

QUALITY OF LIFE IN THE THIRD AGE

Blueprinting Best Practices in Transition Planning

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EXECUTIVE SUMMARY

The Ontario Partnership on Aging and Developmental Disabilities concerns itself with systemic change that builds capacity to support adults with a developmental disability as they age. Since 1999, the partnership has engaged in a series of capacity-building initiatives. These focused on various aspects of transition planning to older adulthood and have included:

1. Aging with a Developmental Disability - Transition Guide for Caregivers.
2. Guide on Accessing Seniors Community Programs.
3. Guide to Property and Personal Care.
4. Best Practices in Transition Planning.

OPADD assembled the preliminary model of best practices in transition planning on the basis of findings from the Transition Study and subsequent experience of members across Ontario. The current project is designed to take the preliminary model a few steps closer to a blueprint that can be formally evaluated and shaped into a validated model. The deliverables for this project are:

- The current report with findings on transition planning practices.
- A revised Best Practices in Transition Planning model and PowerPoint presentation.
- A brief guide which frames the model for planners and managers.
- A briefing document for the Ministry of Community and Social Services, the Ministry of Health and Long Term Care and the Seniors Secretariat.

The report presents the findings from a questionnaire to measure transition planning practice and distributed to a convenience sample of developmental service and long term care service providers. The findings indicate that:

- The cross sector partnership is perceived favourably by participating organizations and is helping to build systemic capacity.
- Cross sector partnering between DS and LTC is still in its early stage and requires continuing support to develop sufficiently.
- There are identified opportunities for the sectors to collaborate on specific skill-building relative to transition planning.
- The total average cost of all forms of transition-related support is \$8225.00 per client: \$5344.00 for direct support to the client and \$2881.00 for support to the agency.

Respondents from both sectors support the proposed seven elements of the transition planning model. This support and the other findings from the transition planning questionnaire provide the basis for refining the model. The refinement moves the model closer to a blueprint which can provide the basis for formally evaluating transition planning and moving toward evidence-based practice. This will require consultation, and data-gathering with a larger cross section of players in both sectors than has been possible with the current project.

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BACKGROUND

The Ontario Partnership on Aging and Developmental Disabilities concerns itself with systemic change that builds capacity to support adults with a developmental disability as they age. The partnership believes this support must be grounded in the values surrounding Quality of Life. Such support can best be achieved through sharing of information, knowledge, skills and resources among all players in the developmental services (DS) and long term care (LTC) sectors.

Since 1999, the partnership has engaged in a series of capacity-building initiatives. Several of these focused on various aspects of transition planning to older adulthood.

In 2004, OPADD formed the Transition Planning Task Group to study transition planning for people with developmental disabilities who are aging. The goal was to identify best practices, tipping points, barriers and issues. The task group gathered data from: a transition planning questionnaire distributed to caregivers in both sectors; case studies; current literature; and Internet-based resources. The study found:

- Variations across Ontario in the willingness to enter into cross partnership arrangements with concomitant inequality of access to seniors services for older adults with a developmental disability.
- Long term care providers and families of adults with a developmental disability generally engaged in transition planning while a very small proportion of developmental service providers did so.
- DS agencies were twice as likely as families to think of transition planning in terms of placement in a long term care home; the vast range of services available to Ontario seniors was generally unknown among DS providers.
- All respondents from the DS and LTC sectors perceived that planning bodies from both sectors should be key players in transition planning but such participation was often lacking.
- There were gaps between the transition support provided by DS agencies and the support needed by LTC providers.
- The provision of transition support over a specific period of time is a pre-condition to successful transition planning that provides orientation and training to long term care staff and benefit to the client.
- Extra resources were provided by a minority of DS and LTC providers during the transition process; the vast majority of these resources were realized through internal reallocations. New transition planning funds and/or flexibility in the allocation of existing funding was required to support transition planning activities.

The study also identified several factors associated with success in transition planning.

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The findings from the study and recommendations of the transition report resulted in several subsequent projects that developed resources for building transition planning capacity. These resources include:

1. Aging with a Developmental Disability - Transition Guide for Caregivers.

Information on the aging process as it pertains to adults with a developmental disability; checklists of issues and questions to help caregivers with planning and the provision of appropriate support.

2. Guide on Accessing Seniors Community Programs.

Information presented in three streams for each of: DS front line staff; seniors community programs staff; and older adults with a developmental disability.

3. Guide to Property and Personal Care.

Information about financial and personal care planning for older adults with a developmental disability.

4. Best Practices in Transition Planning.

A PowerPoint presentation of the essential elements for successful transition planning gathered from OPADD's research and the experience of care-giving agencies.

The development of these resources served to inform service providers and establish a foundation on which to build a model of transition planning. A model is required for three important reasons:

- It informs and provides guidance to a system that has little previous experience and training about aging and developmental disabilities.
- It provides a rational and explicit explanation of best practice in transition planning that, if generally adopted, can contribute to systemic planning capacity.
- It provides a baseline against which practices can be formally evaluated to identify needed improvements; this offers the system a means to introduce evidence-based practice into support services for older adults with a developmental disability.

FROM SKETCHING TO BLUEPRINTING

The current project, Blueprinting Best Practices in Transition Planning, follows through on recommendations of the 2004 Transition Report. It is the next step in the development of a model. The project was designed to continue to provide DS and LTC providers with guidance in successful transition planning practices.

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The project objectives are:

1. Review the existing “best practices in transition planning”.
2. Receive input to the model from the experience of service providers.
3. Prepare a revised model based on this input.
4. Prepare a brief guide which frames the model for managers and planners.
5. Revise the existing OPADD PowerPoint as a resource for use with a broad audience, including managers, planners and front line staff.

This report provides a summary of the findings from the input provided by service providers. The findings will be added to previous work on transition planning to refine the model.

METHOD

This study was planned to add to the body of knowledge about transition planning related to older adulthood and to accessing programs in the other sector. The study does not provide final answers but helps to frame questions and point to further research efforts.

The study relied on both quantitative and qualitative data. A qualitative phenomenological approach was used to complement quantitative data and provide a more robust set of information from which to draw findings pertaining to actual and preferred transition planning practice. Questions were designed to gather data on the seven elements of the OPADD PowerPoint Best Practices in Transition Planning. These elements had been identified through work of the 2004 Transition Study.

DATA-GATHERING

The Blueprint Task Group designed a questionnaire to elicit input from a convenience sample of LTC and DS providers. The finite resources available to this study mitigated against a more comprehensive approach to data collection. Moreover, a limited study was seen as a practical next step on the road to building a transition planning model. The data would be used to introduce new insight into transition planning practice and to define more clearly the questions that need to be answered and next steps that need to be taken in standardizing and testing a model for use in Ontario.

Every effort was made in the design phase to eliminate or minimize ambiguity on the part of those who would respond to the questionnaire. A draft questionnaire was reviewed by the task group and tested with people working in each sector. The resulting feedback was incorporated into the final design.

OPADD’s regional committees were engaged to help with distribution of the questionnaire. The questionnaire asked service providers to respond within each of seven elements of transition planning. These elements, identified through OPADD’s earlier work on transition planning, are:

1. Documentation.
2. Focus on Quality of Life.

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3. Monitoring the individual's health and consultation with health care practitioners.
4. Training and development.
5. Working with the system and developing partnerships.
6. Monitoring and advocacy.
7. Resource requirements.

Respondents were asked to:

1. Identify their current transition planning practices.
2. Provide their perspective on what should be part of a transition planning model.
3. Describe the activities and costs they incurred relative to providing transition planning support.

ANALYSIS

The data were aggregated and organized within each of the seven elements of transition planning. Quantitative data were examined for similarities and differences within each respondent's data set as well as between respondents and between sectors. Qualitative data were reviewed using an ethnographic analysis technique to uncover important differences among respondents and to identify themes common across respondents and sectors.

Details pertaining to transition planning costs were found to range very widely. Due to resource limitations it was not possible to follow-up with respondents to clarify why these differences existed. However, it was expected that the cost data would provide a reasonable basis on which to affirm the types and general levels of transition supports needed. A first cut at cost information provides a basis upon which more precise costs can be identified through a subsequent study.

The aggregated data was shared with the task group for review and comment via a teleconference. The resulting dialogue among people working within each sector provided additional insight into the data and contributed to a more robust analysis.

It should be noted that the data sometimes show actual practice to be rated better than best practice. For example, the average response rate pertaining to use of a baseline for LTC respondents shows actual practice at 83% and best practice at only 67%. The primary reason for this is that one LTC respondent did not answer the second set of questions pertaining to best practice. There are some other instances of respondents missing a particular question. The limited resources available to complete this project precluded follow-up work with respondents to clarify their answers. Despite these limitations the data do provide insight into transition planning practice and the aspirations of service providers to achieve best practice.

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FINDINGS

Findings are arranged with each of the seven transition planning elements.

DOCUMENTATION

Documentation - Close-Ended Questions

Both long term care and developmental service providers were asked a series of close-ended questions to indicate their current practice relative to documenting the transition plan for individual adults with a developmental disability. The set of close-ended questions pertaining to documentation appears in Table 1. The purpose of these questions was to gather information on:

1. The degree to which care-giving agencies had formalized their documentation for older adults with a developmental disability relative to what is currently known about best practice in transition planning; and
2. The perceived difference between actual and best practice.

Table 1: Questions Pertaining to Documentation

1. Do you currently have a process in place for documenting changes in individuals as they age?
2. Do you begin the documentation process prior to the onset of any visible aging process?
3. Do you use a set of criteria to determine when to begin the transition planning process?
4. Do you develop baseline data on each client so there is a point of reference against which to measure change in the individual's functioning and support needs?
5. Do you use a consistent format for entries to this documentation?
6. Do you have an established set of information items that you use to record information about an individual? (e.g. age, food preferences, etc.)

The data show that there are interesting similarities and differences between actual and perceived best practice within each sector as well as between sectors. A summary of the data set for documentation questions appears in Table 2.

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Table 2: Summary of Responses Pertaining to Documentation

DOCUMENTATION	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	#	%	#	%	#	%	#	%
1. Doc indiv changes	20	66	27	90	3	50	4	67
2. Begin doc prior	16	53	25	83	1	17	4	67
3. Criteria re transition	5	17	24	80	1	17	4	67
4. Baseline	13	43	23	76	5	83	4	67
5. Consistent format	11	36	22	73	5	83	4	67
6. Set of info items	19	63	23	76	6	100	4	67
Total	84	46	144	80	21	58	24	67

An examination of the responses from the 30 participating DS agencies shows a significant difference between actual and perceived best practice. Overall, DS respondents perceive their average actual practice (46%) to be about half as high as their perception of best practice (80%).

The DS perceived strengths relative to actual practice include documentation of changes to an individual as he/she ages (66%) and use of an established set of information items to record information about an individual (63%). DS perceived weaknesses of actual practice include use of a set of criteria to determine when to begin the transition planning process (17%); use of a consistent format for documentation of entries (36%); and development of baseline data on each client (43%). The data suggest that DS practice is strongest relative to ensuring documentation is reflective of the individual and weakest relative to consistency and providing a point of comparison against a baseline.

Overall, based on the relatively low proportion of reported actual practice among DS providers (46%), documentation related to transition to older adulthood is not well established across the sector. However, there is a perception that best practice could be significantly better (80%).

The responses of the 6 LTC agencies reveal a degree of difference between actual (58%) and perceived (67%) best practice. This small degree of difference between actual and preferred practice, compared to DS respondents, is likely related to one respondent who did not answer the questions pertaining to preference.

LTC perceived strengths relative to actual practice include: use of an established set of information items to record information about an individual (100%); use of a consistent format for entries to this documentation (83%); and development of baseline data on each client so there is a point of reference against which to measure change in the individual's functioning and support needs (83%).

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LTC respondents perceive their weakness in documentation to include beginning the documentation process prior to the onset of any visible aging process (17%) and use of a set of criteria to determine when to begin the transition planning process (17%). The low rate of documentation prior to the onset of the aging process can likely be attributed to the average age of adults with a developmental disability who reside in a LTC home. Data available from the Ministry of Health and Long Term Care, Long Term Care Homes Branch, indicates that the average age is 53 years.¹

The data suggest that LTC practice is strongest relative to consistency and use of a baseline and weakest relative to commencing prior to the aging process and with reference to criteria. These weaknesses may be attributable at least in part to the average age of adults with a developmental disability who reside in LTC homes.

The differences between the sectors in perceived actual practice indicates there are opportunities where each sector can share its knowledge and skill with the other. For example, LTC could inform DS about use of a consistent format in collecting client information. DS could assist LTC with documenting changes prior to the aging process for appropriate individuals.

Documentation – Description of Best Practice

LTC and DS respondents were asked to indicate their perception of a proposed description of documentation for the aging of an adult with developmental disabilities. The proposed description provided was:

“Caregivers supporting adults with a developmental disability implement effective documentation processes to record baseline and age-related changes and maintain a profile of each individual during the aging process.”

83% of LTC respondents and 86% of DS respondents agreed with the sentence as a good description of what is meant by “documentation for the aging of an adult with developmental disabilities.” There is reasonably strong support for the description.

Documentation - Open-Ended Questions

Respondents were asked to make suggestions and provide comments pertaining to documentation. Nine DS respondents (30% of the sample) and 2 LTC respondents (33% of the sample) offered comments.

DS comments reinforced the importance of establishing baseline information on individuals.

“It is important to document using a baseline at all times...”

¹ Long Term Care Homes Branch Community Health Division, Ministry of Health and Long Term Care, LTC Residents with Developmental Disabilities, March 2007, p. 2.

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“We maintain documentation on all of the folks we support...a baseline for each person...against which daily observations are compared.”

“...a psychosocial assessment is completed regarding the client's social, medical and psychological histories...mental and physical abilities at the time of his/her admission... strengths and needs are identified...”

The importance of baseline data is reflected in LTC comments.

“Ensure documentation includes baselines...”

DS agency respondents described the need for a systemic approach to guide their documentation practice.

“There should be guidelines with...processes for updating...”

“Any tool that would assist us in recognizing when to start transition planning...”

“A common community template by both sectors...”

One DS respondent provided a detailed description of their agency's current practice.

Documentation – Summary of Findings

The data suggest that DS practice is strongest relative to ensuring documentation is reflective of the individual and weakest relative to consistency and establishing a baseline.

The data suggest that LTC practice is strongest relative to consistency and use of a baseline and weakest relative to commencing prior to the aging process and with reference to criteria. These weaknesses may be attributable at least in part to the average age of adults with a developmental disability who reside in LTC homes. Both LTC and DS respondents perceive their weakest point relative to documentation to be lack of a set of criteria to determine when to begin the transition planning process. This finding suggests that information on the currently known criteria has not been made sufficiently explicit nor been disseminated adequately to LTC and DS providers. The data indicate that “consistency”, which is the strongest area of documentation practice for LTC, is the weakest for DS. This difference suggests that LTC knowledge and practice pertaining to consistency in documentation could be helpful to DS providers. It would be worth exploring the feasibility of reciprocal cross sector consultation/training on each sectors' strengths relative to documentation.

There is high acceptance of the proposed statement describing best practice relative to documentation: “Caregivers supporting adults with a developmental disability implement effective documentation processes to record baseline and age-related changes and

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maintain a profile of each individual during the aging process.” Moreover, when given the choice on each of the elements of documentation, respondents generally perceive that their practice could be better than it is.

Respondent comments reflect an understanding of the importance of establishing a baseline and the need for a systemic cross sector approach to documentation for older adults with a developmental disability.

FOCUS ON QUALITY OF LIFE

Focus on Quality of Life – Close-ended Questions

OPADD believes Quality of Life is integral to any transition planning model. Quality of Life frames transition planning in terms of the individual and his/her needs. This perspective frees the system from the distraction of ideological debate which reinforces sector boundary issues rather than ensuring that inclusion remains a driving force of support throughout the life cycle.

LTC and DS respondents were asked a series of close-ended questions about Quality of Life to indicate their current practice relative to incorporating Quality of Life considerations into their transition planning practice. The set of close-ended questions pertaining to Quality of Life appears in Table 3. A summary of responses appears in Table 4. The purpose of these questions was to gather information on:

1. The degree to which care-giving agencies had incorporated Quality of Life considerations into their support for older adults with a developmental disability; and
2. The perceived difference between actual practice and best practice relative to Quality of Life as an integral part of the transition planning process.

An examination of the data on actual practice pertaining to Quality of Life shows a reasonably positive response (DS 77%; LTC 69%). There is a concomitant smaller gap between actual practice and best practice for Quality of Life for both DS (actual 77%; best 83%) and LTC (actual 69%; best 64%). The lack of a response to questions about preferred practice by one LTC respondent is the reason for the lower average rating for best practice.

The lowest average ratings among DS respondents pertain to the actual inclusion of the Quality of Life model in their practice (66%) and whether their practice includes consideration of the full range of the aging process (63%). The low rating pertaining to the full range of the aging experience is not surprising given that the DS sector has little previous experience with adults living into the third age. However, this finding reflects the need of the DS sector to develop capacity for thinking and planning around the aging process.

DS strongest Quality of Life responses include: developing the best possible array of support around the individual to support quality of life (90%); considering the individual's personal experience of aging (83%); and impact aging may have on other people in the

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individual's life (83%). These responses reflect the importance of Quality of Life considerations among DS service providers.

Table 3: Questions Pertaining to Quality of Life

1. Does your organization use a "Quality of Life" model to provide a framework within which transition planning decisions are made?
Which of the following do you think about in the transition planning process:
a. The full range of the aging process?
b. The individual's personal experience of aging?
c. Provision for substitute decision-making?
d. The impact aging may have on other people in the individual's life (staff, roommates, friends, family) and how to plan for this?
e. Risk factors such as: family history; the presence of a syndrome; living situation; and lifestyle?
f. How to develop the best possible array of support around the individual to support quality of life?

Table 4: Summary of Responses Pertaining to Quality of Life

QUALITY OF LIFE	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	#	%	#	%	#	%	#	%
1. Q of L Model	20	66	23	76	3	50	4	67
1a. Full range of aging	19	63	27	90	2	33	3	50
1b. Indiv experience	25	83	26	86	4	67	4	67
1c. SDM	23	76	26	86	6	100	4	67
1d. Aging impact others	25	83	24	80	3	50	4	67
1e. Risk factors	23	76	23	76	5	83	4	67
1f. Array of support	27	90	25	83	6	100	4	67
Total	162	77	174	83	29	69	27	64

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LTC strengths pertaining to Quality of Life include provision for substitute decision-making (100%) and developing the best possible array of support around the individual to support quality of life (100%). It is interesting to the parallels between the two sectors in terms of planning around the needs of the individual. This similarity in the data is important when considering the transition of an adult with a developmental disability to the LTC sector.

Low Quality of Life response rates for LTC include consideration of the full range of the aging process (33%); use of the Quality of Life model (50%); and consideration of the effect that the aging process may have on others (50%).

Both DS and LTC share lowest ratings for actual use of a Quality of Life model and consideration of the full range of the aging experience in actual practice. These findings suggest topic areas for further cross sector training in order to strengthen the capacity of the system to support older adults with a developmental disability.

Provision for substitute decision-making is integral to LTC planning around Quality of Life (100%) but receives only a moderate level of acknowledgement from DS (76%). This finding reflects the general perception that LTC is more conversant and compliant with SDM legislation and practice compared to DS. It also suggests an area where LTC could offer training assistance to DS in how to incorporate SDM requirements into practice.

Focus on Quality of Life – Open-ended Questions

Respondents were asked to add any suggestions about Quality of Life as part of the transition planning process. Three LTC and three DS respondents offered comment.

Most of the comment reflected the need for systemic capacity to ensure appropriate support could be provided to each individual.

“The setting needs to be able to offer suitable care to meet the holistic needs of the individual.”

“Funding limitations affect appropriate placements. Need to be more group placements available for those with developmental disabilities who are aging.”

“Looking at planning for the future as a key for quality of life, not just the present. If planning is done in a crisis, then quality of life can be affected such as very limited choice in living arrangements.”

Greater understanding and improved implementation of the Quality of Life model was perceived to offer a specific strategy for supporting quality of life for individuals.

“Needs to be developed as a universal model of support and funded by the province.”

“Quality of life - measurements should be standardized.”

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Focus on Quality of Life – Summary of Findings

Both DS and LTC share lowest ratings for actual use of a Quality of Life model and consideration of the full range of the aging experience in actual practice. These findings suggest topic areas for cross sector training to strengthen the capacity of the system to support older adults with a developmental disability.

There is evidence that DS must continue to strengthen its capacity to fully implement substitute decision-making legislation and regulations where required. The experience and knowledge of LTC in this area can provide a resource for cross sector training on this topic.

Respondents generally support the need to build capacity through learning about and applying the Quality of Life model.

HEALTH MONITORING AND CONSULTATION

The findings of research into aging with a developmental disability, and aging generally, stress the importance of maintaining health and minimizing the progression of chronic health conditions. Consequently, health monitoring and consultation with health practitioners becomes an important part of support during the aging process.

Health Monitoring and Consultation – Close-ended Questions

Respondents were asked five questions to assess the practice of service providers relative to health monitoring and consultation with health practitioners. The questions posed are presented in Table 5. A summary of responses is presented in Table 6. The purpose of these questions was to gather information on:

1. The degree to which care-giving agencies had incorporated practices of monitoring health and consulting with health practitioners relative to the support provided to aging adults with a developmental disability; and
2. The perceived difference between actual practice and best practice relative to health monitoring and consultation as an integral part of the transition planning process.

Table 5: Questions Pertaining to Monitoring Individual's Health and Consultation

1. Does your staff follow an identified and systematic process of support related to an individual's health?
2. Does your staff have sufficient knowledge about the healthcare needs of adults as they age?
3. Is your staff aware of the health risks associated with specific genetic disorders?
4. Does your staff have the skills needed to engage in meaningful and professional consultation, assessment and intervention with health care and mental health care practitioners?
5. Does your staff monitor and document the health status of adults as they age?

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Table 6: Summary of Responses - Monitoring Individual's Health and Consultation

HEALTH MONITORING AND CONSULTATION	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	#	%	#	%	#	%	#	%
1. Systematic support	20	66	23	76	5	83	4	67
2. Staff knowledge	12	40	26	86	4	67	4	67
3. Aware risks genetic	13	43	24	80	3	50	4	67
4. Consult skills	16	53	24	80	5	83	4	67
5. Monitor and doc	22	73	24	80	5	83	3	50
Total	83	55	121	81	22	73	19	63

DS responses indicate that actual practice relative to health monitoring and consultation falls below the level of perceived best practice (Actual 55%; Best 81%). DS responses indicate that actual practice is relatively low for:

- Sufficiency of staff knowledge about the healthcare needs of adults as they age (40%).
- Staff awareness of the health risks associated with specific genetic disorders (43%).
- Skill level of staff to engage in meaningful and professional consultation, assessment and intervention with health care and mental health care practitioners (53%).

It is surprising to find the low level of perceived actual practice on these variables considering the importance of maintaining health during the aging process as a means to support Quality of Life and maximize capability to live independently. There are significant implications of sub-optimal support related to health care:

- Debilitating conditions can complicate individual support requirements.
- Individuals may require more prolonged and complex health care relative to dealing with health conditions.
- There will be added stress on health care resources.
- Support staff must deal with more complex and challenging conditions.
- DS agencies are put at risk of neglecting due diligence requirements.

LTC respondents indicate relatively stronger proficiency with two of the three variables on which DS respondents report lower aptitude:

- Sufficiency of staff knowledge about the healthcare needs of adults as they age (67%).
- Skill level of staff to engage in meaningful and professional consultation, assessment and intervention with health care and mental health care practitioners (83%).

However, LTC respondents indicate their level of staff awareness of the health risks associated with specific genetic disorders to be on a par with DS respondents (DS 43%;

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LTC 50%). This suggests that both sectors are somewhat lacking in background knowledge about genetic conditions of older adults with a developmental disability and consequently may not be sufficiently equipped to monitor for prevalent health conditions associated with specific genetic disorders.

These data suggest that important areas of staff knowledge pertaining to health care require strengthening.

Health Monitoring and Consultation – Description of Best Practice

All respondents were asked to indicate whether a proposed sentence provided a good description of what is meant by “health monitoring and consultation with health care providers”:

“Caregivers supporting older adults with a developmental disability are engaged in continual monitoring of the health status of older adults in their care; such monitoring is carried out on a daily basis through observation and through regular consultation/client appointments with various health care practitioners.”

All respondents from both DS and LTC indicated the sentence provided a good description.

Health Monitoring and Consultation – Open-ended Questions

Respondents were asked to provide any comments or suggestions pertaining to health monitoring and consultation. Four DS and no LTC respondents provided comment. All of these comments speak to the need for a level of expertise in monitoring health. One respondent suggests that experienced staff can provide the knowledge required.

“...we need to [have] people at the management level [as] a part of this process...people in those roles have known the person for years and can detect changes that someone offering support for less than a year does not notice.”

Another suggests that professional training is a requirement.

“Monitoring of a person physical or mental health will only be as effective as the professional's level of training as to what to look etc. etc. training is critical...”

A third respondent indicates the agency has created a position focused on health care coordination.

“We have hired a Health-Care Coordinator who works with our staff in consultation with the medical professionals.”

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Two respondents note that partnering with health care and allied professions can provide the resources and knowledge necessary to strengthen capacity relative to health monitoring.

“Important partner in this area is the CCAC, Reg. Ger. Prog; Possible to include in dementia screening; Risk assessments by CCAC, RGP and OTs; Supervisors are key to involve CCACs - important to have external individuals monitor individuals since direct care staff may not realize when they are approaching risky areas - for example able to identify early signs of skin breakdown.”

“We require active health monitoring through general practitioners...”

Health Monitoring and Consultation – Summary of Findings

Both DS and LTC respondents indicate a relatively low level of staff awareness of the health risks associated with specific genetic disorders.

DS respondents indicate a relatively low and LTC respondents a relatively high level of actual practice with respect to:

- Sufficiency of staff knowledge about the healthcare needs of adults as they age.
- Skill level of staff to engage in meaningful and professional consultation, assessment and intervention with health care and mental health care practitioners.

DS respondents perceive that actual practice falls short of best practice relative to health monitoring and consultation. Options suggested to strengthen capacity include:

- Reliance on experienced staff.
- Training and education.
- Dedicated staff position focused on health care coordination.
- Partnerships with health care and allied professionals.

The data suggest that important areas of staff knowledge pertaining to health care require strengthening. All respondents concurred with the proposed description of best practice relative to health monitoring and consultation.

TRAINING AND DEVELOPMENT TOPIC AREAS

Aging of people with a developmental disability is a new phenomenon. Transition planning to older adulthood is a relatively uncharted area of learning but is quickly becoming one of the most important. The questionnaire was designed to gather data on staff training and development pertaining to aging and transition planning.

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Training and Development Topic Areas – Close-ended Questions

A series of questions were posed to assess the degree to which transition planning topics were part of staff training programs. These questions are presented in Table 7. The purpose of these questions was twofold; to gather information on:

1. The degree to which care-giving agencies had incorporated training in:
 - Transition planning to older adulthood.
 - Transition planning to access programs in the other sector.
2. The perceived difference between actual and best practice relative to transition planning training.

Table 7: Questions Pertaining to Training and Development Topic Areas

1. Does your organization offer training and development programs to help staff acquire skill sets to support people as they age?
2. What topics are/should be covered within staff development programs:
a. The aging process?
b. Supporting people as they age?
c. Health care and health conditions associated with aging?
d. Mental health and emotional issues associated with aging?
e. Transition planning to older adulthood?
f. Orienting staff about both service systems (i.e. developmental services and seniors services)?
g. How to develop working relationships with counterparts in the other service system?
h. Orienting staff to the coordinated access processes (how to access services) within the developmental services and seniors systems?

A summary of responses to these questions appears in Table 8.

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Table 8: Summary of Responses – Training and Development Topic Areas

TRAINING/ DEVELOPMENT TOPIC AREAS	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	YES		YES		YES		YES	
	#	%	#	%	#	%	#	%
1. In-house training	19	63	27	90	6	100	5	83
2a. Aging process	21	70	23	76	5	83	5	83
2b. Support aging	24	80	25	83	4	67	5	83
2c. Health care	21	70	25	83	6	100	5	83
2d. Mental health	21	70	26	86	5	83	5	83
2e. Transition planning	18	60	25	83	3	50	4	67
2f. Service systems	22	73	25	83	2	33	6	100
2g. Work w other sectors	20	66	24	80	3	50	6	100
2h. Coord access	19	63	25	83	2	33	5	83
Total	185	69	225	83	36	66	46	85

An examination of total responses for how each sector actually provides training and how it perceives training should be provided reveals a gap between actual and best practice.

DS sector responses indicate that of the eight topic areas, training is lowest for:

- Transition planning (60%).
- Coordinated access (63%).
- Working with other sectors (66%).

Training is rated at the median point for:

- The aging process (70%).
- Health care (70%).
- Mental health (70%).

The relatively low average rating provided to transition planning, coordinated access and working with other sectors suggests that the attention to these topic areas is less than optimal. It also suggests that some service providers within the DS sector remain isolated from the opportunities of cross sector partnering. The only topic of the eight to show up as particularly strong is support for aging (80%). The relatively low ratings for the other seven topics suggest that there is no provincial strategy in place to deal with the training and development requirements of DS staff within the sector.

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LTC responses indicate that of the eight topic areas, training is lowest for:

- Service systems (33%).
- Coordinated access (33%).
- Transition planning (50%).
- Working with other sectors (50%).

Training is rated highest for:

- The aging process (83%).
- Health care (100%).
- Mental health (83%).

Generally, a comparison of the ratings provided by respondents within the two sectors shows:

- The DS sector does not have a provincial strategy in place to deal with staff training requirements relative to aging and transition planning.
- LTC sector training focuses on health care, mental health care and the aging process.
- Neither the DS nor LTC sectors are paying sufficient attention to training that specifically supports cross sector planning capacity.

A comparison of relative strengths in each sector suggests there are opportunities for each to share its knowledge with the other through cross sector training. For example, health care and mental health care are perceived to be strong suits for LTC respondents while they are rated as medium by DS respondents. It is worth exploring these possible opportunities further to determine the extent to which they can be harnessed to build capacity.

Training and Development - Best Practice

Respondents were asked to indicate whether they perceived that the following sentence provided a good description of what is meant by training and development related to aging and developmental disabilities:

“Caregivers in the developmental services and seniors services systems engage in cross sector and other training programs that provide them with requisite knowledge and skill sets to support individuals with a developmental disability as they age.”

The sentence proposed to describe best practice in training and development was endorsed by 90% of DS respondents and 83% of LTC respondents.

Training and Development Topic Areas – Open-ended Questions

Respondents were asked to provide information and suggestions pertaining to training and development. Six DS and two LTC respondents offered comment.

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LTC respondents indicated that training which deals with developmental disabilities is required.

“The training and education available in LTC is usually specific to the aging related to an epidemiology and it has not traditionally included persons with developmental disabilities...”

And such training can be provided through cross sector initiatives.

“...unless sectors are crossed we will not know what opportunities are available to staff...Sharing is necessary to best meet the needs of persons needing care and support.”

DS respondents also perceive the need for cross sector initiatives as a means to address their training requirements.

“Cross sector training is an excellent idea.”

And perceive the need to focus training on aging and the transition process.

“...staff working in DS need much higher level of awareness of aging issues.”

“...Content is great to show factual evidence of how aging takes place and helps people recognize the changes in people they support...”

“...Now that the population in our residential services is beginning to age, we need to refocus our efforts to accommodate issues associated with aging.”

However, DS respondents acknowledge that the sector has been slow to emphasize age-related training due to a preoccupation with youth-oriented programs.

“...Typically we as a sector have hired young workers and have focused on the creation of programs and activities that are geared towards a younger lifestyle...”

And a denial of the aging process.

“Many need to begin with a process to help them realize changes in individuals and the fact that they may need to seek assistance from others - many are still in denial; sometimes the changes are occurring...but they don't acknowledge aging, often see it as something else.”

The need for a more systemic approach to training is suggested.

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“Generally staff do not have time to seek out information or stay on top of the changing needs unless someone in the organization does some seeking for them or arranges training as required.”

“...More comprehensive training needs to be available to all staff.”

“...much more work on values and philosophy of support, myths, coping skills.”

Training and Development Topic Areas - Summary of Findings

Generally, a comparison of the ratings provided by respondents within the two sectors shows:

- The DS sector does not have a provincial strategy in place to deal with staff training requirements relative to aging and transition planning.
- LTC sector training focuses on health care, mental health care and the aging process.
- Neither the DS nor LTC sectors are paying much attention to training to support cross sector planning capacity.
- There are opportunities for each sector to provide training to the other in areas of its own strength.

Respondents indicate that cross sector training initiatives are useful and that greater emphasis has to be placed on training related to aging and developmental disabilities.

A strong majority of respondents from both sectors (DS 90%; LTC 83%) endorsed the sentence describing best practice in training and development.

TRAINING AND DEVELOPMENT DELIVERY METHODS

Training and development is a central component to equipping staff with requisite knowledge and skills. A series of questions were included to gather information on how training is and could be delivered. The data were seen to have utility for future planning of training initiatives. The purpose of these questions was to gather information on:

1. The degree to which care-giving agencies relied on various training delivery methods; and
2. The perceived difference between actual practice and best practice relative to these training delivery methods.

The questions which asked about delivery methods are presented in Table 9. A summary of responses to the questions are presented in Table 10.

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Table 9: Questions Pertaining to Training and Development Delivery Methods

3. How do you/how should staff training be provided around supporting people with developmental disabilities as they age:
a. Printed material?
b. Staff meetings?
c. Scheduled in-house training sessions?
d. Seminars or workshops offered by training organizations or groups?
e. Cross sector (developmental services and seniors services) job shadowing?
f. Cross sector staff exchange visits to program sites?
g. On line or web-based training modules?
h. Cooperative training initiatives with academic institutions?

Table 10: Summary of Responses - Training and Development Delivery Methods

TRAINING AND DEVELOPMENT DELIVERY METHODS	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	YES		YES		YES		YES	
	#	%	#	%	#	%	#	%
3a. Printed	23	76	24	80	4	67	5	83
3b. Meetings	23	76	23	76	4	67	5	83
3c. In-house	23	76	23	76	4	67	5	83
3d. Out-Seminars	26	86	25	83	3	50	5	83
3e. Job shadowing	11	36	18	60	2	33	5	83
3f. Exchange visits	14	46	20	66	1	16	5	83
3g. On line	13	53	25	83	2	33	4	67
3h. Coop w academic	14	46	23	76	3	50	4	67
Total	147	61	181	75	23	48	38	79

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Respondents from both LTC and DS indicate that the most prevalent methods of delivering training include:

- Printed material.
- Meetings.
- In-house training sessions.

There is an interesting difference in reliance on seminars or workshops offered by outside training organizations or groups:

- DS 86%.
- LTC 50%.

Despite the efforts of OPADD to promote cross sector training initiatives across Ontario a minority of respondents from both sectors indicate that training via such partnerships is in place:

- Cross sector job shadowing (DS 36%; LTC 33%).
- Cross sector exchange visits (DS 46%; LTC 16%).

OPADD regional committees and some local networks have facilitated cross sector workshops over the past few years. However, these are few in number relative to the number of agencies and staff that must be reached. It appears that individual agencies are not yet taking full advantage of opportunity for cross sector partnering on local training initiatives.

It is interesting to note that despite the move to computer-based training and the availability of such training in the private sector, online or web-based training remains relatively low among DS staff (53%) and LTC staff (33%).

Generally respondents perceive that best practice in training would be reflected in:

- Sustained use of printed material, meetings and in-house seminars.
- Greater use of job shadowing, exchange visits and on-line training.

Both sectors perceive that outside training would contribute to best practice in this area:

- DS respondents perceive an increase in cooperative programs with academic institutions to be an important element in achieving best practice.
- LTC respondents perceive that seminars or workshops offered by training organizations are an important element in achieving best practice.

There is a greater perceived gap between actual and best practice among LTC respondents (actual 48%; best 79%) compared to DS respondents (actual 61%; best 75%).

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Training and Development Delivery Methods – Summary of Findings

Both sectors:

- Tend to rely on traditional methods for delivery of training: printed material; meetings; and in-house seminars.
- Do not appear to be taking advantage of the efficiencies available through on line training.
- Perceive that best practice in delivery would be reflected in greater reliance on cross sector initiatives; online modalities and training offered from outside their organizations (DS - cooperative programs with academic institutions; LTC - seminars or workshops offered by training organizations).

There is a greater perceived gap between actual and best practice among LTC respondents compared to DS respondents.

WORKING WITH THE SYSTEM AND DEVELOPING PARTNERSHIPS

Working with the System and Developing Partnerships – Close-ended Questions

OPADD believes that systemic capacity can derive from effective cross sector collaboration in planning, training and service delivery. Three questions were posed to assess the activity of DS and LTC service providers relative to cross sector work that supports transition planning to older adulthood for people with a developmental disability. The questions appear in Table 11. A summary of responses is presented in Table 12.

Table 11: Questions Pertaining to Working with the System and Partnerships

1. Is your organization a member of /or affiliated with a cross sector committee on aging and developmental disabilities?
2. Does your organization engage in establishing partnerships with service providers in the other system (developmental services or seniors services) in order to develop cross sector training, planning and service delivery models?
3. Does your organization participate in joint meetings with service providers in the other sector?

Responses indicate a fairly high degree of participation in cross sector activity. It is important to note that despite this high perceived degree of cross sector work, respondents perceive that cross sector training still requires strengthening. This may be attributable to the relative newness of cross sector work and that new ground must continue to be broken in developing fluent and comprehensive cross sector working relationships.

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It is worth noting that this is the only set of questions where respondents do not generally perceive that actual practice falls short of best practice. This suggests that cross sector activity is becoming a normal part of the business of agencies which responded.

Table 12: Summary of Responses - Working with the System and Partnerships

SYSTEM PARTNERS	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	YES		YES		YES		YES	
	#	%	#	%	#	%	#	%
1. Cross sector committee	25	83	24	80	5	83	5	83
2. Establish partners	23	76	22	73	5	83	4	67
3. Joint meetings	22	73	25	83	6	100	5	83
Total	70	77	71	78	16	88	14	77

Working with the System and Developing Partnerships – Best Practice

All respondents were asked whether the following sentence provides a good description of what is meant by “working with the system and developing partnerships”:

“Caregivers supporting older adults with a developmental disability are aware of the systems offering appropriate planning and service delivery options for adults as they age. Caregivers engage in partnership arrangements with other service systems to facilitate transition planning and concurrent access to developmental services and seniors services.”

There was strong concurrence with the sentence as indicated by 90% of DS and 100% of LTC respondents.

Working with the System and Developing Partnerships – Open-ended Questions

Respondents were asked to provide comments and suggestions pertaining to working with the system. Eight DS and two LTC respondents offered remarks.

DS respondents perceive that they are engaged in working on a systemic basis with long term care through planning committees and direct working relationships with service providers in LTC.

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“...a sub committee of the Developmental Services Planning Group that specifically deals with seniors. This committee has membership from both the developmental services and long term care sectors.”

“...cross sector exchanges...organized through the Niagara Network and OPADD.”

“...on an "as needed" basis with agencies such as CCAC...”

“We create partnerships around specific members... We currently are connected to CCAC to support one man in his home...also have a member...living in LTC...We provide support for her medical appointments ensuring she has access to a few days of support outside the LTC facility... [and] supporting her family...”

“We have approached the senior homes to have some of our seniors attend their programs.”

“We work in partnership with other agencies, physicians, WMHC to provide in home specialized support...”

Some DS respondents point to the need for additional collaboration and partnership.

“...there is a great deal of opportunity for joint training, protocol development etc. between the two systems...”

“...We wish to see further collaboration between the two sectors and desire to be part of it...”

“Hospitals (some) need to work more in partnership with DS agencies in supporting persons.”

LTC respondents perceive that cross sector work is not yet sufficiently established to facilitate transition planning.

“New area. In response to specific resident considerable time is spent discovering/investigating the developmental services sector systems and the limitations to the present transition planning process; there was little in the way of transitioning to the nursing home setting.”

“Start the process of partnering with agencies that support individuals with developmental disabilities.”

One DS respondent points out that cross sector work is still new to the agency and suggests that government funding is necessary to continue building the process.

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“We have only recently engaged through the OPADD initiatives. This must continue and needs to be funded by the province.”

Working with the System and Developing Partnerships – Summary of Findings

Responses indicate a fairly high degree of participation in cross sector activity.

There was strong concurrence with the sentence describing best practice in working with the system and developing partnerships as indicated by 90% of DS and 100% of LTC respondents.

DS respondents perceive that they are engaged in working on a systemic basis with long term care through planning committees and direct working relationships with service providers in LTC.

Some LTC and DS comments suggest cross sector work is not yet sufficiently established and must develop further to facilitate transition planning.

MONITORING AND ADVOCACY

Transition planning into the third age for adults with a developmental disability is a new phenomenon which the system has not yet fully embraced in its planning processes, service delivery, training and education. Consequently, the reception of older adults with a developmental disability varies among jurisdictions and among service providers. OPADD is working to make the system aware of the changes required to ensure effective support for people with developmental disabilities as they age. However, the system must take on the work of re-shaping itself to meet this emerging challenge. The experience of regional committees and local projects supports the need for monitoring and advocacy as caregivers search for those practices that work best. Monitoring and advocacy will contribute to the development of a mature transition planning model.

The questionnaire asked respondents to reply to three questions pertaining to monitoring and advocacy. These questions appear in Table 13. A summary of responses to these questions appears in Table 14.

The data show that respondents from both sectors perceive they are reasonably strong at monitoring, adjusting and implementing plans for individual clientele but not so strong at systemic monitoring and advocacy. Both DS and LTC respondents perceive that their actual practice relative to individuals is about as it should be.

The DS perception of best practice relative to systemic advocacy and monitoring shows some gap pertaining to monitoring to reshape the system (actual 50%; best 73%) and very little gap pertaining to networking to identify trends (actual 73%; best 76%).

The LTC perception of best practice relative to systemic advocacy and monitoring is inconclusive based on the replies received. LTC respondents perceive a much lower rate of monitoring trends by their organizations (16%) and only one third (33%) feel their

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organizations should do so. However, among LTC respondents, there is a relatively high rate of perceived organizational participation with regional committees and networks (83%). However a much smaller proportion (33%) perceive that their organizations should be doing so.

Table 13: Questions Pertaining to Monitoring and Advocacy

1. Does your organization work with your front line staff to monitor existing transition planning processes of individuals and identify adjustments needed on an individual or agency-wide basis?
2. Does your organization implement identified adjustments in a timely manner?
3. Does your organization monitor and confirm trends in the needs of the aging population with developmental disabilities and apply that knowledge to re-shaping transition planning practices?
4. Does your organization work with the regional committee or other network on aging and developmental disabilities to confirm emerging issues and trends in transition planning and identify needed resources or regulatory amendments?

Table 14: Summary of Responses – Monitoring and Advocacy

ADVOCACY	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	YES		YES		YES		YES	
	#	%	#	%	#	%	#	%
1. Monitor/adjust plans	24	80	24	80	4	67	4	67
2. Implement timely	24	80	24	80	5	83	5	83
3. Monitor to reshape	15	50	22	73	1	16	2	33
4. Network to ID trends	22	73	23	76	5	83	2	33
Total	85	71	93	78	15	63	13	54

The data show a general difference in the two sectors. Overall, DS respondents perceive that actual practice is not as good as best practice (71% versus 78%). LTC respondents perceive that actual practice exceeds what best practice should be (63% versus 54%). While these data are not definitive given the difference in the size of the convenience sample and the incomplete returns from one LTC respondent, they do help to frame questions about how the two sectors can work together in terms of systemic monitoring and advocacy via regional committees and networks.

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Monitoring and Advocacy - Best Practice

All respondents were asked to identify whether they perceive that the following sentence provides a good description of what is meant by “monitoring and advocacy”.

“Service providers in developmental services and seniors services work with planning and funding bodies to build awareness of the phenomenon of aging and developmental disabilities and propose changes in service delivery and planning processes that build system capacity.”

The same proportion of DS and LTC respondents (83%) agreed with this statement. The concurrence level to this statement in contrast to the difference in responses between DS and LTC pertaining to questions about agency monitoring and networking is curious. It may be that while both sectors agree on the definition of best practice, LTC respondents perceive that their organizations have less capacity to engage in it due to other service pressures. The anomaly raises questions about how capacity-building can be achieved through a cross sector model if there are impediments to joint advocacy work. The data is unclear here but the questions require closer examination.

Monitoring and Advocacy – Summary of Findings

DS and LTC respondents perceive that:

With respect to individual monitoring and advocacy, service providing organizations are:

- Reasonably strong at monitoring and adjusting plans for individual clientele and that actual practice is considered to be best practice.

With respect to systemic monitoring and advocacy, service providing organizations are:

- Relatively strong at working with a committee/network on aging and developmental disabilities to confirm emerging issues and trends in transition planning and identify needed resources or regulatory amendments (DS 73% and LTC 83%).
- Relatively less strong at monitoring to confirm trends and applying that knowledge to re-shape the service system (DS 50% and LTC 16%).

RESOURCE REQUIREMENTS

OPADD has managed to encourage and facilitate innovative cross sector initiatives to build systemic capacity without significant new funding. Experience with transition planning suggests that many DS service providers face resource pressures related to providing the change in support required as an individual ages. Moreover, both DS and LTC sectors indicate there are resource issues related to orientation and adaptation when an individual with a developmental disability accesses a LTC program. Consequently, OPADD wanted to investigate the scope of the issue and gather some preliminary evidence about resources that may be required to support the transition planning process.

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The questions posed via the questionnaire separated out two components of resource requirements. Those pertaining to:

1. Transition planning to older adulthood.
2. Transition planning to access programs in the other sector.

RESOURCE REQUIREMENTS - TRANSITION PLANNING TO OLDER ADULTHOOD

Transition Planning to Older Adulthood – Close-ended Questions

One question was included in the questionnaire to gather information about agency provision of staff support relative to transition planning to older adulthood:

“Does your organization ensure appropriate staffing requirements to implement transition planning to older adulthood on a case by case basis?”

Responses are summarized in Table 15.

Table 15: Summary of Responses – Resource Requirements: Transition to Older Adulthood

RESOURCE REQUIREMENTS - TRANSITION TO OLDER ADULTHOOD	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	YES		YES		YES		YES	
	%	#	%	#	%	#	%	#
Appropriate Staffing	18	60	24	80	2	33	3	50

The data show that 60% of responding DS agencies ensure appropriate staffing requirements to implement transition planning to older adulthood on a case by case basis while only 33% of LTC agencies do so. The lower proportion of positive responses among LTC agencies may be attributable to the older age of most admissions to LTC Homes. However, both DS and LTC respondents perceive that best practice in this area exceeds current practice.

Transition Planning to Older Adulthood – Open-ended Questions

Respondents were asked one open-ended question:

“Please add any comments/suggestions you have about resource requirements as part of transition planning to older adulthood for people with developmental disabilities.”

Two DS and one LTC respondent provided comment. All three indicate the need for additional resources.

“We currently look at supports at the time transition is necessary, but need to begin the process much earlier. Transition documentation would assist with this.”

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“As people age, needs increase. To date my experience has been that MCSS is reluctant to provide additional funding based on increased needs that are age related.”

“Education and back fill for staff, using additional staff to help transition client over a period of three months, social worker.”

The comment of one respondent illustrates confusion about the role of cross sector partnership. The respondent appears to believe that the partnership is a vehicle for moving people to LTC beds. However, OPADD’s Vision is much broader and seeks to build cross sector partnership so that older adults with developmental disabilities enjoy the same rights and opportunities to service and support as every senior in Ontario. This includes access to the full range of programs available to Ontario seniors. LTC beds are a small component of the LTC sector relative to spaces in all other seniors programs.

“My experience is that we are encouraged to look to LTC when the person may choose to be cared for at home. I think the Aging in Place initiative, if truly supported, may give people more options and choice.”

Resource Requirements: Transition Planning to Older Adulthood - Summary of Findings

DS and LTC agencies perceive a need for additional resources to support transition planning to older adulthood. The perceived need is more acute among DS agencies than LTC. There may be continuing confusion among some service providers about the scope of the cross sector partnership with concomitant limitations in how DS and LTC organizations support access to seniors programs.

RESOURCE REQUIREMENTS: TRANSITION PLANNING TO ACCESS PROGRAMS IN THE OTHER SECTOR

Transition Planning to Access Programs in the Other Sector – Close-ended Questions

Respondents were asked a series of questions to gather information on the types of transition support required. These are presented in Table 16. Responses to these questions are summarized in Table 17.

LTC respondents reported some difficulty in answering questions pertaining to a client accessing programs in another sector since this is not a situation they face regularly. Consequently, the LTC data for this question is incomplete and somewhat inconclusive but does provide some insight into resource issues.

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Table 16: Questions Pertaining to Resource Requirements – Accessing Programs

1. Does your organization provide staff to support a client who is accessing programs in the other sector?
2. How are the staffing requirements for each individual (client) determined:
a. Based on the differences they will encounter in accessing a program in the other sector?
b. By your organization acting alone?
c. In consultation with the service provider(s) in the other sector?
d. In consultation with the individual (client)?
e. In consultation with the individual's (client) support circle?
f. Through a cross sector planning process?
3. Do you fund transition planning support for the individual (client) who is accessing programs in the other sector:
a. Through re-allocations of internal agency funds?
b. Through additional external fund-raising?
c. With funds from a foundation or other external fund-raising arm of the agency?
d. With special funding from the government of Ontario?

A majority of DS respondents (73%) indicate that staff support is provided to support a client who is accessing programs in the other sector. The same proportion of DS respondents indicates that this meets their perception of best practice.

DS respondents indicate that the staffing/resource requirements are rarely determined by the organization acting alone (23%) and only sometimes through a cross sector planning process (53%) but usually determined in consultation with:

- The support circle (70%).
- The client (66%).
- Other service providers (66%).

DS respondents perceive that best practice would be reflected in a higher proportion of consultation with these players and in a higher proportion of cross sector planning processes.

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Table 17: Summary of Responses: Resource Requirements – Accessing Programs

RESOURCE REQUIREMENTS – ACCESSING PROGRAMS	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	YES	YES	YES	YES	YES	YES	YES	YES
1. Staff support	22	73	22	73	2	33	2	33
2a. Differences in accessing	15	50	19	63	2	33	2	33
2b. Org act alone	7	23	6	20	NR	0	1	16
2c. In consult w other svc provider	20	66	23	76	3	50	2	33
2d. In consult w client	20	66	23	76	2	33	3	50
2e. In consult w circle	21	70	23	76	4	67	3	50
2f. Via cross sector planning	13	53	22	73	2	33	2	33
3a. Fund via internal	9	30	12	40	1	16	NR	0
3b. Fund external	3	10	5	16	NR	0	NR	0
3c. Fund via foundation	4	13	8	26	NR	0	NR	0
3d. Fund via government	3	10	15	50	1	16	3	50
Total	155	47	178	54	19	29	18	27

Note: NR – No Response

DS respondents indicate that funding of transition planning to access programs in the other sector varies among internal reallocations (30%); external sources (10%); foundations (13%); and government (10%). DS perception of best practice with regards to funding includes a mix of government funding (50%) and internal reallocations (40%).

LTC respondents perceive that staffing/resource requirements are usually determined in consultation with:

- The support circle (67%).
- Other service providers (50%).

And less frequently:

- Based on differences to be encountered in accessing the other program (33%).
- In consultation with the client (33%).
- Via cross sector planning processes (33%).

And never by the organization acting alone.

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Overall, there is little perceived gap between actual and best practice for either sector (LTC actual 29%, best 27%; DS actual 47%, best 54%). The two groups of respondents do not show much concurrence on best practice relative to these variables. However, 50% of both DS and LTC respondents perceive that best practice relative to funding would encompass government dollars.

Transition Planning to Access Programs in the Other Sector – Open-ended Questions

Respondents were asked to provide any comments/suggestions about resource requirements and funding as part of transition planning to access programs in the other sector. Five DS and one LTC respondent provided comments. DS respondents perceive that the current lack of resources is problematic.

“When past transitions included a move to LTC the individuals was discharged from our service since we could not fund supports in LTC. Any existing funding was used to fill the vacancy left by that person.”

“Funding for transition planning and shared staffing supports is not supported financially within our region and needs to be. Currently it is absorbed out of existing agency allocations.”

“This is a challenge, for individuals that move from our system to long term care we fund transition staffing, but can only afford about 4 hrs a week for long term support...”

And indicate that government funding is necessary.

“This should be a funded service and provided for within our budgets.”

“Needs to happen at all levels of both ministries and systems.”

“...the facility initiative offers some community capacity to use the funds allocated for the future and not all for one client, but could be used to support a small cluster of individuals with a long term care home.”

“There needs to be additional funding coming from either or both MCSS and MHLTC to plan for and meet the needs of people aging and transitioning to aging programs and supports. We are heading in this direction and there has been talk but no action to date that I am aware of.”

The LTC respondent pointed out the need for additional funding on top of ODSP to ensure adults with a developmental disability are on a level playing field vis a vis access to LTC placements.

“Most of the residents coming from the developmental sector have only ODSP which isn't enough even for a basic room. Because of

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related care needs they often require a private room. They are also on a lengthy waiting list. Need top up to give them an equal chance of getting into a LTCF of their choice and place them on an even playing field as the rest of the applicants.”

Transition Planning to Access Programs in the Other Sector – Summary of Findings

Generally both DS and LTC providers engage other players in the transition planning process:

- The support circle (DS 70%; LTC 67%).
- Other service providers (DS 66%; LTC 50%).

There are differences between the sectors with respect to engagement of:

- The client (DS 66%; LTC 33%).
- Cross sector planning processes (DS 53%; LTC 33%).

Respondents perceive the need for funding to support transition planning processes. DS perceives funding from internal reallocations (40%) and government (50%). LTC perceives the need for government funding (50%).

MAKING THE DECISION TO ACCESS A PROGRAM IN THE OTHER SECTOR

Respondents were asked two additional questions to gather information on how the decision is made to access a program in the other sector. These appear in Table 18. A summary of responses is presented in Table 19.

Table 18: Questions Pertaining to the Decision to Access a Program in the Other Sector

1. Do you have a set of objective criteria that you use to identify when a client should access a program in the other service sector?
2. Do you know how to use the access protocol in the other sector when seeking services for a client in that other sector?

Table 19: Summary of Responses: the Decision to Access a Program in the Other Sector

ACCESS DECISION	DS RESPONDENTS = 30				LTC RESPONDENTS = 6			
	DS IS		DS SHOULD		LTC IS		LTC SHOULD	
	YES		YES		YES		YES	
1. Use criteria	7	23	17	56	1	16	2	33
2. Know access protocol	19	63	20	66	3	50	3	50
Total	26	43	37	62	4	33	5	42

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Respondents of both sectors perceive that objective criteria are not generally used to identify when a client should access a program in the other service sector (DS 23%; LTC 16%). Respondents perceive the need for greater use of such criteria in achieving best practice (DS 56%; LTC 33%).

A higher proportion, but not a strong majority of respondents in the sectors know how to use the access protocol in the other sector when seeking services for a client in that other sector (DS 63%; LTC 50%).

Making the Decision to Access a Program in the Other Sector – Summary of Findings

Objective criteria are not generally used to identify when a client should access a program in the other sector. About half of respondents indicate they know how to use the access protocol in the other sector. There is no strong perception that these areas require strengthening to achieve best practice other than some perception among DS respondents to make better use of criteria (DS 56%).

TRANSITION PLANNING COSTS

Respondents were asked to identify the types of support provided during the transition process and to estimate the time requirements and costs associated with this support. Five types of direct support to the client and seven types of support to the service provider were offered in the questionnaire.

Responses were aggregated and averaged to arrive at a reasonable representation of resource requirements pertaining to various forms of transition support. It is important to note that this data should not be accepted as unequivocal but provides a point of departure for closer examination of transition support requirements.

The data show that the level of support provided by service providers ranges from as little as one week to as much as one year. An examination of the raw data indicates that the low of 1 week and high of 52 weeks is attributable to data provided by two or more respondents. There is no one respondent that lies clearly at the upper or lower range of the data distribution for duration. Consequently no outliers have been removed from the data for duration as this will have no identifiable and significant impact on average duration.

The cost of specific support types ranges from a low of \$2.00 to a high of \$22,921.00. An examination of the raw data for costs identifies the presence of a single respondent at the low end and a single respondent at the upper end of the cost data distribution. These outliers exert identifiable influence over the data. Consequently, the cost outliers are removed from further consideration. A summary of all data for duration and for cost with the outliers removed, is presented in Table 20.

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Table 20: Summary of Responses – Transition Planning Resource Requirements

CATEGORY	SUPPORT	N	DURATION (WKS)			COST (\$)			
			LOW	HIGH	AVG	TOTAL	LOW	HIGH	AVG
DIRECT TO CLIENT	Orientation visits	16	1	52	8	3,014.00	109.00	2,081.00	763.00
	Staff travel time	13	1	52	10	2,723.00	27.00	2,254.00	379.00
	General staff support	10	1	52	19	11,278.00	40.00	9,100.00	2,066.00
	Specific staff support	11	1	52	16	14,589.00	40.00	12,600.00	1,880.00
	Other: liaison	1	2	52	23	845.00	256.00	256.00	256.00
	TO SERVICE PROVIDER	Discharge Planning	11	1	52	9	1,686.00	45.00	1,300.00
Orientation to client		10	1	52	9	901.00	30.00	579.00	230.00
Staff training		9	1	12	3	1,758.00	100.00	1,280.00	362.00
Consultation		9	1	12	5	811.00	51.00	450.00	292.00
Trouble-shooting		9	1	26	8	1,196.00	48.00	751.00	362.00
On call		9	1	52	12	704.00	100.00	362.00	177.00
Other/ Appointments		3	7	52	30	4,343.00	175.00	2,900.00	1179.00

An examination of the types of support, ranked by their average duration and average cost, offers some greater insight into transition support resource requirements. These rankings are presented in Tables 21 and 22.

The total average duration of all forms of transition support are 152 hours: 76 hours of direct support to the client and 76 hours of support to the service provider. More than half of support based on duration includes:

- Direct support to the client in the form of liaison and staff support.
- Support to the service provider in the form of appointments, being on call and discharge planning.

The total average cost of all forms of transition-related support is \$8225.00 per client: \$5344.00 for direct support to the client and \$2881.00 for support to the agency.

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Table 21: Rank Order of Transition Support by Duration

CATEGORY	SUPPORT	AVG
DIRECT TO CLIENT	Other: liaison	23
	General staff support	19
	Specific staff support	16
	Staff travel time	10
	Orientation visits	8
TO SERVICE PROVIDER	Other/ Appointments	30
	On call	12
	Discharge Planning	9
	Orientation to client	9
	Trouble-shooting	8
	Staff training	3
	Consultation	5

An examination of the ranked data for duration indicates that just more than half of all time providing direct support to the client is spent on:

- Liaison.
- General staff support.

And just more than half of all time providing support to the agency is spent on:

- Other/Appointments.
- On call.

An examination of the ranked data for costs indicates that just more than half of all dollars providing direct support to the client is spent on:

- General staff support.
- Specific staff support.

And just more than half of all costs providing support to the agency is spent on:

- Other/appointments.
- Staff training.

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Table 22: Rank Order of Transition Support by Cost

CATEGORY	SUPPORT	AVG
DIRECT TO CLIENT	General staff support	2066.00
	Specific staff support	1880.00
	Orientation visits	763.00
	Staff travel time	379.00
	Other: liaison	256.00
TO SERVICE PROVIDER	Other/ Appointments	1179.00
	Staff training	362.00
	Trouble-shooting	362.00
	Discharge Planning	279.00
	Consultation	292.00
	Orientation to client	230.00
	On call	177.00

Transition Planning Resource Requirements – Summary of Findings

The total average cost of all forms of transition-related support is \$8225.00 per client: \$5344.00 for direct support to the client and \$2881.00 for support to the agency.

The most important forms of support in terms of duration are:

To the client: Liaison.
 General staff support.

To the service provider: Other/Appointments.
 On call.

The most important forms of support in terms of cost are:

To the client: General and specific staff support.

To the service provider: Other/appointments.
 Staff training.

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SUMMARY OF FINDINGS

Documentation – Summary of Findings

The data suggest that DS practice is strongest relative to ensuring documentation is reflective of the individual and weakest relative to consistency and establishing a baseline.

The data suggest that LTC practice is strongest relative to consistency and use of a baseline and weakest relative to commencing prior to the aging process and with reference to criteria. These weaknesses may be attributable at least in part to the average age of adults with a developmental disability who reside in LTC homes. Both LTC and DS respondents perceive their weakest point relative to documentation to be lack of a set of criteria to determine when to begin the transition planning process. This finding suggests that information on the currently known criteria has not been made sufficiently explicit nor been disseminated adequately to LTC and DS providers. The data indicate that the strongest area of documentation practice for LTC (consistency) is the weakest for DS. This difference suggests that LTC knowledge and practice pertaining to consistency in documentation could be helpful to DS providers. It would be worth exploring the feasibility of reciprocal cross sector consultation/training on each sectors' strengths relative to documentation.

There is high acceptance of the proposed statement describing best practice relative to documentation: "Caregivers supporting adults with a developmental disability implement effective documentation processes to record baseline and age-related changes and maintain a profile of each individual during the aging process." Moreover, when given the choice on each of the elements of documentation, respondents generally perceive that their practice could be better than it is.

Respondent comments reflect an understanding of the importance of establishing a baseline and the need for a systemic cross sector approach to documentation for older adults with a developmental disability.

Focus on Quality of Life – Summary of Findings

Both DS and LTC share lowest ratings for actual use of a Quality of Life model and consideration of the full range of the aging experience in actual practice. These findings suggest topic areas for cross sector training to strengthen the capacity of the system to support older adults with a developmental disability.

There is evidence that DS must continue to strengthen its capacity to fully implement substitute decision-making legislation and regulations where required. The experience and knowledge of LTC in this area can provide a resource for cross sector training on this topic.

Respondents generally support the need to build capacity through learning about and applying the Quality of Life model.

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Health Monitoring and Consultation – Summary of Findings

Both DS and LTC respondents indicate a relatively low level of staff awareness of the health risks associated with specific genetic disorders.

DS respondents indicate a relatively low and LTC respondents a relatively high level of actual practice with respect to:

- Sufficiency of staff knowledge about the healthcare needs of adults as they age.
- Skill level of staff to engage in meaningful and professional consultation, assessment and intervention with health care and mental health care practitioners.

DS respondents perceive that actual practice falls short of best practice relative to health monitoring and consultation. Options suggested to strengthen capacity include:

- Reliance on experience staff
- Training and education
- Dedicated staff position focused on health care coordination
- Partnerships with health care and allied professionals.

The data suggest that important areas of staff knowledge pertaining to health care require strengthening. All respondents concurred with the proposed description of best practice relative to health monitoring and consultation.

Training and Development Topic Areas - Summary of Findings

Generally, a comparison of the ratings provided by respondents within the two sectors shows:

- The DS sector does not have a provincial strategy in place to deal with staff training requirements relative to aging and transition planning,
- LTC sector training focuses on health care, mental health care and the aging process.
- Neither the DS nor LTC sectors are paying much attention to training to support cross sector planning capacity.
- There are opportunities for each sector to provide training to the other in areas of its own strength.

Respondents indicate that cross sector training initiatives are useful and that greater emphasis has to be placed on training related to aging and developmental disabilities.

A strong majority of respondents from both sectors (DS 90%; LTC 83%) endorsed the sentence describing best practice in training and development.

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Training and Development Delivery Methods – Summary of Findings

Both sectors:

- Tend to rely on traditional methods for delivery of training: printed material; meetings and in-house seminars.
- Do not appear to be taking advantage of the efficiencies available through on line training.
- Perceive that best practice in delivery would be reflected in greater reliance on cross sector initiatives; on-line modalities and training offered from outside their organizations (DS - cooperative programs with academic institutions; LTC - seminars or workshops offered by training organizations).

There is a greater perceived gap between actual and best practice among LTC respondents compared to DS respondents.

Working with the System and Developing Partnerships – Summary of Findings

Responses indicate a fairly high degree of participation in cross sector activity.

There was strong concurrence with the sentence describing best practice in working with the system and developing partnerships as indicated by 90% of DS and 100% of LTC respondents.

DS respondents perceive that they are engaged in working on a systemic basis with long term care through planning committees and direct working relationships with service providers in LTC.

Some LTC and DS comments suggest cross sector work is not yet sufficiently established and must develop further to facilitate transition planning.

Monitoring and Advocacy – Summary of Findings

DS and LTC respondents perceive that

With respect to individual monitoring and advocacy, service providing organizations are:

- Reasonably strong at monitoring and adjusting plans for individual clientele and that actual practice is considered to be best practice.

With respect to systemic monitoring and advocacy, service providing organizations are :

- Relatively strong at working with a committee/network on aging and developmental disabilities to confirm emerging issues and trends in transition planning and identify needed resources or regulatory amendments (DS 73% and LTC 83%).
- Relatively less strong at monitoring to confirm trends and applying that knowledge to re-shape the service system (DS 50% and LTC 16%).

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Resource Requirements: Transition Planning to Older Adulthood - Summary of Findings

DS and LTC agencies perceive a need for additional resources to support transition planning to older adulthood. The perceived need is more acute among DS agencies than LTC. There may be continuing confusion among some service providers about the scope of the cross sector partnership with concomitant limitations in how DS and LTC organizations support access to seniors programs

Transition Planning to Access Programs in the Other Sector – Summary of Findings

Generally both DS and LTC providers engage other players in the transition planning process:

- The support circle (DS 70%; LTC 67%).
- Other service providers (DS 66%; LTC 50%).

There are differences between the sectors with respect to engagement of:

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Transition Planning Resource Requirements – Summary of Findings

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- To the service provider: Other/appointments and on call.

The most important forms of support in terms of cost are:

- To the client: General and specific staff support.
- To the service provider: Other/appointments and staff training.