

# AGING WITH A DEVELOPMENTAL DISABILITY



## TRANSITION GUIDE FOR CAREGIVERS

FROM THE ONTARIO PARTNERSHIP  
ON AGING AND DEVELOPMENTAL DISABILITIES

SEPTEMBER 2005



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## PURPOSE OF THIS GUIDE

This Guide has been developed to assist families and caregivers with transition planning for people with developmental disabilities as they age. Information has been collected from:

- Current literature.
- Applied research on transition planning conducted by the Transition Task Group of the Ontario Partnership on Aging and Developmental Disabilities.
- The collective experience of task group members.
- Interviews with caregivers experienced in aging and developmental disabilities.
- Knowledge gained at the local level through cross sector partnership projects.

We have distilled the information to give you the most important points to be considered in supporting a person with developmental disabilities as they age. The Guide also provides checklists for planning. The checklists allow you to identify any changes or issues that may be developing. While the information and checklists are intended to help you, they are not a replacement for your intimate knowledge of the person you are supporting. Neither does the guide contain detailed information about the planning issues contained in its pages. We have provided references so you can obtain more information from other publications, web sites and government offices.



You may also wish to visit our web site at [www.opadd.on.ca](http://www.opadd.on.ca) for additional information on caregiver support and links to government and other services available to older adults in Ontario.

## TRANSITION PLANNING

There are many transitions in life. This Guide focuses on the transition to older adulthood for people with developmental disabilities. Within this transition process, the guide also provides information about transitions between services or programs. However, it is important to keep in mind that transition to older adulthood is not merely about accessing a variety of programs available to senior citizens. It is above all a planned and conscious evolution to embrace life as it presents itself during the aging process.

### The Life Plan

The Life Plan of the individual provides the basis for the support provided by members of the support circle. As the person enters older adulthood, the life plan changes to include consideration of emerging issues and needs related to aging. Transition planning is not about replacing the Life Plan but provides a framework for thinking about and adjusting the Life Plan as the person ages.

### The Role of the Individual in the Planning Process

The Task Group considered the role of the person with a developmental disability in the transition planning process. The person centred approach to planning requires that the individual be the source of information about their own life plan. The realization of this principle may be influenced by the person's capacity to become involved and to make his/her needs known. Where there are limitations on capacity caregivers must rely on more on their personal knowledge of the individual. In all cases, the communications of the client however they may be expressed, are relied on to inform planning decisions.

## Definition of Transition Planning

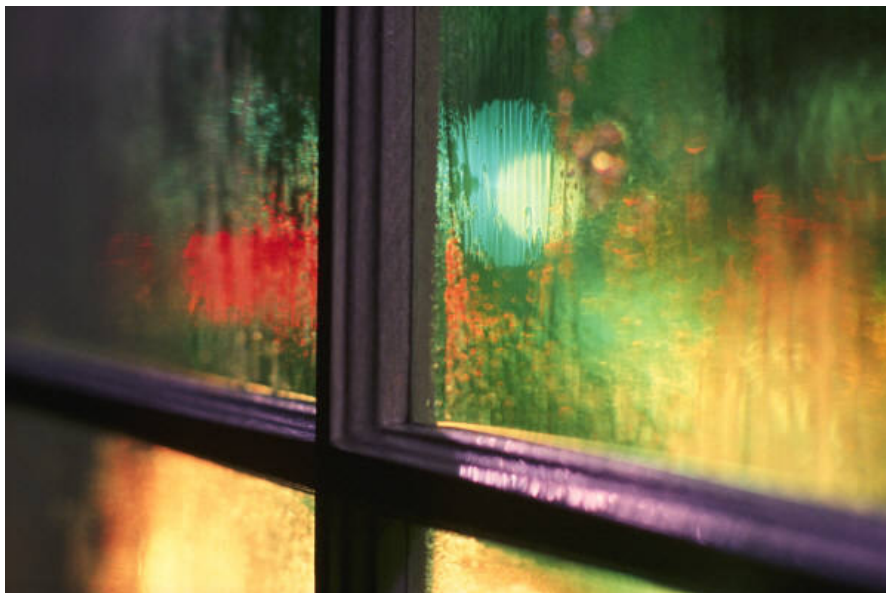
The Transition Task Group developed a definition of Transition Planning to Older Adulthood to help caregivers in their planning work. The definition can help to put all caregivers on the same page in their understanding of the transition planning process.

Transition Planning is a planned process that:

- Supports the individual in maintaining quality of life as he/she ages.
- Allows the individual to be the driving force in shaping the plan and to be involved in all plan-making to the extent of his/her capacity.
- Helps the person with developmental disabilities to plan for changes in their support needs as they age (aging is not necessarily related to a chronological age such as 65).
- May involve changes in how the family provides support or in the amount of support provided.
- May include access to day supports for older adults such as Meals on Wheels or a senior's day program, so the person can remain at home, and / or
- May involve preparing for a move to a new residential setting where more appropriate support can be provided.
- Always includes the person with a developmental disability.

And may include a variety of people and organizations such as:

1. The family, guardian or advocate.
2. Friends of the individual.
3. Direct care staff of a developmental services agency and / or older adult services agency.
4. Facilitators and members of support circles.
5. A case resolution coordinator.
6. A medical practitioner and / or psychiatrist and / or psychologist.
7. Coordinating bodies such as the local Community Care Access Centre.
8. The Ministry of Community and Social Services developmental services coordinated access process.



## Transition Guide

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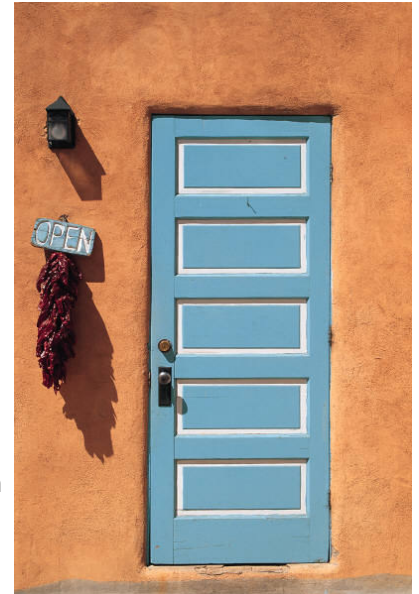
### Checklist for Transition Planning

How comfortable are you and your planning group with the idea of Transition Planning?

- There is a clear idea of the transition planning process that all members of the support circle share.
- The group needs to meet to develop a common understanding of transition planning.
- We need more information about transition planning.

### GETTING READY

The most important thing in supporting the individual and planning with them for their transition to older adulthood is to start early. It is very important to conduct an assessment prior to the onset of any aging symptoms. The results of this first assessment serve as a baseline and provide a point of reference for any changes that come later. There is no specific age to take a baseline assessment but the sooner the better. It is recommended that an assessment be done by the time the person reaches 40. However due to the prevalence of Alzheimer Disease among people with Down Syndrome and the tendency for its symptoms to show up earlier among this population group, in such a case a baseline assessment may be best done in the person's early 30's. Baseline assessments can include standardized tests conducted by professionals and baseline information can be kept in a life book that tracks changes with the person over time.



### Checklist for Getting Ready

- Identify the age of the individual when you feel it would be best to begin planning \_\_\_\_\_.
- Gather and maintain history and background information on the individual.
- Create baseline data on the person prior to his/her entry into the years when the aging process accelerates.
- Acquire new skill sets related to support, intervention, health and emotional conditions associated with aging.
- Develop capacity to talk with physicians, specialists and other health practitioners and to keep a record of their diagnoses and treatments.
- Become aware of the full range of services available to older adults and how to access them.
- Get to know the contact people at the CCAC and all seniors programs/services; visit these programs to become familiar with what they offer.
- Develop transition planning that encompasses the full range of the aging experience - physical, emotional, employment, decision-making.
- In the transition planning process, consider the impact that aging has on all other people in the client's life (staff, roommates, friends, family) and how this may influence planning decisions.
- Ensure the individual's plan includes clearly identified risk factors arising from family history, the presence of a syndrome, living situation and lifestyle.

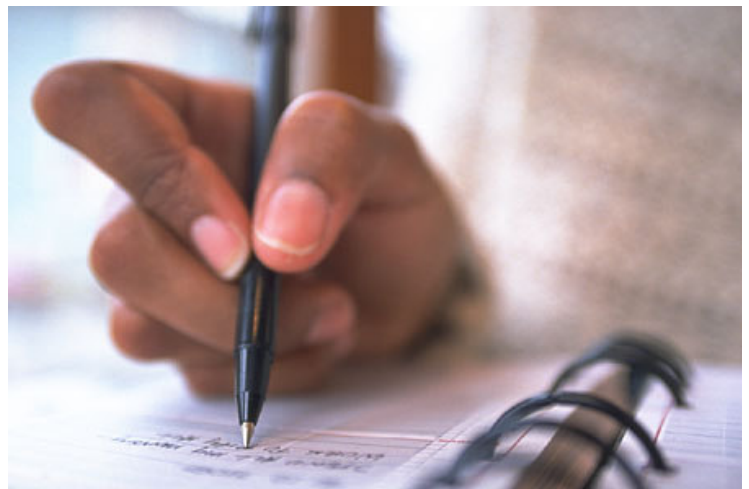
## KEEPING A HISTORY

Because of the complexity of the aging process for people with developmental disabilities and the presence of different care givers and agencies in their lives over time, it is important to create and maintain a clear history. The history may include information about the birth, health conditions during childhood and the family history of illness that may predispose the individual to certain conditions (for example, diabetes or heart conditions). In many cases these records may be with the family or family physician. However it is important to assemble them in such a way that they are available to future potential caregivers in the event that a current caregiver is unable to continue in the care giving role.

### Checklist for Creating a History

This checklist provides some guidance to thinking about the kinds of things that may be important to put into the history and where the items may be obtained.

- Birth history
- Family history
- Childhood illnesses
- Psychomotor assessments
- Psychological testing
- School assessments and reports
- Support agency assessments and reports
- Physician visits
- Specialist visits
- Immunizations
- X-rays
- Vision Check-ups
- Hearing Tests
- Dental Check-ups
- Special health conditions and needs
- Other \_\_\_\_\_



## PRINCIPLES FOR TRANSITION PLANNING

Support circles allow family, friends, neighbours and paid caregivers to work together in helping the individual realize his/her life plan. Transition planning to older adulthood may introduce new issues and additional caregivers from the long term care sector into this equation. The Transition Task Group believes that support circles can be helped in their work by adopting principles to guide their interactions and decision-making. Your circle may have developed its own guidelines or philosophy. However the Task Group found the following set of principles helpful to think through the issues that arise with aging and to provide a point of reference when new members enter the circle.

These principles were developed by the Huron Trillium Partnership. The partnership was formed by developmental service and long term care providers as well as coordinating and planning bodies in Huron County. They created the principles as a result of their transition planning experience with older adults who have developmental disabilities. They are provided here to help you think about some of the key aspects of transition planning.

### 1. Respect for the Individual

Each person is unique in his or her abilities, preferences, emotional nature, physical characteristics and learning. Transition Planning should respect the dignity of the supported individual and ensure that plans reflect their needs and aspirations. Moreover plans should support the rights of each individual under the Canadian Constitution, the Ontario Human Rights Code, the Ontarians with Disabilities Act and other government legislation.

### 2. Family Involvement

The relationships that each person may have with members of his/her family are to be encouraged and respected. Transition Planning should always allow for the inclusion of family or other significant people in the individual's life and in the Transition Planning Process.

### 3. Continuity of the Life Plan

Transition Planning is not a substitute for life planning but an integral part of it. Transition Plans should consider how to uphold the person's pre-existing life plans and be attentive to the whole person.

### 4. Respect for All Relationships

People vary in their capacity to form relationships and to engage in the many aspects of relationship-building. Transition Planning should allow each person to form and to enjoy relationships with others, both persons with and persons without an intellectual disability.

### 5. Valuable Community Involvement

Transition Planning should consider every aspect of community life:

- Social relationships
- Recreation, education, employment, self-improvement groups, leisure activities
- Participation in a worship community
- Citizenship roles such as voting, participation in political processes, access to elected representatives and involvement in civic affairs.

### 6. Balance of Risk with Safety

The pursuit of goals in life is often accompanied by risk. Transition Planning should allow for risk while ensuring the person does not put themselves in danger.

### 7. Communication

Persons with a developmental disability may have different ways of communicating with others. This may include eye contact, sounds, motions, phrases and complete sentences. Transition Planning must include careful listening to each message in whatever format it is offered. In this way respect may be assured for the dignity and wishes of the person. Moreover, it is important to inform new caregivers who become part of the person's support system about their unique communication methods and messages.



## AGING WITH A DEVELOPMENTAL DISABILITY

There is evidence that men and women with developmental disabilities are subject to some differences in the onset and progress of aging due to hereditary, environmental and lifestyle factors. This adds to the complexity of the aging process for this population and increases the challenge facing caregivers.

### Onset of Aging

While many people with a developmental disability enjoy the same life expectancy as the general population, there is evidence that the effects of aging can begin earlier and progress more quickly in some cases. Consequently, while all people begin to experience the effects of aging in their 40's, some persons with a developmental disability may require a greater level of adjustment in support at a younger age than the general population. Caregivers must pay attention to factors associated with aging such as changes in social roles, activity level, interests, behaviour patterns, response to things in the environment and health conditions, if they are to provide effective support.

### Genetics

Some of the genetic aspects of specific developmental disabilities may impact the aging process. For example, persons with Down Syndrome are subject to a number of factors that can influence the onset and progression of aging. These include:

- A greater tendency to experience respiratory difficulties, which can in turn limit capacity for physical activity.

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- Early onset of hearing loss in some individuals - as early as their 20's; if undetected this could lead to behavioural symptoms that may be misinterpreted as a psychiatric disorder.
- Genetic predisposition to develop Alzheimer Disease; symptoms often show up in the mid 40's but have been reported as early as the mid 30's for some individuals.

People with Prader-Willi syndrome are at higher risk of diabetes mellitus. Diabetes results in the debilitation of internal organs and can result in severe compromises to health and even death.

### Nervous System Compromise

Central nervous system compromise resulting in an associated developmental disability such as epilepsy, cerebral palsy and some forms of visual impairment may exacerbate the onset and progression of aging.

### Environmental Factors and Lifestyle

Where a person lives may influence health and result in conditions that effect the aging process. For example institutional settings may pose risks of infections; community group home settings may pose risk due to lifestyle choices that result in lack of exercise, smoking, alcohol consumption, poor diet, unsafe sex, drug use.

### Access to Basic Healthcare Services

Access is not merely about getting an appointment with a physician or visiting a clinic. People with developmental disabilities often have health problems associated with their developmental disability. For this reason it is important that the health care practitioner, who may not have much knowledge of developmental disabilities, receives guidance on a monitoring regime that fits with the needs and risks of the individual. It is also important to find the right practitioners with the requisite specialties that are needed by the individual.



### Communication

Persons with a developmental disability may not always have insight into the effect that aging is having on them. They may be unable to articulate what they are experiencing in ways that other people understand what they are experiencing. Consequently there is the potential for signs of aging to go unnoticed until they become more pronounced. Caregivers should consider how to inform and educate people with developmental disabilities about aging and the ways in which they may choose to adjust their lifestyle to accommodate older adulthood. Caregivers must also educate themselves about aging issues so they are prepared to monitor and to intervene with age-related needs. Finally, caregivers who know the person well should be sure to educate others in the support circle and caregivers in new services which the person may access, about the communication style of the individual and some of the key messages that they generally communicate to others.

### Summary

The aging of persons with a developmental disability may occur at a younger age than the general population and be affected by factors related to their specific disability. It is important that caregivers pay attention to the indicators of aging such as changes in social roles, activity level, interests, behaviour patterns, response to things in the environment and health conditions. More information about specific developmental disabilities and their potential effects on aging can be obtained from your physician, local library and Internet sites.





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### Checklist on Aging

Have you noticed any changes in the person over the past year?  YES  NO

If YES, what kinds of changes?

- Activity level
- Social roles
- Interests
- Tendency to be more withdrawn
- Emotional changes
- Behaviour
- Response to things in the environment
- Communication level
- Eating Habits
- Sleeping patterns
- Health (health is looked at in more detail in the next two sections of the guide)



### LIFESTYLE CONSIDERATIONS

Health and longevity is related to lifestyle and predisposition to certain health conditions. Aging well depends on maintaining one's health by making healthy choices. The next checklist can help to identify aspects of the individual's lifestyle that may result in health problems and those that promote good health. After completing the checklist, a good next step is to develop a plan for helping the person adjust their lifestyle choices wherever possible.

#### Checklist on Lifestyle

Do the person's eating habits reflect awareness of and adherence to the Canada Food Guide? (For more information on the Canada Food Guide go to <http://www.nms.on.ca/Elementary/canada.htm>)

- YES  NO

If not what areas need to be changed?

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What is the person's weight and height? Is this a concern? How does it compare to the norm?

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What does the person do for exercise? IS it done regularly? If not what are the possible physical activities the person may wish to start?

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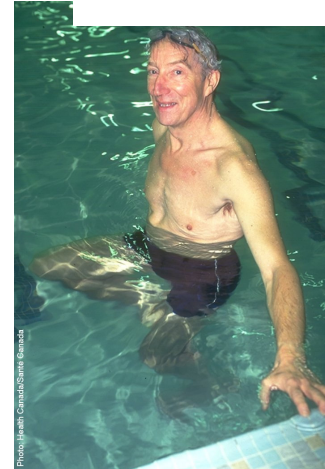
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- Walking
- Golfing (without a ride-on cart)
- Yard and garden work
- Propelling a wheelchair ("wheeling")
- Cycling
- Skating
- Continuous swimming
- Tennis
- Dancing



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- Gardening
- Mopping the floor
- Yard work
- Vacuuming
- Stretching exercises
- T'ai Chi
- Golf
- Bowling
- Yoga
- Curling
- Dance
- Heavy yard work (e.g. cutting/piling wood)
- Raking and carrying leaves
- Lifting and carrying groceries
- Climbing stairs
- Exercises (e.g. abdominal curls/push-ups)
- Wearing a backpack to carry groceries or other items
- Weight/strength-training routines



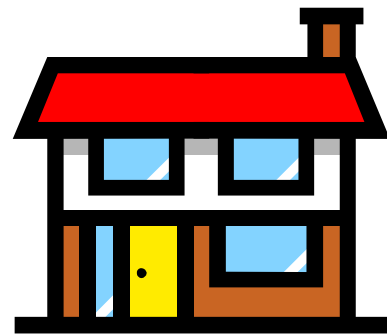
## Living Situation

Where does the person live?

- Central location close to amenities and services
- Good location close to some amenities and services
- Poor location, difficult to get to amenities and services

What are the risk factors associated with his/her place of residence?

- Air pollution
- Room mates with poor health
- Inadequate kitchen for cooking
- Street traffic
- Poorly insulated premises
- Windows/doors that do not close properly
- Water supply
- General cleanliness of the home
- Multiple levels / stairs



## HEALTH

Good health is of central importance to aging well. Health conditions will arise with aging and require attention and adjustments in routines and lifestyle. A proactive approach where the individual is involved in monitoring his/her health and active in making choices that promote good health is the best approach to avoid chronic health conditions and to identify and deal with emerging health conditions at their early stages.

The capacity of the individual to be involved and to make choices may be limited by their disability and the information to which they have been exposed. Supporting the person's health is an important part of the care giving role. The care giver is in a key position to foster understanding, acceptance and responsibility on the part of the individual towards his/her own health.

Care giving that deals with health is an area where most people have general knowledge but may not be familiar with the complexity of health issues that arise for people with developmental disabilities. The Checklist for Health that follows is not a replacement for sound medical assessment and intervention with the appropriate health care practitioner. The checklist can serve as a guide to help you in identifying some potential trouble spots in the individual's health. Your increased awareness can assist you in your conversations with physicians and health practitioners on behalf of the individual you are supporting. Finally, the knowledge you gain about the person's health situation can help you provide guidance to the individual in taking greater responsibility for his/her own

**Checklist for Health**

- |  |  |
|--|--|
| <input type="checkbox"/> Illness/injuries since last exam                  | <input type="checkbox"/> Eye trouble                       |
| <input type="checkbox"/> Ear trouble or deafness                           | <input type="checkbox"/> Nose or throat trouble            |
| <input type="checkbox"/> Hay fever-Asthma-Sinusitis                        | <input type="checkbox"/> Headaches                         |
| <input type="checkbox"/> Head injuries                                     | <input type="checkbox"/> Fainting spells—convulsions       |
| <input type="checkbox"/> Heart disease                                     | <input type="checkbox"/> Rheumatic fever                   |
| <input type="checkbox"/> Palpitations                                      | <input type="checkbox"/> Lung disease or chronic cough     |
| <input type="checkbox"/> Shortness of breath                               | <input type="checkbox"/> Indigestion                       |
| <input type="checkbox"/> Jaundice  | <input type="checkbox"/> Rupture                           |
| <input type="checkbox"/> Haemorrhoids                                      | <input type="checkbox"/> Kidney and/or bladder trouble     |
| <input type="checkbox"/> Venereal disease                                  | <input type="checkbox"/> Varicose veins                    |
| <input type="checkbox"/> Tropical diseases                                 | <input type="checkbox"/> Skin disease                      |
| <input type="checkbox"/> Back injuries / back problems                     | <input type="checkbox"/> Broken bones                      |
| <input type="checkbox"/> Foot troubles                                     | <input type="checkbox"/> Rheumatism or joint trouble       |
| <input type="checkbox"/> Bleeding disorders                                | <input type="checkbox"/> Nervous disorders                 |
| <input type="checkbox"/> Use alcohol to excess                             | <input type="checkbox"/> Operations                        |
| <input type="checkbox"/> Allergies   | <input type="checkbox"/> Drug allergies                    |
| <input type="checkbox"/> Presence of Diabetes                              | <input type="checkbox"/> Diabetes management plan in place |
| <input type="checkbox"/> Chest X-Ray                                       | <input type="checkbox"/> ECG                               |
| <input type="checkbox"/> Thyroid (especially in the case of Down Syndrome) |  |



**For Women:**

- Breast Examination
- Gynecological Examination (including pap smear)

**For Men:**

- Prostate Examination



Medications:

Name	Dosage	Purpose

**DEMENTIA**

Persons with a developmental disability may exhibit symptoms of dementia in the same way and at the same time as the general population. There is one exception. Persons with Down Syndrome are more likely than the general population to suffer with one specific form of dementia, Alzheimer Disease, and are more likely to experience an earlier onset of symptoms than the general population.

There are several types of dementia. Generally, dementia is a progressive brain dysfunction that leads to a gradual decrease in functioning and daily activities. Dementia not only affects the person with the symptoms but also their friends and family who experience the loss of the person they know.

Some facts about Alzheimer Disease (one form of dementia) and people with developmental disabilities:

- Alzheimer Disease occurs among persons with a developmental disability at about the same rate as the general population (6% of persons aged 60 years or older)
- Alzheimer Disease occurs more frequently among persons with Down Syndrome than among the general population and than among the population of persons with other developmental disabilities (the occurrence of Alzheimer Disease among persons with Down Syndrome is 25% among persons aged 40 years and older and 65% among adults aged 60 or older)

## Checklist for Dementia

The symptoms of dementia vary among individuals. The few symptoms provided in the checklist do not provide a scientifically based assessment. They can help you think about whether dementia may be a problem. If you suspect dementia you can contact the Alzheimer Society in your area for more information. You may also want to make an appointment with your family physician. In some regions of Ontario, you can obtain help from a psycho-geriatrician. Consideration must also be given to the appointment of substitute decision-makers. In all cases of suspected dementia a thorough medical examination should be carried out as soon as possible. Some other conditions mimic dementia and are amenable to treatment.

- Frequent or persistent forgetting of names of objects and people.
- Loss of recent memory (something that has just occurred such as having eaten breakfast).
- Loss of a sense of time or place.
- Decline in the ability to perform some activities of daily living (such as washing and eating).
- Personality changes (For example: an outgoing person may become withdrawn; a quiet person may exhibit increased agitation or anger over small things).



## THE ROLE OF THE FAMILY

Families are the principle care giver for most people with developmental disabilities. Often families share this care-giving role with a service provider such as a developmental service agency. The transitions that occur during the aging process may require changes in the care-giving support provided by various family members and these agencies. It is important that each family have a sense of which family members are available to share in the support and how this family support may change over time. These changes may be brought on by new needs of the person being supported, by the aging of care-giving family members and by changes in circumstances of the family.

### Checklist on the Role of the Family

Who are principle care-giving family members now and how much support does each provide?

- Mother \_\_\_\_\_
- Father \_\_\_\_\_
- Sister \_\_\_\_\_
- Brother \_\_\_\_\_
- Aunt \_\_\_\_\_
- Uncle \_\_\_\_\_
- Cousin \_\_\_\_\_
- Other Relations \_\_\_\_\_

What circumstances might impact the ability of family members to continue to provide support?

- New job
- Moving away
- Health conditions
- Lack of respite
- Need for vacation
- Retirement
- Reduction in income
- Other \_\_\_\_\_



## THE ROLE OF SERVICE AGENCIES

There are a range of services and programs for people with developmental disabilities and another variety of services and programs for older adults. Being aware of these service providers and what they offer can help you plan as the person with a developmental disability grows older. Your community may have a directory of such services or they may be listed on the Internet.

It is important to keep in mind that the legislation governing services for people with developmental disabilities is different from legislation pertaining to developmental services. This may influence how to apply to programs, the criteria for admission and the relationship between the agency and other caregivers. Generally there are waiting lists for programs, regardless of legislation or the service system in which they operate. Consequently it is important to anticipate future service needs whenever possible and plan ahead. Planning may involve becoming aware of what a program can offer, knowing the admission criteria, getting to know the contact person at the agency and visiting the program site. This can help to speed the application process along later when admission is actually being sought.

Some programs and services are also available from other providers. For example, municipal recreation departments often offer a variety of general interest, fitness and recreation programs. Local clubs and organizations may offer opportunity for members to learn new skills, meet with others who have common interests or to engage in a hobby.

## COORDINATED ACCESS TO DEVELOPMENTAL SERVICES

The Ministry of Community and Social Services established a system known as coordinated access to services for people with developmental disabilities. These coordinated access agencies handle all applications to residential services within the developmental services sector. They also keep a directory of all other non-residential support programs and can help you with finding the right agency and the contact person. For information on the coordinated access agency in your area contact the regional office of the Ministry of Community and Social Services - see the key contacts section at the end of this guide.

## COORDINATED ACCESS TO LONG TERM CARE

Access to long term care programs is coordinated by Community Care Access Centres (CCAC's). Each CCAC provides a simplified service access point and is responsible for:

- Determining eligibility for visiting professional and homemaker services provided at home and in publicly-funded schools.
- Determining eligibility for, and authorizing admissions to long-term care facilities (nursing homes and homes for the aged).
- Service planning and case management for each client.
- Providing information/referral to all other long-term care services, including volunteer-based community services.
- A variety of services that may include:

### Visiting Services

Health and support services provided in the home on a visitation basis to enable people to:

- Remain in their own homes
- Return home more quickly from hospital, or
- Delay or prevent the need for admission to a hospital or long-term care facility

### Homemaker and Personal Support Services

- Personal hygiene activities and routine personal activities of living, including assistance with walking, climbing or descending stairs, getting into and out of bed, eating and dressing.
- Homemaking Services include house cleaning, laundry, ironing, essential mending, shopping, banking, paying bills, planning menus, preparing meals and caring for children.

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### Nursing

Service performed by a Registered Nurse or Registered Psychiatric Nurse.

### Therapy Services

A variety of therapies such as occupational therapy , dieticians and physiotherapy.

### Placement Coordination Services

- Determine eligibility for admission to long-term care facilities
- Assist in finding community-based alternatives where they exist and are appropriate to an individual's needs,
- Assist a person and his/her substitute decision-maker during the admission process to ensure the best possible admission in keeping with the person's preferences,
- Authorize admission to long-term care facilities and work collaboratively with them during the admission process

All persons requesting admission to a long-term care facility must apply to the CCAC placement coordination services to have their eligibility determined. A functional assessment is required to determine if placement is required or if the person's needs can be met by community services. The CCAC may carry out the assessment or can arrange for an assessment to be carried out by a service provider in the community.

A person cannot be admitted to a long-term care facility unless he/she consents to the admission. If the person is not capable of making a decision regarding admission, the consent of a substitute decision-maker is required as described in Part III of the Health Care Consent Act.

For complete information on the CCAC in your area log on to the web site of the Ontario Association of Community Care Access Centres at <http://www.oaccac.on.ca/index.php>

## SUPPORT OPTIONS

Today's service systems for older adults and for people with developmental disabilities are under a lot of pressure due to increasing demand for services. It is not usually possible to find one service that will provide for all the needs of each individual. Moreover the needs of the person will change during the aging process and new services may be needed.

Sometimes, the idea of admission to some form of 24 hour residential program is seen as the solution to meet all of a person's requirements. However, residential programs cannot provide for every need. The person still requires other things in his/her life such as social activities, hobbies, maintaining old friendships, attending worship services, engaging in civic activities, joining a club or group, physical exercise and much more.

Planning must consider the varied needs of each individual and then find the right mix of programs and services to fill those needs and to complement support provided by unpaid care givers. This means that it is important to understand the range of services available so the best match can be made between a person's needs and those programs. However the service systems are large and complex. People who work within the systems often are not aware of everything that may be available. However the Coordinated Access Services described earlier can be a big help.

The Support Options Checklist provides you with types of programs and services to help you think about the range of services within each system and so you can ask questions when speaking with a Coordinated Access office.



Keep in mind that each community is unique and the way services are organized and delivered will vary from this list. In addition, some of the options in the list are not funded programs per se but are options to consider when thinking about living arrangements.

During the aging process, the individual you are supporting may need a mix of services that are available within both the developmental services and long term care sectors. Developmental services have the expertise to support people with developmental disabilities. However, the long term care system knows about aging and can help to maintain health and quality of life. Understanding and working with both systems gives you and the person you are supporting more options for living well. There are regional and local cross sector groups emerging in communities across Ontario to help the two sectors work together in planning for people with developmental disabilities as they age. These groups, where they exist, can offer help in accessing the options available in your community.

### Support Options Checklist

#### Developmental Services

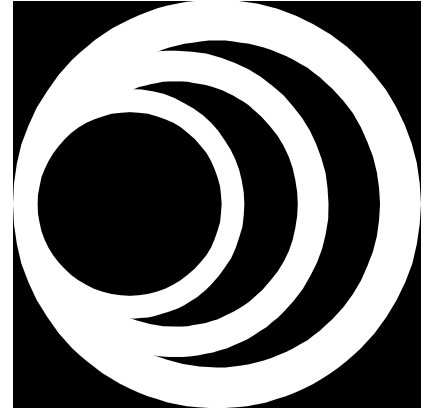
- Assessment
- Counselling
- Behaviour Intervention
- Associate Family Living
- Adult Protective Service Worker
- Special Services at Home
- Supported Independent Living
- Personal Care Attendant
- Adult Day Programs
- Summer Programs
- Social/Recreational Programs
- Evening/Week-end Social Programs
- Caregiver Respite Services
- Independent Living with Partial Staff Support (alone or with others)
- Staff Supported Residential Programs (alone or with others)
- Retirement Planning
- Volunteers / Volunteer Programs

#### Long Term Care Services

- Elderly Persons Centres (Also known as Older Adult Centres and Seniors Centres)
- Seniors Clubs
- Telephone Visiting
- In-home Visiting
- Meals on Wheels
- Wheels to Meals
- Diners Clubs
- Congregate Dining
- Foot care
- Home Maintenance Assistance
- Adult Day Programs
- Personal Support Services
- Home-making Services
- Visiting Health Professionals
- Caregiver Respite Services
- Psychogeriatric Consultation and Assessment
- Seniors' Apartments
- Seniors' Apartments with on site Support Services
- Retirement Homes
- Long Term Care Homes
- Assistive Devices and Equipment
- Home Maintenance and Repair
- Volunteer Hospice

### THE SUPPORT CIRCLE

The people involved in the care of an individual are often thought of as members of the support circle. Often these members are family, friends, neighbours and staff of service agencies. A checklist is provided to help you think about who is and who should be in the support circle.



sup-

#### Checklist for the Support Circle

- The individual (client)
- Family members
- Friends
- Neighbours
- Guardian
- Public Guardian and Trustee
- Developmental Services staff
- Long Term Care Provider staff
- Community Care Access Centre
- Developmental Services Coordinated Access Agency
- Private Support Circle Facilitator
- Case Resolution Coordinator
- Physician
- Psychiatrist / Psychologist
- Other: \_\_\_\_\_

### CONFIDENTIALITY, PRIVACY AND SHARING INFORMATION

Paid and unpaid caregivers must pay attention to legislation that governs confidentiality of information. These laws stipulate how personal information about clientele is stored and communicated. The legislation ensures that only authorized caregivers have access to the information and that the information is used only for the purposes it was collected. Authorization requires the signature of the client or the client’s guardian.

Sometimes service providers and other caregivers who are involved in a support plan can be left out of the communication loop if they are not identified in the release of information authorization. This can result in loopholes in the support plan and make it more difficult to coordinate services. It is important to identify all of the service providers and other caregivers who have a role to play in the support plan and ensure authorizations for release of information include them - or make alternative plans for their involvement. It may be helpful to also consider potential caregivers that have not previously been involved and who may be needed at this time.

Two pieces of legislation govern protection of information in Canada:

1. The Privacy Act
2. Personal Information Protection and Electronic Documents Act

For more information on these visit the web site of the Office of the Privacy

Commissioner of Canada at [http://www.privcom.gc.ca/legislation/02\\_06\\_01\\_01\\_e.asp](http://www.privcom.gc.ca/legislation/02_06_01_01_e.asp)

#### Checklist for Sharing Information

Who we wish to include in authorizations for release of information:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_





## PHYSICAL CHANGES IN THE HOME

One of the important things that can make a difference to remaining in one's own home may be the accessibility features of the residence. If a person experiences lessened mobility, stairs may pose a challenge. A person with symptoms of dementia may wander away from the home resulting in the need for electronic systems to monitor their whereabouts. It is important to consider the various accessibility features of the home and the potential of retrofitting to add new features. Some homes may lend themselves to such changes and some may not. Knowing what the potential is for the person's present home can help to plan ahead for remaining at home or moving if certain circumstances present themselves.

### Checklist for Physical Changes in the Home

#### General

- If the house is accessible via a staircase, there is room to install a ramp if required.
- Walkways are smooth and free of changes in elevation.
- Stairs if present have railings and railings extend beyond the top and bottom stair.
- Doorknobs are easy to turn (handles instead of knobs).
- If necessary a lift could be installed in the stairwell.
- The thresholds of doorways between rooms are level - there is no step up or step down when going from one room to another.
- If a wheelchair were necessary, there is room to create pathways wide enough to accommodate the wheelchair.
- There are phone jacks where they are needed if the person were unable to move about easily.
- There are sufficient outlets to accommodate additional lighting.
- If necessary a fence can be installed.
- Scatter rugs can be removed where necessary

#### Bathroom

- Ease of access to bathtub/shower.
- Need for a bath bench.
- Adequacy of wall space for grab bars around tub/shower.
- Adequacy of wall space for grab bars beside toilet.
- Need for a raised toilet seat.

#### Kitchen

- Accessibility to kitchen cupboards.
- Dining area in the kitchen or nearby.

#### Bedroom

- Distance from bedroom to bathroom.
- Presence of phone jack.

#### Living Room

- Chairs and couches are easy to get in and out of.



## ADVANCE CARE PLANNING

Getting older may require changes in how a person makes decisions about certain aspects of his/her life and the kinds of decisions that he/she must make. A change in income, loss of loved ones, dementia and chronic health conditions are some of the factors that may affect the how and what of decision-making.

It is important to prepare for the possibility of a change in decision-making ahead of time. The factors that could affect personal care and financial decisions may be gradual or abrupt. A sudden change could result in the person losing capacity to make decisions for him/herself. If there is no plan in place for substitute decision-making, the family and the support circle will be faced with a difficult challenge.

## Checklist for Advance Care Planning

This checklist is provided to help with thinking about the various decisions that must be made in setting up a plan for substitute decision-making. There is no single formula for substitute decision-making. The plan must fit the individual, the family and the support circle. Before beginning, it is important to be aware that the government of Ontario has divided the appointment of substitute decision-makers into two regulated processes known as:

1. Power of Attorney for Personal Care.
2. Continuing Power of Attorney for Property.

Each of the Powers of Attorney must be set up by the individual who wants to appoint a substitute decision-maker. The appointment is done through a document signed and dated by the person appointing the attorney. Two witnesses must watch the person do this and then must co-sign the document in the presence of that person and in the presence of each other. The resulting legal documents are known as a) Power of Attorney for Personal Care; and b) Continuing Power of Attorney for Property.

Since the Powers of Attorney are legal documents and the appointment of substitute decision-maker(s) is a very significant event, it is recommended that a lawyer be consulted in all cases. The lawyer can provide help with final wording to ensure it is done correctly and that the person's wishes are fully protected..

### Power of Attorney for Personal Care

Power of Attorney for Personal Care allows the substitute decision-maker(s) to make decisions related to personal care, such as health care, shelter, clothing, nutrition and safety.

- Describe in detail how decisions are made now.
- Review with the person, what is important to him/her (beliefs, values, preferences and wishes).
- Identify the details of what the person wants a substitute decision-maker to do in the event that he/she can no longer make decisions.
- Identify who the substitute decision maker(s) will be:

The person named for personal care must:

- Not be someone who is paid to provide the individual with health care, residential, social, training or support services unless the person is a spouse, partner or relative.
- Be mentally capable.
- Be at least 16 years of age.

The Power of Attorney for Personal Care only takes effect when the person becomes mentally incapable of making decisions for their own personal care. Government legislation also regulates that in the event no one has been appointed by the individual as an Attorney, the government may appoint a substitute decision-maker. While this provides some protection for the individual, it may be less suitable than an appointment made by the person him/herself.

### Power of Attorney for Property

Continuing Power of Attorney for Property allows the substitute decision-maker(s) to make decisions concerning banking, signing cheques, buying or selling real estate and buying consumer goods. The appointed attorney can do almost anything with the person's property that the person him/herself could do. The appointment may define limits on the attorney's power over certain property and transactions.

- Describe in detail how decisions are made now.
- Review with the person, what is important to him/her (beliefs, values, preferences and wishes).
- Identify the details of what the person wants a substitute decision-maker to do in the event that he/she can no longer make decisions.
- Identify who the substitute decision maker(s) will be.

An Attorney named for Property must:

- Be at least 18 years of age
- Be mentally capable of fulfilling the attorney responsibilities.

The Continuing Power of Attorney for Property comes into effect when the person signs the Power of Attorney document or at such other time as the person indicates on the document.

#### Naming More Than One Substitute Decision-Maker

If the person names more than one Attorney for Personal Care or for Property then they must also specify how the parties are to make decisions about personal care. There are three options available when there is more than one attorney.

- Joint Decisions - substitute decision makers must make any decisions together or jointly. No one attorney can act alone.
- Several Decisions - any one of the substitute decision makers may make a decision on his/her own.
- Joint and Several Decisions - substitute decision-makers can act alone or together depending on circumstances such as who is most readily available.

#### For Complete Information

- View and print booklets by visiting the website of Community Legal Education Ontario (CLEO) at [www.cleo.on.ca](http://www.cleo.on.ca) or order a printed copy by calling 416-408-4420.
- View and print booklets by visiting the website of the Advocacy Centre for the Elderly: <http://www.advocacycentreelderly.org/>.
- View and print copies of Ontario legislation that governs the appointment of substitute decision-making under various circumstances. There are three acts that deal with the topic: Substitute Decisions Act, Health Care Consent Act and Mental Health Act. You can access the legislation on line by typing in "Ontario E-Laws:" on your Search Engine or go directly to the site at: [http://www.e-laws.gov.on.ca/browse\\_E.asp?lang=en](http://www.e-laws.gov.on.ca/browse_E.asp?lang=en)
- Speak to an attorney.

## FINANCES

Income changes for most people when they reach older adulthood. Persons retiring from employment and receiving a pension, experience a drop in income to about 65% of their pre-retirement level. Persons receiving a fixed income on a government support program will also experience a change in income level as they become ineligible for one program and must move to others. For example a person with a developmental disability who receives Ontario Disability Support Program Income (ODSP) will have to move to a mix of federal and provincial income support programs at the age of 65.

A smooth transition in income can be achieved by planning ahead. This is important for people with developmental disabilities because a majority are receiving ODSP and living on a lower income than most of the rest of the population.



### Ontario Disability Support Program (ODSP)

ODSP provides financial support, employment support and additional benefits. Some of the additional benefits include eyeglasses, hearing aids, special diet allowance, diabetic supplies, ostomy supplies, surgical supplies, transportation to attend medical appointments, wheelchair/mobility device repairs and batteries, guide dog allowance, back to school and winter clothing allowance for dependent children, community start-up benefit, employment start-up benefit, extended health benefits and emergency home repairs. These additional benefits do not continue once ODSP payments cease. ODSP recipients will receive a letter from the ODSP office a few months before their 65<sup>th</sup> birthday informing them that ODSP payments will cease once they turn 65. The correspondence will also advise the recipient to apply for income support benefits available to seniors in Ontario and Canada, such as Old Age Security (OAS), the Guaranteed Annual Income Supplement (GIS) and the Ontario Guaranteed Annual Income System (GAINS).

The ODSP maximum income level for a single person (September 2005) is \$959.00 monthly or \$11,508.00 per year. Couples may receive up to \$1460.00 per month or \$17,520.00 per year. The table below, prepared from Statistics Canada data, presents information on the poverty levels in Canadian communities. It illustrates that persons with a developmental disability on ODSP are among the poor of Ontario before they reach retirement age. Consequently, income is an important element of Transition Planning.

FAMILY SIZE	COMMUNITY SIZE				
	Cities of 500,000+	100,000-499,999	30,000-99,999	Less than 30,000	Rural Areas
1	\$19,795	\$16,979	\$16,862	\$15,690	\$13,680
2	\$24,745	\$21,224	\$21,077	\$19,612	\$17,100

For more information on ODSP contact the Ministry of Community and Social Services provincial office at 1-888-789-4199 or visit these web sites:

Ministry of Community and Social Services [www.cfcs.gov.on.ca](http://www.cfcs.gov.on.ca)

Advocacy Centre for the Handicapped

[http://www.archlegalclinic.ca/publications/legislation/A73\\_1999\\_000709/03\\_assets.asp](http://www.archlegalclinic.ca/publications/legislation/A73_1999_000709/03_assets.asp)

ODSP Handbook available online from the government of Ontario

[http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP\\_handbook.htm](http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm)

### Old Age Security (OAS)

Old Age Security is a monthly payment that goes to most Canadians 65 years of age or older. Eligibility criteria for Old Age Security (OAS) include:

- A person must be 65 years of age or older
- Be a Canadian citizen or legal resident of Canada
- Must have lived at least 10 years in Canada after reaching age 18.

The amount of OAS paid to the individual will depend on how long they have resided in Canada. A full OAS pension may be paid to those who have lived here at least 40 years. The maximum OAS rate for all recipients is \$466.03 (September 2004). Payments usually arrive during the last three banking days of the month.

Application for Old Age Security can be made by picking up an application from any Human Resources Development Canada office or downloading it from their Internet site at [www.hrdc-drhc.gc.ca/isp](http://www.hrdc-drhc.gc.ca/isp)

### Guaranteed Annual Income Supplement (GIS)

The Guaranteed Income Supplement (GIS) provides additional money on top of the Old Age Security pension for seniors on a low or modest income. Eligibility criteria for GIS include:

- A person must be receiving OAS
- Meet the income requirements.

The supplement is based on the person's previous year's income or the combined income of the person and their spouse/common law partner. Consequently, the recipient must renew the supplement each year.

The GIS payment is added to the OAS payment each month. The maximum GIS rate for a single person is \$554.59 (September 2004). More information is available from the HRDC web site at [www.hrdc-drhc.gc.ca/isp](http://www.hrdc-drhc.gc.ca/isp) or by calling 1-800-277-9914.

You can obtain current information on Old Age Security and GIS Maximum Monthly Benefits and Maximum Allowable Income at The Government of Canada website <http://www.sdc.gc.ca/asp/gateway.asp?hr=/en/isp/oas/oasrates.shtml&hs=rzp>

### Guaranteed Annual Income System (GAINS)

The Government of Ontario provides money to seniors who get the federal Old Age Security (OAS) and the Guaranteed Income Supplement (GIS), so that they do not fall below the provincial guaranteed income level. It is not necessary to apply for GAINS.

The GAINS payment is based on an individual's income or combined income as a married couple or common-law partnership, which is reported on the GIS application, filed with Human Resources Development Canada (HRDC) or which is reported on the income tax and benefit form filed with the Canada Revenue Agency (CRA).

The specific amount of GAINS benefit is directly linked to the amount of your GIS monthly payments. GAINS payments range from a minimum of \$2.50 to a maximum of \$83.00 per month. Cheques are mailed automatically around the 25th day of each month. Direct deposit to one's bank account is also available.

For more information on GAINS visit the Ontario Government website at [http://www.trd.fin.gov.on.ca/userfiles/HTML/cma\\_3\\_6571\\_1.html](http://www.trd.fin.gov.on.ca/userfiles/HTML/cma_3_6571_1.html)

### Canada Pension Plan (CPP)

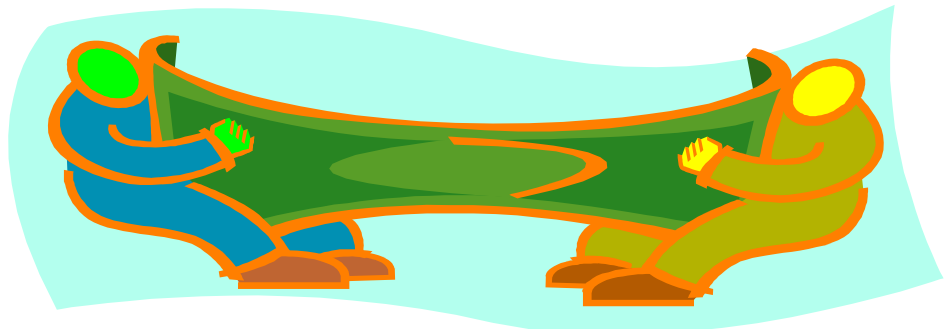
The Canada Pension Plan (CPP) is provided to persons who have paid into the fund, usually through deductions from employment income. A person may become eligible for CPP at their 60<sup>th</sup> birthday. Eligibility criteria for CPP benefits include:

- A person has made at least one valid contribution to CPP, and
- Has reached their 60<sup>th</sup> birthday and has wholly or substantially ceased pensionable employment, or
- Has reached their 65<sup>th</sup> birthday (persons aged 65 do not have to stop working to receive their CPP pension).

More information about the CPP is available by calling 1-800-277-9914 or on the Internet at [www.hrdc-drhc.gc.ca/isp](http://www.hrdc-drhc.gc.ca/isp)

### Goods and Services Tax Rebate (GST)

THE GST Rebate provides cash payments to low and middle income Canadians to help offset the costs of paying the GST on taxable purchases. The rebate amounts include a basic amount of \$213 per adult and \$112 per child and a supplement of up to \$112 for singles and single parents.



The phase-in threshold for the supplement is \$6,911 for singles without children and the threshold for the regular GST credit phase-out is \$27,749. Visit the Canada Customs and Revenue Agency for more information at: [http://www.cra-arc.gc.ca/benefits/gst\\_hst-e.html](http://www.cra-arc.gc.ca/benefits/gst_hst-e.html)

### How Much Money to Expect at Age 65

While most Canadians who are engaged in full-time employment will experience a decline in income after retirement, persons receiving the maximum ODSP payment will experience a small increase of income. However, the amount still remains within the poverty level. A comparison of pre and post age 65 amounts paid is summarized in the table below. It is important to note that these amounts are provided to illustrate the comparison. Please be sure to check current information for the specific situation.

MAXIMUM PAYMENTS	BEFORE AGE 65	AFTER AGE 65			
		OAS	GIS	GAINS	TOTAL
SINGLE PERSON	ODSP				
Monthly	\$959.00	476.97	566.87	83.00	\$1126.84
Annually	\$11,508.00	5723.64	6802.44	996.00	\$13,522.08

### Checklist for Finances

- What is the individual's current total monthly/annual income? \_\_\_\_\_ / \_\_\_\_\_
- What are the sources and amounts of this income?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
- When will the person retire or when will any other event occur that will change the level of their income?  
\_\_\_\_\_
- If the individual is receiving ODSP, when will this stop? \_\_\_\_\_
- If it is 6 months or less to the individual's 65th birthday and he/she is receiving ODSP, has ODSP sent a letter advising of the date that ODSP will cease?
- If it is 6 months or less to the individual's 65th birthday has the person files for the post retirement income to which they may be entitled?
- What are the sources and amounts of income expected at age 65?
  - Old Age Security (OAS) \_\_\_\_\_
  - Guaranteed Annual Income Supplement (GIS) \_\_\_\_\_
  - Guaranteed Annual Income System (GAINS) \_\_\_\_\_
  - Goods and Services Tax Rebate \_\_\_\_\_
  - Canada Pension Plan (CPP) \_\_\_\_\_
  - Employment Pension \_\_\_\_\_
  - Registered Retirement Savings Plan (RRSP) \_\_\_\_\_
  - Other Income \_\_\_\_\_

## BEST PRACTICES IN TRANSITION PLANNING

The Transition Task Group sought to identify best practices in transition planning and to build a model that would be helpful to caregivers and people with developmental disabilities. More than 1200 surveys were distributed across the province to service providers, planning groups and family caregivers. Just under 200 surveys were returned. The findings from the task group's research on building a model of transition planning has been summarised here to illustrate emerging best practices around the province.



### Partnering

Transition planning is not an isolated activity. It relies on cooperation among the client, paid and family caregivers, and additional service providers who may be needed to complete an evolving support plan.

### Family Involvement

All service providers and families themselves express the importance of maintaining family involvement throughout the transition planning process.

### Direct Transition Support to the Individual

Effective transitioning requires staff support to ensure orientation of the individual to a new milieu and continuity of care. The staff support must come from the agency that has a history of support with the person and be provided on the site of the program or service to which the client is moving. It is important that there is discussion to identify the amount and type of support that is needed and what can actually be provided.

### Funding

Service providers indicate that providing direct transition support requires additional resources. Some service providers are able to reallocate small amounts of existing resources for a limited period of time. However long term care providers indicate that while the support is helpful and appreciated, it is generally insufficient. Additional resources for transition planning are required.

### Training

Service providers in both sectors note that training aimed specifically at aging and developmental disabilities is a must to equip staff with the knowledge and information they need to plan appropriate support as a person ages. Unpaid caregivers also report the need for training opportunities. In some communities, groups plan regular cross sector training sessions for paid and unpaid caregivers to fill this need. The OPADD website at [www.opadd.on.ca](http://www.opadd.on.ca) offers information on caregiver support.

### Availability of Appropriate Services For Older Adults

Best practices require learning about and accessing existing services for older adults. However, each community is unique and services may be offered in different ways; it may be necessary to work with older adult service providers to help them understand and respond to the unique needs of people with developmental disabilities.

### Guidance from Funding Ministries

Regional Ministry offices may have information that can help a specific service provider or community. Keeping in touch with Ministry offices about transition planning issues and practices is part of the success formula.

## Community Care Access Centre Assessment Tools

Community Care Access Centres have the expertise to provide assessments that can inform caregivers about the current needs of an individual and track changes in these needs over time. It is important to work closely with the CCAC in your region and to include them in your planning process.

### Philosophy

Effective transition planning is based on a philosophy that puts the individual at the centre of the process and that stresses:

- Flexibility in making choices.
- Choosing living environments that support quality of life, that focus on the abilities of the individual and that provide a place where the person feels at home.
- Access to programs and services available to all Ontario seniors.
- Collaborative planning that includes all caregivers and community resources.
- Continuing to support the individual in existing “homelike” environments in the community for as long as possible; the more residential options that are available in any community, the more likely this can be accomplished.

### Key Players

Each transition planning process requires the involvement of key players who together can make the decisions and provide the resources necessary. The key players should include:

- The client
- The family
- Members of the individual’s support circle
- Developmental Services Agency
- Developmental Services Coordinated Access Office
- Long Term Care Agency(ies)
- The Community Care Access Centre.

Other players may include:

- Private Resource Facilitator
- Case Resolution Coordinator
- Physician
- Psych-geriatrician (where available and required)
- Psychiatrist
- Psychologist.

### Coordination

The transition planning process requires coordination to ensure plans are developed and implemented effectively. Since there is no single program or body that offers such coordination, each transition planning process will have to find the person or service provider who can fill this role. Some jurisdictions have cross sector planning committees on aging and developmental disabilities that can offer guidance on coordination and cross sector transition planning. Regardless of who is providing a coordinating role, transition planning requires that all members of the process have some means of regular communication and feedback such as a meeting at set intervals.





## TIPPING POINTS

The term “tipping point” is used to refer to a moment in time when circumstances warrant a change in support arrangements for an individual. Just as chronological age does not provide a clear indicator of a person’s place in the process of aging, there are no absolute “tipping points”. There is however, a way to think about “tipping points” that can help caregivers recognize when a change in support may be emerging.

There are three principal aspects of support to an individual:

1. The individual’s personal support needs.
2. The support capacity of the environment in which he/she is living.
3. The support capacity of the caregivers.



The interplay among these three factors will converge to determine a tipping point. For example an individual may show early signs of dementia. The environment in which he/she is living may be adaptable to prevent risk to the person and to others with whom he/she lives. This may involve for example, installation of a security monitoring system that lets everyone know if the individual leaves the premises. In addition, the caregivers may have knowledge about dementia that guides them in adjusting support that offsets this risk. The caregivers may have consulted with the Alzheimer Society and attended a cross sector training workshop on dementia.

Several months later the symptoms of dementia become more pronounced. This may involve, for example, aggression or disruptive vocalizations by the individual. The caregivers assess the situation and realize there are no further changes that can be made to the environment. Their assessment may confirm that they are unable to stretch existing resources any further to ensure the health and safety of the individual. They may also become aware that there are no additional resources available to support the existing situation. They have arrived at a point where the existing situation cannot be maintained and there are unreasonable risks to the health and safety of the person supported. This is a “tipping point” where they have to rethink what is possible and find a new situation of support for the individual.

Situations that may give rise to tipping points include:

- A person’s loss of capacity to perform their own personal care.
- Incontinence.
- More advanced behaviours of dementia such as aggression, disruptive vocalizations, remaining awake and agitated at night and disrupting others, excessive wandering that cannot be monitored effectively.
- Illness or death of the principal unpaid caregiver.
- Inability of the unpaid caregivers or agency to provide a safe lift or transfer.
- Increase in other support requirements beyond the capacity of caregivers or the agency to provide.
- An incident that alerts the caregivers to the potential for injury to someone or that actually results in injury.

The important thing to keep in mind about factors that give rise to “tipping points” is that they provide signs of future or imminent limitation in the support situation. When assessing the capacity of the current situation to provide what the individual needs, it is important to think about:

1. The three principal aspects of support to the individual, and
2. Current or emerging situations that may give rise to a “tipping point.”

## PREPARING FOR TRANSITION TO AN ALTERNATIVE LIVING ARRANGEMENT

Some older adults will eventually plan to move to another residential setting where their health and other support needs can be provided more suitably. In some cases the developmental services agency Usually, this will mean a move to a home setting operated by another agency and will require careful transition planning. There are three general categories of residential settings for older adults:

1. Supportive Housing  
Rental housing with possible government subsidized rent geared to income; may offer additional support services on a 24 hour basis; may also include additional optional services such as meals and social programs; does not provide 24 hour nursing or specialized health services; related forms of supportive housing include seniors affordable housing and life lease housing.
2. Retirement Homes  
Wheelchair-accessible rental accommodation with your own room or apartment; includes other optional services such as meals and social activities; is not subsidized by government; does not provide 24-hour nursing or specialized health services.
3. Long Term Care Homes  
24-hour availability of nursing care and high levels of personal care; can accommodate varying health needs with on-site supervision for personal safety; government-funded nursing and personal care; offers government subsidized accommodation; does not offer 24-hour hospital care

More information about these types of residential programs is available at the Ministry of Health and Long Term Care web site at: [http://www.health.gov.on.ca/english/public/program/ltc/ltc\\_mn.html](http://www.health.gov.on.ca/english/public/program/ltc/ltc_mn.html)

### Checklist for Transition Planning to an Alternative Living Arrangement

The decision to move is always an important one. This checklist provides a number of things to think about before a decision to move and during the transition to a new home. The checklist also covers important topics that can be addressed during planning meetings with the potential residential service provider. The checklist has been developed for use with planning a move to any type of home. You may want to cover additional issues depending on the type of home being considered.

#### Assess the Capacity of Current Services

Before arranging for alternative residential placement you will want to ensure that nothing more can be done to support the person in his/her current living arrangement.

- CCAC is involved and the individual is receiving the maximum supports available.
- Other specialized services have been accessed as needed such as geriatricians, neurologists, the regional geriatric program, Alzheimer Society, etc.
- Current service provider has maximized supports to the individual and adapted the physical environment to the extent possible.
- Service provider is concerned that current living situation and staffing level can no longer ensure the health and safety and quality of life of the individual.
- The individual has been assessed by the CCAC and/or RGP and the assessment results indicate that consideration of alternative living arrangements are required.

#### Establish a Working Relationship / Partnership with the Other Residential Provider

In the case that the current service provider does not have a partnership or working relationship with the new home, it is necessary to establish one. These are important steps to take in establishing a working relationship.

- Contact the Director of Care and introduce yourself; arrange a lunch meeting if possible to get to know one another.

## Transition Guide

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- Drop off your agency information package with a covering letter to the Administrator and Director of Care.
- Invite the Administrator and Director of Care to visit your agency and to have an initial discussion to talk about your agency, the types of clients you support and the services that you provide.
- Once you have determined that the alternative residential provider is appropriate to the needs of the particular client, set up a transition planning meeting - invite the Director of Care and other staff from both organizations who are appropriate to a transition planning meeting; speak with everyone in person or by phone to discuss the agenda prior to the meeting.
- Inform the home of the role that the family plays with their son or daughter and discuss how the home can support a continuation of this role.
- Establish the means by which support continues from your end and from the home to keep the family involved before, during and after the move.
- Arrange support to families and ensure opportunity for them to learn about the residential placement and ask questions.

### Involve Families

Some families may be very involved with their family member. Other families may be more distant. Assess the current involvement of the family to determine their potential level of involvement in the transition planning process.



- Family members are highly involved and visit their son/daughter/sibling regularly; they notice and openly discuss the changes occurring to their son or daughter with staff.
- Family members are sometimes involved; they visit occasionally and sometimes notice changes occurring with the family member; they may sometimes to discuss things with staff.
- Family members are not involved; they may visit on rare occasions or have contact by telephone only.



Assess the factors that may affect a change in the future involvement by the family:

- Ages of parents.
- Presence of siblings.
- Possible health conditions of family members.
- Travel distance between family members and the new home.
- Other.
- Family member(s) have been appointed Attorney for Personal Care or for Property.

### Inform Families

There are key points during any transition planning process where the family must be involved to the extent possible.

- Family is made aware of the challenges facing the current service provider in supporting the individual; arrangements are made to review the current situation and how it is changing over time.
- Family and current service provider acknowledge that support has been adapted to the maximum extent possible given available resources and the needs of other clientele supported by the agency.
- Service provider keeps the family members informed and aware of all services accessed for the individual including those available through the CCAC.
- Service provider discusses the possible need for the individual to move to an alternative living arrangement/long term care home when they are no longer able to be supported in their current home.
- Service provider and family discuss how the service provider can offer support to the family during the transition planning process and how provider remains involved with the individual before, during and following a move.

## Transition Guide

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### Inform Distant Families

Communication with the family must be remembered even where the family is rarely involved.

- The service provider communicates information to the distant family using the transition planning checklist; communication may be by telephone or other means that facilitates family receipt and response to the information.
- Encouragement is provided to the distant family to engage in the transition planning process and to in decision making.
- Identify the substitute decision-maker to the family where the family is not the appointed attorney.

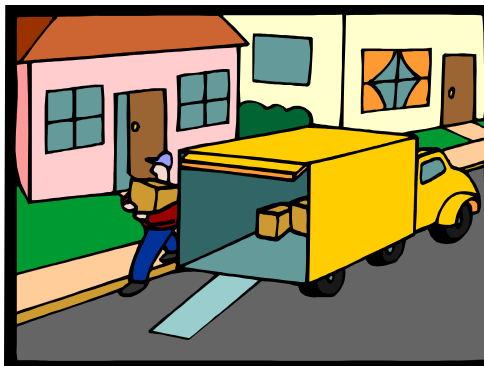


### Involve the Public Guardian and Trustee

- If there is no family, then the Public Guardian and Trustee (PGT) is involved. The PGT is to be treated as the family member - the service provider keeps the PGT informed.
- PGT is invited to all meetings including the annual planning meeting and all transition planning meetings.
- Service provider ensures that the PGT receives all necessary information about the individual's changing needs and advocate on behalf of the individual to support the PGT in making decisions that are in the best interest of the individual.
- The service provider makes the PGT aware of the individual's various relationships and living requirements including information about how the service provider's staff and other clientele fill the role of an extended family.

### Make the Decision to Move and Take the Initial Steps

- The service provider designates a staff person from the individual's support team who will take the lead with transition planning; the designate may be a manager, supervisor or front line staff depending on the service provider's strategy for supporting the process; the designate will be the key contact and will chair meetings called by the service provider.
- A meeting takes place with the CCAC Case Coordinator; the meeting serves to advise the family and individual about the role of the Case Coordinator, how the placement planning process works, begin and continue discussion of the need for a move to an alternative living arrangement and how to choose an alternative home that supports quality of life for the individual.
- The service provider may have a partnership with a long term care home or homes that have specialized knowledge to support older adults with developmental disabilities; this is explained to the family and to the CCAC Case Coordinator to ensure the most suitable residential option for the individual; the Case Coordinator should be asked to make every effort to arrange placement to a home that understands and has capacity to support older adults with developmental disabilities.
- Once a home is chosen, a plan is developed to visit the home, arrange for daytime and overnight visits by the individual as appropriate and arrange for visits by the family and members of the support circle.



## TRANSITION PLANNING WITH THE OLDER ADULT MOVING TO AN ALTERNATIVE LIVING ARRANGEMENT

It is important to establish and maintain a transition planning process with the home before, during and after the move. The following checklist provides a guide to transition planning meetings with the provider of the alternative home whether it is a long term care or retirement home or supported seniors apartment.

### Get Ready

- Identify the participants and ensure they are available to support the transition planning process; participants may include: Supervisor and/or Manager, Primary Support Worker - Residential and Day Program, Family members, CCAC Coordinator, other involved services, Director of Care from the LTC home and other appropriate individuals from the home or long term care facility.
- Set a schedule for meetings in advance if possible so everyone can reserve these dates in their respective schedules.

### Set the Agenda

The points of discussion for a transition meeting or series of meetings will vary with the needs of the individual and the paid and unpaid caregivers involved in the process. The checklist below provides a picture of many possible items that should be discussed at some point during the transition planning meetings.

### *Background Information on the Person*

- History of the individual, the factors that led to the decision to seek alternative residential or LTC placement, his/her current needs, strengths and wishes.
- History of the involvement of the family - some families have been very involved in the support of their son or daughter throughout their life, others have not; in the case of the PGT as the decision-maker ensure early involvement of the PGT staff and identify the nature of the relationship of DS agency staff to the client in the absence of family.

### *The Individual's Current Living and Support Situation*

- Living Independently
- Living at home with his/her family
- Supportive Housing
- Supported by a Developmental Service Agency (DS agency)

Current Provider Name (if applicable) \_\_\_\_\_

Address \_\_\_\_\_

Telephone number: \_\_\_\_\_ E-mail address: \_\_\_\_\_

Key contacts at current providing agency:

Supervisor and/or Manager \_\_\_\_\_ Contact Number: \_\_\_\_\_

Primary Support Worker \_\_\_\_\_ Contact Number: \_\_\_\_\_

- Other supports the person is receiving:

CCAC—supports provided via CCAC \_\_\_\_\_

Day Program - (provider name) \_\_\_\_\_

Therapeutic - \_\_\_\_\_

Medical - \_\_\_\_\_

*The Individual's Support Needs*

- Review the individualized supports needed for this individual and how these will be put in place during transition and after the move to the new residential placement.
- Determine how existing social relationships will be maintained.
- Confirm staffing during and after transition in the LTC home - identify the role and responsibilities of the staff from the DS agency when they are supporting the individual living in the LTC home.
- Confirm the plans of the DS agency for long-term contact with the client - e.g. ongoing visits by the staff and the individual's friends.
- Supports that need to be put in place while the individual is waiting to move (via the CCAC or other sources).

*Orientation*

- Arrange for pre-move visits to the home by the family, individual and DS agency staff.
- Arrange pre-move visits by the home staff to the group home.
- Schedule pre-move visits by the individual. This may be gradual beginning with day visits and extending to overnight.
- In the case of a move to a long term care home investigate possible use of respite services for overnight stays.

*Cross Sector Information Exchange*

- How the DS agency staff will train and provide information about the individual to the staff at the LTC home (this may need to be provided in different formats and on several occasions for different shifts of staff - this may also be needed to be repeated when necessary).
- Provide other information that may be needed to the LTC home such as psychological and medical reports.
- Consider how financial management has occurred in the past and how it may have to be adapted to the current living situation. (in many cases, the DS agency has managed the individual's finances; some families may wish the LTC home to take over this responsibility)

*Moving In*

- Identify what the individual should bring to the new home and what items need to be purchased ahead of time.
- Schedule the time and date of the move.
- Arrange for support to the individual during the move both at the old and new locations.

*Developing Partnerships Between the DS Service Provider and Family*

- Visits, activities, outings.
- Participation in case conferences and other meetings.
- Ongoing communication processes / protocols among the family, DS agency and residential provider.
- Involvement in decision-making regarding the support plan.
- Participation in the resolution of issues and challenges - being part of the problem-solving team - offering possible resources.
- Supporting family in finding out about and joining the family council or other participatory processes within the residential setting.

*Developing Partnerships With the Residential Provider*

- Establish and maintain ongoing communication with the family and the new residential provider.
- Inform and involve family and DS agency in significant events such as: case conferences, plan of care meetings, decisions regarding the support/care of the individual.
- Orient DS agency staff and family to the home.
- If DS agency staff are working in the home during transition or ongoing - orient and train staff about the routine, activities and any necessary policies and procedures.

*Identifying Key Contacts in the New Home and With Other Providers Involved in the Support Plan*

It is important to keep in close touch with other players in the person’s transition plan and ongoing support. Keeping a contact list of all the players and sharing it with everyone involved can facilitate smooth communication.

Residential Provider

Administrator: Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Director of Care: Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Other: \_\_\_\_\_ Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

DS Agency

Executive Director: Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Program Director: Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Other: \_\_\_\_\_ Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Family

Parents: Name \_\_\_\_\_

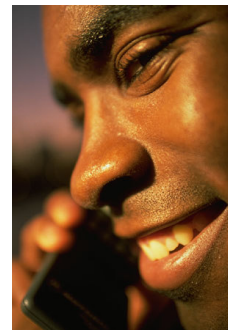
Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Siblings: Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Other: \_\_\_\_\_ Name \_\_\_\_\_

Contact Number: \_\_\_\_\_ E-mail: \_\_\_\_\_



## ADDITIONAL RESOURCES

The Internet provides a wide variety of information that can help you in your care giving role.

### ONTARIO PARTNERSHIP ON AGING AND DEVELOPMENTAL DISABILITIES (OPADD)

A provincial collaboration of developmental service, long term care, education, planning and government bodies concerned with planning and service delivery issues in the area of aging and developmental disabilities; includes information and links to many other sites in the developmental services and long term care sectors including all provincial associations, groups and organizations who are participating in the partnership project. The OPADD web site is available to regional aging and developmental disabilities committees who wish to post information on their work so others can learn from it. The site also includes information on care giving. You can link to all of the partnering organizations via the OPADD website.

[www.opadd.on.ca](http://www.opadd.on.ca)

### PROVINCIAL ASSOCIATIONS PARTICIPATING IN OPADD

Several of the fifty organizations actively involved in OPADD are provincial associations representing service providers in the long term care and developmental services sector.

Alzheimer Society [www.alzheimer.ca](http://www.alzheimer.ca)

Community Living Ontario [www.communitylivingontario.ca](http://www.communitylivingontario.ca)

L'Arche [www.larchecanada.org](http://www.larchecanada.org)

Older Adult Centres Association of Ontario (OACAO) [www.oacao.org](http://www.oacao.org)

Ontario Agencies Supporting Individuals with Special Needs (OASIS) [www.oasisonline.ca](http://www.oasisonline.ca)

Ontario Association of Non Profit Homes and Housing for Seniors (OANHSS) [www.oanhss.org](http://www.oanhss.org)

Ontario Association of Community Care Access Centres (OACCAC) [www.oaccac.on.ca](http://www.oaccac.on.ca)

Ontario Community Support Association (OCSA) [www.ocsa.on.ca](http://www.ocsa.on.ca)

Ontario Gerontology Association (OGA) [www.ontgerontology.on.ca](http://www.ontgerontology.on.ca)

Ontario Long Term Care Association (OLTCA) [www.oltca.com](http://www.oltca.com)

Ontario March of Dimes [www.dimes.on.ca](http://www.dimes.on.ca)

Ontario Retirement Care Association (ORCA) [www.orca-homes.com](http://www.orca-homes.com)



### GOVERNMENT

Ontario Ministry of Community and Social Services  
[www.cfcs.gov.on.ca/CFCS/en/default.htm](http://www.cfcs.gov.on.ca/CFCS/en/default.htm)

Ontario Ministry of Health and Long Term Care  
[www.health.gov.on.ca/](http://www.health.gov.on.ca/)

Ontario Senior's Secretariat  
[www.gov.on.ca/citizenship/seniors/](http://www.gov.on.ca/citizenship/seniors/)

Health Canada  
[www.hc-sc.gc.ca/](http://www.hc-sc.gc.ca/)

Social Development Canada  
[www.hrdc-drhc.gc.ca/](http://www.hrdc-drhc.gc.ca/)





# Ontario Partnership on Aging and Developmental Disabilities

## 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.

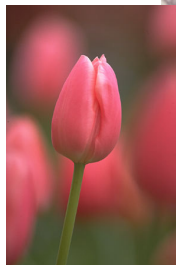
## OUR PRINCIPLES

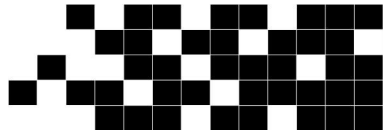
- CREATIVE OPTIONS
- CHOICE
- ACCESS
- INDIVIDUALIZED PLANNING

## LOCAL SOLUTIONS

OPADD believes that local community groups are key to producing tangible results by linking both sectors at the level of the local agency with participation from local planning bodies.

Each organization retains its autonomy and enriches its capacity to support people with a developmental disability as they age.





# Ontario Partnership on Aging & Developmental Disabilities

## Building Bridges Between the Long Term Care and Developmental Services Sectors

Development of the Transition Guide is a project of

The Transition Task Group:  
Ontario Partnership on Aging and Developmental Disabilities.

The Ontario Partnership is comprised of 50 provincial associations, regional planning groups, local projects, government ministries and planning bodies. The partnership was formed to support the quality of life of adults with developmental disabilities as they age. The partnership has received funding from the Ontario Trillium Foundation for a 5 year project on aging and developmental disabilities.



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E-mail: [rcoristine@reena.org](mailto:rcoristine@reena.org)  
Web: [www.opadd.on.ca](http://www.opadd.on.ca)