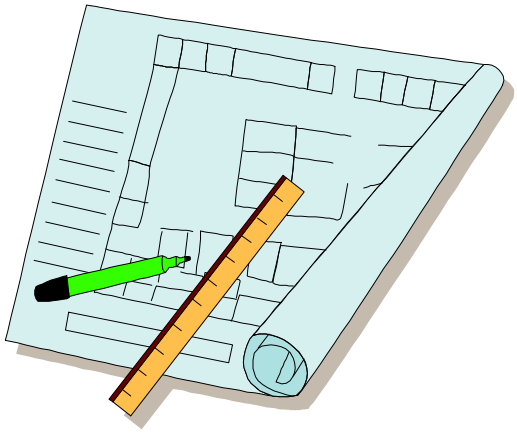
Ontario Partnership on
Aging & Developmental Disabilities

BLUEPRINT FOR TRANSITION PLANNING



Blueprint for building a model of transition planning to older adulthood for people with developmental disabilities

A GUIDE FOR MANAGERS AND FRONT LINE STAFF

BLUEPRINT FOR TRANSITION PLANNING

A GUIDE FOR MANAGERS AND FRONT LINE STAFF

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A Vision For The Future

The Ontario Partnership's Vision for the Future is one where every person with a developmental disability has the same rights to support and services as all older Ontarians. This vision is based on the value of each human as a unique individual and the belief that quality of life must be available to all of us regardless of age.

The partnership sees communities across Ontario where persons with a developmental disability are supported to plan for all aspects of their older adulthood. Each person's unique life situation, preferences and capabilities are the starting point for such planning. Service providers, support circles and families are aware of the range of opportunities, resources and services available and appropriate for older adults. Moreover these services and resources are fully accessible and accepting of the older adult with a developmental disability. This includes civic organizations, worship communities, voluntary organizations, government offices, various service providers and the health care system.

The Vision for the Future is one where service providers, policy makers, funders and communities work together responsibly in the interests of the aging person and his/her family. Working relationships are collegial and effective. It is a Vision where service to the client takes precedence over professional differences, bureaucracy and other factors that tend to fragment the system. Service providers are willing to innovate. Government legislation and regulation is flexible to permit the testing of new cross sector methods and models. Funding bodies encourage new strategies of service delivery to meet the complex and intertwining needs of older adults with a developmental disability. The system of supports adapts itself to planning that is individualized for each person and inclusive of his / her family.

In the Vision for the Future, comprehensive strategic planning not only crosses boundaries among agencies but between the sectors. New knowledge informs direction-setting. The person with a developmental disability lives a life that continues to be enriching and valued into old age.

BACKGROUND

The Ontario Partnership on Aging and Developmental Disabilities is founded on a cross sector working relationship between the developmental services sector and the long term care/seniors community programs sector. We continue to find that we can frame issues more clearly and solve problems more easily when we work together. The partnership concerns itself with systemic change that builds capacity to support adults with a developmental disability as they age. Individual service providers working with partners in the other sector are helping to re-shape the Ontario service system. 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.

Best Practices in Transition Planning were developed on the basis of findings from the OPADD Transition Study and subsequent experience of members across Ontario. Then OPADD conducted a follow-up study to identify how transition planning practices were evolving. This study was also the next step in moving to a standardized model or blueprint for transition planning. The idea here is to define the model as clearly as possible on the basis of what we now know. The defined model or blueprint provides:

1. A guide for care-giving organizations to implement transition planning.
2. A map for evaluating the various pieces of the model once implemented.
3. A means to move to evidence-based practice.

The model or blueprint described in this Guide has been developed from the experience and feedback of many care-giving organizations in both the developmental services sector and the long term care/seniors community programs sector. The elements of the model have been found to work by those who are using them. While the model offers a standard it also allows for flexibility in how to best implement it within any specific organization. For example, while the model requires a defined method for documenting it allows the service provider to design or adopt a system that works best within the organization. This Guide can be used alone or with the complementary PowerPoint Presentation,

"Quality of Life in the Third Age: Blueprinting Best Practices in Transition Planning".

Together the Guide and PowerPoint provide the tools for learning about the model and training staff in its implementation. You can find the Blueprint PowerPoint, the various Guides referenced above as well as more information about transition planning to older adulthood at www.opadd.on.ca

THE MODEL

The Model has eight elements. These elements are those that we found to be associated with effective transition planning to older adulthood. Some, such as using a quality of life framework, are backed up by extensive research. This Guide provides a description of each element and identifies the factors that ought to be part of effective implementation. It is not a complete set of instructions. You will have to think about how you design the details of the model to meet your needs. You may wish to establish a work group with representation from front line staff and managers to work through the model and design how it can best be implemented within your organization. The time invested up front will pay off later in the effectiveness of your Transition Planning Model.

You may adapt how you implement or design each of the elements to the needs of your organization. However, it is important that the elements not be watered down or essential aspects of them ignored.

Once in place, you can evaluate the effectiveness of the model and make adjustments to it based on your findings. As we collectively gain experience with the use of the model we may discover things that need to be adjusted or added. This is a work in progress.

Each of the eight elements that are part of the blueprint as we understand it today are explained in this Guide by:

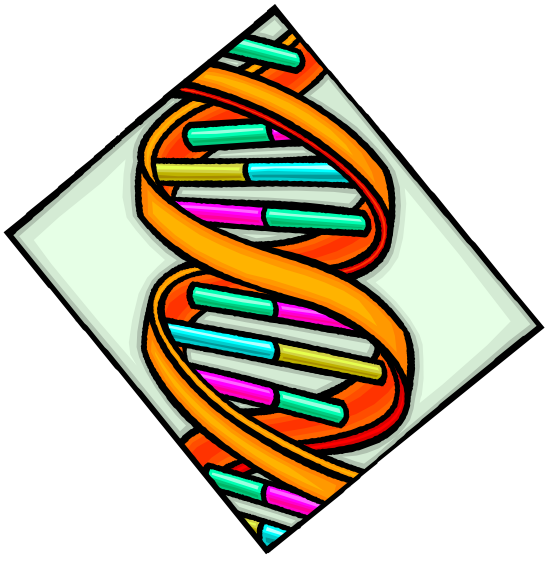
1. **A Statement of Best Practice** — a brief description of the element.

2. **A Checklist** — a quick reference to the important aspects of each element.

3. **Building Best Practice** — a few key ideas for developing best practice with this element.

THE EIGHT ELEMENTS

1. **Documentation**
2. **Focus on Quality of Life**
3. **Health Monitoring and Consultation**
4. **Training**
5. **Partnerships**
6. **Advocacy**
7. **Funding**
8. **Maintenance**



1. Documentation

Documentation is how service providers keep track of each individual's support needs. During the aging process, people's needs will change. Moreover, the attention of caregivers to the effect of the aging process can lead to less attention being paid to who that person is. Who the person is can even be lost when the individual becomes involved in another service or program during the aging process. For example, if you have an aging client, Joe, who is going to attend a seniors day program, how do you ensure that the staff at the new program really understand who Joe is? How do you ensure that your own staff understand Joe and can help him adapt to the aging process?

Useful documentation is an important and necessary part of a caregiver's responsibility. Documentation that supports transition planning to older adulthood is critical to ensure that the service provider is able to:

1. Remember who each individual is.
2. Track how the aging process is affecting the individual.

Documentation: Statement of Best Practice

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.**

Documentation Checklist

Documentation is based on:

- ✓ A defined process for recording changes.
- ✓ A consistent format.
- ✓ A clear set of information items.
- ✓ Begins prior to onset of visible aging.
- ✓ Uses clear criteria to initiate transition planning.
- ✓ Creates a baseline for each person.

Establish a defined process for recording changes

How do you want changes to be identified and documented as a person ages? Identify who will identify changes, how these will be added to the client's record and how the information will be made available to all those who need access to the information. You may wish to create a new system for this or adapt your existing record-keeping to incorporate changes related to aging. Doing this right will require that you learn about and categorize key aspects of the aging process. It will then require that any forms or systems be designed or adapted to record required data.

Establish a consistent format

The format design must be consistent. Ensure that there is one approved format for all staff to use and that it is simple enough for all staff to understand and follow. There is no point in building a recording system that is overly sophisticated or requires too much time to maintain. This will simply contribute to frustration for staff and the possibility that entries will not be made in a timely way or include the specific information all staff require.

Define a clear set of information items

Information items must be clearly defined so everyone shares the same understanding of what is required. You may wish to test the definitions that you develop by sharing them with a sample of staff for feedback. Each staff person brings a different educational background and set of experiences to the job. Make sure your information items mean the same thing to every-one regardless of these differences among them.

Begin prior to onset of visible aging

Documenting the age-related changes of each person requires that recording begins before the aging process begins to affect them in a significant way. A clear starting point for identifying when age changes must be recorded ensures that you will not miss important information. Each person's profile will then provide a reasonable picture of how they are aging and how quickly or slowly changes are occurring.

Use clear criteria to initiate transition planning

We tend to think about aging as related to a person's age. However, we know each individual is unique and gerontologists inform us that the aging process affects each person differently depending on their lifestyle, genetic make-up and how they adapt to their own aging. This makes the identification of a time to begin transition planning tricky. It is important to identify a set of criteria that can be applied to each person and provides a reasonable signal of when to begin paying closer attention to their aging. This model has not yet been sufficiently developed to provide a standard set of criteria. We do know that we should watch for:

- Chronological age (and this age may vary depending on the person's known syndrome).
- Changes in a person's energy level or interests.
- Changes in health.
- What the person is telling us (either in words or actions).

Create a baseline for each person

Documentation is a means to establish a clear baseline of the person before the aging process begins to affect them. The baseline provides a point of reference during the aging process so we know how they are changing and can adapt support to meet their emerging needs. The baseline is a critical ingredient in remembering who the person is and sharing that memory of them with new staff as the aging process continues. Experience with baseline data has taught us that we can maintain our relationship with the individual in a more meaningful way when we remain aware of their unique personality, preferences and needs.

Documentation: Building Best Practice

Developing your organization's best practice with documentation will take some time. Start with what you have in place and build on that. Once you have started, keep assessing and revising your practice to make it better. In summary, building your best practice with documentation requires that you:

1. Assess what's in place.
2. Identify what's missing.
3. Build your documentation practice.
4. Test and revise.

2. Focus on Quality of Life

Quality of Life is an important idea that helps to shape effective planning and support. It is also a concept that is still relatively new. Our understanding of it is evolving as researchers test the concept and add to the body of knowledge about it. Building competence with a Quality of Life Framework will require investment to develop a thorough understanding of what it is and how to work with it.

While there are several different models of Quality of Life, they share many similarities. This Guide suggests one Quality of Life Framework that has been developed by the Quality of Life Research Unit at the University of Toronto. The model has three domains, each of which has three sub-domains:

1. Being
   a. Physical Being
   b. Psychological Being
   c. Spiritual Being

2. Belonging
   a. Physical Belonging
   b. Social Belonging
   c. Community Belonging

3. Becoming
   a. Practical Becoming
   b. Leisure Becoming
   c. Growth Becoming

The model, which can be viewed online, illustrates and explains how these domains and sub-domains can be applied to an understanding of Quality of Life for each individual. The website also provides information on assessment tools that can be purchased.

More information about this model is available at: http://www.utoronto.ca/qol/

Quality of Life: Statement of Best Practice

Caregivers supporting adults with a developmental disability use a Quality of Life (QoL) model that provides perspective on the whole person during the aging process. Quality of Life frames transition planning in terms of the individual's needs so planning is free of sector boundary issues and inclusion remains a driving force throughout the life cycle.

Quality of Life Checklist

- ✓ A Quality of Life framework is in place to make transition planning decisions.
- ✓ Encompasses full range of aging process.
- ✓ The QoL framework considers the individual's experience of aging.
- ✓ Includes provision for substitute decision-making.
- ✓ Addresses impact of aging on other people.
- ✓ Considers risk factors unique to the individual.

A Quality of Life framework is in place to make transition planning decisions

Consider the Quality of Life Frameworks available and choose one that fits your organization and that is fairly easy to work with. The one suggested in this Guide has a description and resources that are available on line.

The QoL framework encompasses the full range of the aging process

The QoL framework you choose must speak to the aging process. It should be dynamic and include consideration of the various aspects of aging. This may require some study about aging so you can make an informed decision when you choose the framework you will adopt.

The QoL framework considers the individual's experience of aging

One of the challenges facing care-giving organizations is how to understand the individual client and his/her needs. This challenge can be all the more daunting when the individual is unable to fully articulate how the aging process is affecting him/her. However, staff can deepen their understanding of an individual's aging if the framework reminds them of the full range of the aging process and helps to make the link to what the person is experiencing. This is not a simple process and will require judgment decisions informed by the individual, his/her family, support circle and other staff.

The QoL framework includes provision for substitute decision-making

One aspect of aging that is well understood among people working in the long term care/seniors community programs sector is the importance of making provision for substitute decision-making related to property and personal care decisions. This is currently less well understood in the developmental services sector. However, provincial legislation is in place to provide safeguards in how substitute decision-making is established for each person.

Find out more about substitute decision-making by referring to provincial legislation and various guides available online. You may also find out more from OPADD's Guide to Personal Care and Property available online at www.opadd.on.ca

The QoL framework addresses the impact of aging on other people

Aging not only affects the individual. It also has significant impact on those people who are close to him/her. We are who we are in a variety of roles and relationships. We may act differently with close friends than we do with parents. Each individual being supported by your organization will fulfill different roles and have different expectations placed on him/her by others. How will aging affect these roles and fulfillment of expectations? Caregivers can remain attentive to how each individual's aging is affecting those around him/her if the QoL framework includes consideration of this important variable.

The QoL framework considers risk factors unique to the individual

Each individual has a unique life experience, lifestyle and genetic make-up that may contribute to risks. A person with Down syndrome is very likely to be at risk of the symptoms associated with Alzheimer disease. A person who is very overweight may be more likely to experience a heart attack. Someone whose diet is unbalanced and lacking in basic nutrition may be prone to certain health problems. Effective transition planning to older adulthood requires that the potential risk factors for each individual be identified and monitored. Consider how the QoL framework addresses risk factors and incorporate a system for monitoring those that may be applicable to each person.

Quality of Life: Building Best Practice

Quality of Life is an important and useful idea. It is part of the foundation for sound transition planning to older adulthood. Understanding the QoL framework adopted within your organization and ensuring all staff can work with it will require an investment of training and practice. It will not be sufficient for staff to have a general idea of QoL. Consider how a QoL assessment tool can help staff work effectively with the framework. The general steps to building your best practice with QoL include:

1. Identify and adopt a Quality of Life framework.
2. Use a checklist to assess the individual's Quality of Life.
3. Provide training in using the model.

You may also find it helpful to talk to partners in your sector or in another sector who have experience with the Quality of Life concept and its application. They may be able to provide guidance and shorten your learning curve. You can also find resources online.

3. Health Monitoring and Consultation

Monitoring an individual's health is an integral part of any care plan. It is normal practice among service providers. Over the course of many years a service provider will become familiar with an individual's particular health. Routines may have been established for appointments with health care providers, health maintenance, medications and other interventions. However, as an individual ages his/her health may also change. Consider this:

- The elderly are not a homogenous group.
- Health varies considerably from one individual to another.
- The process of biological aging is continuous from birth to death.
- Age is one of the principal factors determining the nature and extent of an individual's health.
- Other factors affecting health include socio-economic conditions, gender, ethnicity and marital status.
- Each person has lived through and been influenced by different economic, social and political events which can affect health.
- Some diseases are age-dependent: their origins and development are directly related to age. For example, Alzheimer Disease, Parkinson's, strokes and osteoporosis.
- Some genetic conditions may affect the aging process and health.

The changes within an individual and the variability among people mean there will be new challenges to ensure sound monitoring practice relative to the health of each aging person.

A key adjunct to effective health monitoring includes consultation with health care practitioners. This may pose a challenge for service providers when:

- Paid caregivers supporting an individual are not aware of the range of health practitioners and specialists who are available to the elderly.
- Support staff lack basic information pertaining to a health condition.
- Support staff lack the communication skills necessary to converse effectively with a health care practitioner.

These challenges have important implications for staff recruitment, orientation and training programs.

Health Monitoring and Consultation: Statement of Best Practice

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.

Health Monitoring and Consultation Checklist:

- ✓ Support practice includes systematic support for health and mental health.
- ✓ Health status is monitored and documented during the aging process.
- ✓ Care staff understand age-related healthcare needs.
- ✓ Staff are aware of risks associated with specific genetic disorders.
- ✓ Staff are skilled in professional consultation, assessment and intervention with health/mental health practitioners.

Support practice includes systematic support for health and mental health

Proper support includes a routine for maintaining health and mental health. The service provider faces challenges when ensuring any routine or systematic practice because of:

- Staff turnover.
- The need to orient new staff.
- Training requirements for current staff in new practices and policies.
- Differences among the people being supported.
- The number of staff who may have responsibility for an individual client.
- The need to keep all staff up to date on the latest information.

It is important that the service provider have systems in place to deal with each of these challenges. However, there are two important resources which can help with these challenges to some degree. These are the individual client's:

- Personal support plan.
- Support circle.

Best practice related to support for health during the aging process requires that the service provider have clear policy and well-defined practice in place to support staff in this important function. Moreover, managers must be competent in conveying policy and ensuring staff understand implementation requirements.

Health status is monitored and documented during the aging process

Monitoring and documentation is important to ensure the support provider maintains a clear and accurate picture of each individual's health status. This must be done within the context of expected and unexpected changes in an individual's health status, staff turnover, staff returning from vacation or days off and all of the demands on the service provider. It requires that each employee remain aware on a daily basis of each client's health. This awareness relies on access to clear documentation about changes in health, medical appointments, assessments, feedback from health practitioners and the observations of other employees. It requires that each employee have sufficient skills in observation and in written communication and that employees can acquire and/or maintain the requisite skills.

Care staff understand age-related healthcare needs

Since this is the first generation of people with developmental disabilities to live into old age there is generally very little knowledge and experience with age-related changes and consequently with age-related health care needs. This is illustrated by the story of a developmental service agency where one of their first aging clients was showing signs of dementia. However, at that time no employee had seen these signs before. The significance of the client's forgetfulness and small changes in habits were not seen for what they were. One day on his way home from work the client stopped in the middle of an intersection. A passerby helped the man to the sidewalk and called the developmental service provider. A staff person came and brought the man home. It took months and more of these episodes before the service provider connected with the Alzheimer Society, learned about dementia and arranged for the client to undergo an assessment.

This example illustrates the risks and challenges for caregivers with little previous experience of aging and whose clientele are now approaching or entering their older adulthood. It underscores the critical need for staff training and information. There are not resources nor time for each service provider to develop an internal expertise on aging. However, there are rich resources and opportunities for learning through cross sector dialogue, training and collaboration.

Staff exchanges, cross sector workshops and opening agency training sessions to staff from the other sector are just a few ways that a developmental service provider can build expertise with aging while the long term care provider becomes knowledgeable about developmental disabilities. Service providers which have moved to building capacity through cross sector knowledge exchange have a leg up on those that try to go it alone.

Staff are aware of risks associated with specific genetic disorders

People with developmental disabilities are more likely than the general population to also have a genetic disorder or syndrome. Some of these, such as Down Syndrome, Cerebral Palsy, Prader-Willi Syndrome and Fragile X Syndrome, have a known and significant impact on the aging process. It is important that the presence of any such genetic disorder is known to the service provider and to staff. This may require a genetic assessment. In turn staff must understand these disorders and their implications for the individual's health and aging process.

Staff are skilled in professional consultation, assessment and intervention with health/mental health practitioners

Attending an appointment with a client to see a health care practitioner is not an assignment for a new staff person or someone who has been on vacation for two weeks.

Some of the complaints of health care practitioners about care-taking staff is that they can arrive at an appointment:

- Without clear or sufficient information as to why the appointment has been made.
- Lacking in understanding or background information about the client's problem.
- Unable to articulate the client's situation to the health care practitioner or understand the terminology or implications of what the health care practitioner is telling them.

Some of the complaints by care staff about health care practitioners are that the practitioner:

- Doesn't give them time to explain the client's situation.
- Doesn't appear to be listening.
- Doesn't give enough attention to the client to assess them properly.

Communication is always a challenge even between people with a similar background or who know one another well. When we add different education, background, legislative frameworks and jargon into the mix there are bound to be some bumps in the road. Care staff must demonstrate proficient communication skills if they are to be credible and effective at a medical appointment. Moreover, they must prepare for an appointment by reviewing the medical file, gathering information and identifying questions. Care staff must perform at a level fitting to an inter-professional consultation.

Health Monitoring and Consultation: Building Best Practice

The Canadian Consensus Practice Guidelines for the primary health care of adults with developmental disabilities and the complementary learning course for the Primary Health Care of Adults with Developmental Disabilities are important reference documents for care staff. These resources provide information and insight into the challenges faced by health care practitioners in understanding people with developmental disabilities, preventive care, general health, access to health care, genetics centres in Ontario, a health assessment model and much more.

Dialogue with health care practitioners on the topic of effective working relationships can provide a means to pave the road to best practice in your community. The key is to engage those who have the knowledge and experience that can build best practice.

Building Best Practice:

- ✓ Establish requirements for health and mental health monitoring.
- ✓ Identify staff training needs.
- ✓ Engage healthcare experts for training and consultation.
- ✓ Identify existing health and mental health services and resources available to the general
- ✓ population and those specialized services for older adults, such as Psychogeriatric Resource Consultants (PRCs).

4. Training

Professional development is the responsibility of both the employer and employee. It is the means by which employees stay current with new information and best practice. A well-planned and implemented professional development program safeguards the service provider's capacity to ensure the well-being of clientele.

The aging boom brings new challenges which require new understanding and methods of support. The development of a sound transition planning process depends on a training program that addresses the emerging needs of employees to provide support to older adults.

OPADD's experience with cross sector training has demonstrated that it is an economical and effective method to train care-giving staff in both developmental services and long term care/seniors community programs. During dialogue sessions at the OPADD Symposium 2009, delegates identified cross sector training as an essential part of moving forward in the face of the aging boom. In the words of delegates:

> "Bringing sectors together for joint training workshops or educational opportunities that benefit both sectors jointly."
>
> "Staff exchange visits benefits both sectors."
>
> "Develop joint training of the 2 sectors at all personnel levels amongst agencies that are attempting or are partnering."
>
> "LTC Home and Community Living partner to provide education to each other's staff."
>
> "Improved understanding of similarities and differences between LTC and ID sector by presenting of education/training by one sector to another."

Training: Statement of Best Practice

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

Training Checklist

Some of the skill areas required to support people as they age:

- ✓ The aging process.
- ✓ Transition planning to older adulthood.
- ✓ Health care and health conditions.
- ✓ Mental health and emotional issues.
- ✓ Dementia.
- ✓ Orientation to both service sectors (developmental services and seniors).
- ✓ Effective working relationships with counterparts in the other sector.
- ✓ Orientation to coordinated access processes. (CCAC and MCSS Coordinated Access
- ✓ Programs).
- ✓ Individualized care planning / person-centred planning.
- ✓ Quality of Life model(s).

Cross sector training is still in its early stages. As partnering organizations continue to learn from one another and as cross sector training events occur, we become aware of new learning possibilities. Delegates at the OPADD Symposium dialogue sessions identified a range of options for expanding cross sector training. A selection of these suggestions appears below.

"Develop a cross sector/discipline training module for staff."

"Formalizing training: pre-service cross sector information and onsite training (shadowing), overview of different services, more regional workshops, formal education."

"More education/training in DSW curriculum re aging issues, dementia and gerontology."

"Pre-service education – explore opportunity for pre-service cross sector education/training i.e. colleges/universities."

"More medical training from a doctor/nurse when training new staff."

"Use PRCs and geriatrics to do outreach education to LTC…"

"Broadening access to information and education across both sectors including communities of practice (SHRTN)."

Training: Building Best Practice

Developing a strong training program requires consideration of new evidence about adult learning and the skill sets that staff need to support older adults with developmental disabilities. A training program must be defined by policy. Policy and practice must foster an environment in which professional development is respected and supported.

Training is an investment in employees and in supporting the organization's mandate. it costs money. When funding constraints arise, the training budget must not be one of the principal places from which funds are deleted.

A few key ideas for building your training best practice:

- ✓ Develop or re-develop your policy and practice that governs training.
- ✓ Investigate other successful training models.
- ✓ Review adult learning research findings.
- ✓ Explore how emerging technology can be applied to delivery of training.
- ✓ Review your current training processes & curricula.
- ✓ Identify gaps.
- ✓ Engage partners in the other sector.
- ✓ Confirm required training allocations.

5. Partnerships

Partnership is not the end. It is the way. Time and again partnering agencies and cross sector committees have found that we can identify issues more easily, frame them more clearly and develop solutions more easily because we work together. Partnering opens doors to an expanded base of information, knowledge and resources. Working cross sector leverages what is available to build the system's capacity. It is good stewardship on behalf of public funds. Partnership is a core ingredient for transition planning as both developmental service providers and long term care/seniors community program providers must become conversant with one another in developing effective cross sector transition planning processes.

The many players involved in cross sector work attest to the benefits and indicate a desire for more. In the words of some service providers:

> "…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…"

Partnerships Statement of Best Practice

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

Partnerships Checklist

The partnering service provider:

- ✓ Is engaged with a cross sector committee on aging and developmental disabilities.
- ✓ Establishes cross sector partnership ventures for training, planning and development of
- ✓ service delivery models.
- ✓ Formalizes cross sector working relationships via joint meetings, protocols, policies and explicit principles.
- ✓ Ensures partnership also allows for support to the client following admission to a program in the other sector; this may include staff working cross sector.

Engaged with a cross sector committee on aging and developmental disabilities

OPADD, through the work of local players, established eight regional cross sector committees. Other networks and committees on aging and developmental disabilities have emerged in local areas and often link in with their regional OPADD committee. The key is to engage in a sustained dialogue through a process that has some formality and mutual expectations. It is in the dialogue that understanding is born, relationships are formed, ideas and information are shared and innovation grows.

Establishes cross sector partnership ventures for training, planning and development of service delivery models

While the dialogue provides a foundation, it is not the whole building. The partnership tables provide a forum where working relationships give rise to problem identification and practical cross sector initiatives. Many models for supporting older adults with developmental disabilities have emerged across Ontario thanks to the discussion that began at a cross sector table. Achieving best practice in transition planning means moving forward on designing, implementing and testing new ways of planning, training and delivering services in partnership.

Formalizes cross sector working relationships via joint meetings, protocols, policies and explicit principles

Partnership-building is important work. It is far too important to be based on the good will among personalities around the table. This is not to say that good will is not important. It is essential. However, a sustainable cross sector process does not rely on personalities. It moves beyond this stage to create an explicit message and set of mutual expectations among the players. Once the partnership becomes explicit in the form of principles, protocols, vision statements and the like it moves into new territory where the partnership takes precedence over the individual people at the table. It becomes a meeting of the minds of organizations which are committed to the work regardless of who fills which staff positions.

A newly emerging area in cross sector work is the development of policy that governs organizational practice around cross sector dialogue, collaboration on new ventures, transition planning to older adulthood and so on. Policy provides a framework within which expectations for work that takes place at the boundaries of the organization are made explicit.

Ensures partnership also allows for support to the client following admission to a program in the other sector; this may include staff working cross sector

Cross sector partnership is ultimately about each older adult with developmental disabilities. It has as its principal aim to maintain or strengthen Quality of Life while helping the individual adapt to the aging process. There is a rich array of services available for seniors in Ontario. Older citizens with developmental disabilities have the same right to access these services as all Ontario seniors. Consequently, in the name of inclusion and Quality of Life it is essential that the cross sector partnership fosters an environment in which each older adult can move easily within both the developmental service and long term care/seniors community programs sector to access the right mix of services and supports.

Partnerships: Building Best practice

The journey of a cross sector relationship begins with the first step. Find out who your counterpart is in an organization in the other sector and get to know them. Find out about your regional committee on aging and developmental disabilities and how your organization can connect to it. Bring a cross sector problem to an existing network or inter-agency group that you are part of. Consider the partnership checklist and how you can move forward on each of the ideas.

6. Advocacy

Advocacy work is required to build transition planning capacity. In its 2008 study of transition planning best practices, OPADD received feedback from several service providers in both sectors. The data indicate that service providers in both sectors are reasonably strong at:

- Monitoring and adjusting plans for individual clientele.
- Working with a committee on aging and developmental disabilities to confirm emerging issues and trends and identify needed resources or regulatory amendments.

Service providers are generally less strong at:

- Monitoring to confirm trends and applying that knowledge to re-shape the service system.

More must be done at the level of systemic advocacy if cross sector transition planning is to become the norm.

Advocacy Statement of Best Practice

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.

Advocacy Checklist

The service provider:

✓ Monitors and confirms trends in the needs of older adults with developmental disabilities.

✓ Works with the regional committee on aging and developmental disabilities to confirm emerging issues and trends in transition planning and identifies needed resources and regulatory amendments.

Monitors and confirms trends in the needs of older adults with developmental disabilities

Since this is the first generation of adults with developmental disabilities to live into older adulthood there is no precedent to guide planning and activity. Less than ten years ago service providers were discovering for the first time that some of their clientele, older adults with developmental disabilities, were showing signs of dementia. The road to this discovery was filled with unexplained changes in behaviour and frustration among caregivers. Eventually, a link was made to dementia and the needs of these clientele became apparent. Today much more is known about the phenomenon among this population. But aging is a process with many facets.

It is essential that service providers watch closely for changes in individuals and explore how these may be attributable to the aging process. Documentation of each individual's aging and examining the commonalities among a client population can provide the data needed to confirm trends.

Works with the regional committee on aging and developmental disabilities to confirm emerging issues and trends in transition planning and identifies needed resources and regulatory amendments

An agency working alone will tend to have a much smaller perspective than an agency working cross sector. It is not enough to identify the issues. Work must be done to alert all parts of the system and engage all of the players. Insight into emerging issues and trends can be gained by working with the regional committee on aging and developmental disabilities; by reaching out to planning bodies, agencies, clinicians, academics, researchers and policy-makers. In the end it is the system that must re-shape itself to respond to the phenomenon of an aging population with developmental disabilities.

Advocacy: Building Best Practice

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 acceptance 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 and re-shape itself to meet this emerging challenge.

7. Funding

Many service providers are finding creative ways to attract resources or allocate existing resources to support transition planning for older adults with developmental disabilities. As the aging boom progresses the pressures on the system will increase. It is important to identify the cost of transition planning support so individual service providers and the system as a whole can determine the financial impact ahead.

Funding Statement of Best Practice

The organization ensures appropriate staffing requirements to implement transition planning to older adulthood on a case by case basis. This may include staff support as the client accesses programs in the other sector.

Funding Checklist

A consideration of the items in the funding checklist provides a means to consider how to move toward best practice with respect to funding of transition planning.

Staffing requirements for each individual are determined in a deliberate and explicit manner which includes consultation and collaboration with:

- ✓ The individual client (to the extent possible).
- ✓ The individual's support circle.
- ✓ Staff who work with the client.
- ✓ The service provider(s) in the other sector.

Staffing requirements for each individual are determined in a deliberate and explicit manner which includes consideration of:

- ✓ The differences they will encounter in accessing a program in the other sector.
- ✓ Cross sector planning process.

Resource requirements for transition planning are identified. Specific strategies to realize these requirements may include:

- ✓ Re-allocations of internal agency funds.
- ✓ Additional external fund-raising.
- ✓ Funds from the agency's foundation.
- ✓ Funding from the government of Ontario.
- ✓ A strategic mix of various sources.

OPADD collected data from a number of service providers to begin the process of getting a handle on transition planning costs. The data is not definitive but it provides a point of departure for further study and dialogue.

Of those agencies who reported, they indicate the following about where they get the funds for transition planning:

- 30% get it from internal reallocations.
- 10% from external fund-raising.
- 13% from a foundation.
- 10% from the government of Ontario; and
- 34% reported they had no funds available for transition planning.

Agencies were also asked to identify the types and cost of transition support they provide. Of those reporting:

$ 5500.00 is the average cost for support to the client.
$ 3000.00 is the average cost of support to the receiving agency.
$ 8500.00 is the total average cost per client per year.

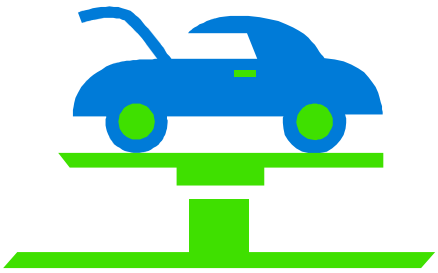
It is important to remember that the data on which these average figures are based, were provided by twenty service providers. While the data is not based on a reasonable sample it does provide a starting point for dialogue and planning. More data is needed to clarify transition planning funding requirements.

Funding: Building Best Practice

- Identify requirements.
- Develop and implement a plan to attract and/or reallocate financial requirements.
- Advocate for resource requirements based on documented and realistic targets.

8. Maintenance

Things work better when they are maintained properly.
The same is true of transition planning.



Maintenance Statement of Best Practice

The service provider ensures that attention is paid to maintaining effective transition planning and support processes both within the organization and with the other sector.

Maintenance Checklist

A sound maintenance plan for transition planning includes these ingredients. The service provider ensures that:

- ✓ Transition planning and support processes remain current and effective.
- ✓ Working relationships with planners and service providers in the other sector are explicit.
- ✓ There is a process in place for both organizations to review the relationship together at regular intervals.

Transition planning and support processes remain current and effective

As we move forward we will learn more, refine models, witness unexpected changes in client needs and adjust responses accordingly. The transition planning processes that work well today may require changes in the future. Since aging is a dynamic process and each individual ages uniquely, there is no cookie cutter transition plan to suit all clients, nor plans that will remain viable for all time. Society will change. Technology will offer new possibilities. Research will inform our understanding of aging and transition planning. The search for best practices and the move to do so through evidence-based practice will unfold and give rise to new expectations.

Working relationships with planners and service providers in the other sector are explicit

When two or more organizations collaborate it is highly important that their expectations, responsibilities and roles are known to one another. Some may opt to describe the relationship in a set of principles, some in a protocol, others in a letter of agreement. The form is not so important so long as all parties share the same understanding based on some explicit document. This paves the way for the relationship to be maintained as individual players come and go. It provides a point of reference in case of a disagreement. It guards against drift from the intended focus of the relationship.

There is a process in place for both organizations to review the relationship together at regular intervals

A crisis is not the time to review the relationship. The relationship is bigger and more important than a specific event or problem. Focus on the relationship exclusively through some form of joint meeting between organizational representatives. Affirm what is working, identify and fix what is not. Clarify mutual expectations.

Maintenance: Building Best Practice:

Affirm that maintaining the relationship with each partner in the other sector is an integral part of transition planning and allocate the appropriate resources to the maintenance role.