. Respondents identified the importance of seamlessness in the transition process. It follows that levels and appropriate forms of involvement by the developmental services sector must be arrived at through cross sector consultation to ensure closer congruence between what is required and what can be provided.

Another factor that may be at play in the difference of perceived involvement may be a lack of resources. Respondents were asked to report on how transition planning was funded. Their replies indicate that additional resources are allocated in a minority of cases and that most often this is achieved through internal re-allocations. Given the tight financial situation of service providers, the capacity for re-allocations may be limited. The details are presented in Table 24.

It appears that transition planning support provides a necessary element in successful adaptation to aging and to maintaining quality of life, given:

- The features of transition planning that the system is striving to support (seamlessness, flexible choices, individualized planning).
- The numbers of people with developmental disabilities who are aged 40 or older.
- The reported need for transition funding.

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What is needed here is further definition of the activities and costs associated with transition planning.

Table 24: Transition Planning - Provision of Extra Resources/Source of Resources

	DEVELOPMENTAL SVCS		LONG TERM CARE	
	#	%	#	%
Provide Extra Resources?				
Yes	16	30%	15	21%
No	37	70%	57	79%
Total	53	100%	72	100%
Source of Resources?				
Internal	15	71%	13	81%
Government	1	5%	1	6%
Raise Locally	5	24%	2	13%
Total	21	100%	16	100%

Cross Sector Coordination Capacity

Considering the cross sector nature of transition planning the survey asked informants for their thoughts on the need for a coordinating body to help aging persons with a developmental disability access services for older adults. Families were asked, on a forced choice scale to identify the role of such a coordinating body. The results are presented in Table 26.

Table 26: Need for a Coordinating Body to Help Persons with DD Access LTC Services

YES		NO		TOTAL	
#	%	#	%	#	%
12	92%	1	8%	13	100%

A large proportion (92%) of family respondents believe a coordinating body should have responsibility for helping access to services. This is supported by responses from long term care and developmental service providers. Table 27 shows the views of all three respondent groups relative to the role that coordinating/planning bodies should play in transition planning.

Table 27: Role that Coordinating/Planning Bodies Should Play in Transition Planning

	DEVELOPMENTAL SERVICES		LONG TERM CARE		FAMILIES		TOTAL	
	#	%	#	%	#	%	#	%
No role	1	2%	2	2%	1	8%	4	3%
Minor	2	4%	8	10%	5	38%	15	10%
Support	29	52%	18	22%	5	38%	52	34%
Major	23	42%	55	66%	2	16%	80	53%
Total	55	100%	83	100%	13	100%	151	100%

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Eighty seven percent of all respondents feel that coordinating/planning bodies should play a major or a support role. While a majority feel the need for such coordination support, a minority of developmental services and family respondents are presently involved with a local cross sector group on aging and developmental disabilities and an even smaller number know how to contact the group in their area. These responses are presented in Table 28.

Table 28: Presence of a Local Cross Sector Transition Planning Group

		LOCAL GROUP EXISTS		AM A MEMBER OF THIS GROUP		HAVE NAME OF A CONTACT	
		DS	FAMILY	DS	FAMILY	DS	FAMILY
NUMBER	Yes	17	5	15	4	13	3
	No	30	4	3	2	0	1
	Total	47	9	18	6	13	4
PERCENT	Yes	36%	56%	17%	67%	100%	75%
	No	64%	44%	83%	33%	0%	25%
	Total	100%	100%	100%	100%	100%	100%

A little more than a third of developmental providers (36%) and more than half of families (56%) report that a cross sector group exists in their area. However a smaller number of respondents answered the follow-up question on whether they were involved with the group. Only 15 of a total 57 (26%) development service provider respondents and 4 out of 15 (26%) of family respondents indicated involvement. Smaller numbers again were able to identify the name of a contact for their group. These findings provide corroboration of the need for OPADD to continue to facilitate cross sector cooperation and planning including partnering with family organizations.

FINDINGS:

SUCCESS FACTORS / KEY STEPS IN THE PROCESS

These findings provide a profile of current practices in Transition Planning:

- The analysis of rankings by all three respondent groups indicates a high priority given to seven aspects of transition planning:
 1. Willingness of other agencies to work with us.
 2. Family involvement.
 3. Funding (Additional funds or flexibility in allocation to cover transition costs).
 4. Staff training.
 5. Availability of appropriate services for older adults.
 6. Guidance from funding Ministries.
 7. Community Care Access Centre Assessment Tools.

- Cross sector cooperative activity may be mitigated by inexperience in cross sector partnering, a lack of information on who or how to contact a provider in the other sector to, funding issues and the lack of connection between some people with developmental disabilities and the developmental services system.

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- The ongoing workshop programs of existing cross sector training groups underlines the continuing need for cross sector training.
- Service providers and families will have to find ways to adapt existing services to accommodate transitioning in the absence of a significant influx of new funds.
- New transition planning funds and/or flexibility in the allocation of existing funding is required to support transition planning activities.
- Important philosophical themes of transition planning include:
 - Flexibility in choices for living for persons with developmental disabilities.
 - Working toward seamless and inclusive supports that overcome access barriers.
 - Providing services that are individualized to the person's needs.
- Quality of life is supported where the focus is on the abilities of each person and where the person feels at home. Aging in place is a preference expressed by respondents and requires a variety of options for living:
 - A continuum of support within the family home.
 - Supportive adult residences.
 - Community living group homes.
 - Homes for persons with Alzheimer's.
 - Non-congregate settings.
 - Retirement/accessible home models.
 - Nursing homes.
 - CCAC cluster care.
 - 24 hr supervised residential care.
 - Specialized units in nursing homes for those with developmental disabilities.
 - Designated number of beds in LTC facilities.
 - Designated clustered units.
 - Separate specialized facilities operating under different regulations to LTC.
- Key players in transition planning (with a combined rating >10) include:

Family or Guardian	17.5
DS Front line staff	16.2
CCAC	12.6
Client	12.5
LTC front line staff	12.2
MCSS Coordinated Access	11.8

- The level of help given by developmental service providers to long term care agencies is rated as more adequate by DS providers than by LTC providers.
- There is closer agreement and a higher rating on the adequacy of help given during transition to long term residential placement than to non-residential access.

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- Extra resources are provided by a minority of DS and LTC providers during the transition process; the vast majority of these resources are realized through internal reallocations.
- All respondent groups see the need for a coordinating body to help persons with developmental disabilities access Long Term Care Services; a majority of opinion is that the body should play a major or support role.
- Few respondents are aware of, or are participants in local cross sector planning groups.

RECOMMENDATIONS:

SUCCESS FACTORS / KEY STEPS IN THE PROCESS

R8. That OPADD facilitate a dialogue between the LTC and DS sectors on the level and types of assistance required during the transition planning process; that a planning document be prepared that describes the forms and costs of this transition assistance.

R9. That OPADD inform the Ministries of the need for transition planning funding for both services sectors to support older adults with developmental disabilities as they access seniors' services and programs and that OPADD provide the Ministries with the transition assistance planning document.

G. GAPS AND BARRIERS TO TRANSITION PLANNING

Some of the gaps and barriers of transition planning identified in this report are summarized below. It is important to note that these gaps and barriers influence the tipping point beyond which the developmental services system is unable to successfully support quality of life. Addressing these issues can not only shift the tipping point for the developmental services sector but can ameliorate the capacity of both sectors to provide a bridge on which older adults with developmental disabilities can move reasonably between services. The challenges and opportunities ahead include:

1. The gap between the numbers of people who are of an age where transition planning should be in progress and the actual numbers reported by DS providers.
2. The high proportion of people in the age range for transition planning (49% are 40 years plus) coupled with the small numbers actually so engaged mitigates against a planned response if the sectors do not immediately develop their cross sector planning capacity.
3. The gap between the physical, health, emotional and retirement planning needs of people with developmental disabilities and the capacity of either sector to respond adequately.
4. A knowledge gap in each sector that the other sector can help to fill.
5. People with developmental disabilities experience barriers accessing long term care services; these barriers include:
 - Inexperience of DS staff with what is available.

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- The position of some DS providers that they can provide all things to their clientele as they age.
 - Lack of awareness among some LTC programs that all older citizens of Ontario are eligible for consideration to access services.
 - Differences among CCAC's in supporting requests for access.
6. There is a large difference of perception between families and DS providers pertaining to the importance of the client as an actor in the transition planning process.
 7. Transition planning processes described in case studies suggest that an ad hoc approach is being taken to developing plans and processes; there is a gap in the knowledge and experience of the system to support proactive planning.
 8. There is a gap between the transition support provided by DS agencies and the level of support LTC providers need.
 9. A minority of developmental services providers are engaged in a local cross sector planning group. See Table 29 for details.

Table 29: Reported DS Provider Involvement in Local Cross Sector Planning Group

	LOCAL GROUP EXISTS		MEMBERS OF THIS GROUP	
	Number	Percent	Number	Percent
Yes	17	36%	15	17%
No	30	64%	3	83%
Total	47	100%	18	100%

10. Case studies reviewed by the Transition Task Group identify a number of factors that give rise to problems of remaining within DS programs and access to some LTC programs; these factors include:
 - a. Continence level changes
 - b. Transportation between sites
 - c. Changes in mobility particularly when coupled with inaccessible features of program sites
 - d. Client behaviour problems
 - e. Waiting lists
 - f. Dementia
 - g. Lack of involvement by the client with the service system.

**RECOMMENDATIONS:
GAPS AND BARRIERS TO TRANSITION PLANNING**

R10. Final Report of the Transition Task Group - that:

- a. OPADD receive and approve the Final Report of the Transition Task Group – May 20 2005
- b. The report be posted on the OPADD website, and

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- c. The report be distributed in hard copy to all OPADD members, regional cross sector planning committees, CCAC's and key stakeholders including regional offices of funding Ministries, the Seniors Secretariat, Health Canada and Social Development Canada.

R11. Transition Guide - that:

- a. OPADD receive and approve the draft Transition Guide
- b. Direct that the guide be tested on a sample of paid and unpaid caregivers from long term care and developmental services
- c. The tested and revised guide be posted on the OPADD website, and
- d. The revised guide be distributed in hard copy to all OPADD members, regional cross sector planning committees, CCAC's and key stakeholders
- e. OPADD arrange for the Guide to be reviewed and updated annually.

H. CONCLUSION

The Transition Task Group began meeting in October 2003 to develop a profile of the current state of transition planning. This report encompasses what the task group has learned. The Transition Guide, also developed by the task group provides a practical tool for paid and unpaid caregivers who must deal with the realities of transition planning.

The recommendations presented in this report serve to build on the knowledge that has been gained and to benefit the sectors in their continuing challenge. While the work of this task group is complete, more work lies ahead for the partnership. The key to our success so far and to our continuing progress is to rely on one another.