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Adults with Developmental Disabilities Experiencing or at Risk of Homelessness:

Report to Ottawa's Community Capacity Building Team

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1.0 INTRODUCTION

Anne Wright and Associates is pleased to present this report for the project: *Adults with Developmental Disabilities¹ Experiencing or at Risk of Homelessness*. Project activities were undertaken in August and September, 2005 by Associate Consultants: Bonnie Dinning (Health and Social Services Consulting) and Pamela Smit (Veradus Consulting).

1.1 Background

The Community Capacity Building Team (CCBT) identified the need to better understand the needs of adults with developmental delays in terms of homelessness, as agencies serving the homeless, were becoming aware of individuals with developmental delays in their client groups.

An urgent situation where aging parents still care for adult children with developmental delays and have limited access to services, except in crisis situations, was described in the project's Terms of Reference (TOR). A review of the TOR with the project reference group focused consultant activity on developing momentum amongst family stakeholders to address this situation. Individuals with developmental delays could become homeless during a crisis in the family home, such as the death or illness of the parent caregiver.

The consultants were asked to:

- Consult with key stakeholders;
- Review recent relevant consultations and reports;
- Identify major issues; and,
- Bring together a family members roundtable to determine a future course of action.

2.0 METHODOLOGY

Information to inform this project was obtained from key informants, a review of relevant documents and websites, and from participants, representing known family member organizations, who attended a roundtable meeting.

¹ The terms: developmental disabilities (developmentally disabled) and developmental delays (developmentally delayed) appear to be used interchangeably in the reviewed literature and by informants of this project. The term intellectual disabilities (intellectually disabled) is also used in the literature.

Information of varying relevance for two different audiences was collected:

1. Information useful to families and family member organizations and work groups wishing to work together to influence change within the developmental services sector - and prevent hidden and absolute homelessness;
2. Information useful to service providers and sector planners in two areas: a) working with/supporting family member organizations striving to address needs of adult children with developmental delays living at home and their families; and b) serving adults with developmental delays who are homeless and possibly dealing with mental health issues and/or substance involvement.

Although both audiences require similar knowledge, the detail each requires around either the developmental service sector or incidences of homelessness for individuals who are developmentally delayed, is different.

With this in mind, the information contained in the attachment: ***The Role of Family Members in Transforming Policies and Services for Individuals with Developmental Delays in the City of Ottawa: A Discussion Paper***, was developed for use by families with developmentally delayed members and family member organizations.

This report, ***Adults with Developmental Disabilities at Risk of or Experiencing Homelessness (including the attachment)***, was developed for the CCBT, and possible wider distribution at its discretion.

2.1 Key informants

Interviews were conducted with service providers, family members, organizations, municipal and provincial representatives. Some interviewed service providers represented agencies serving individuals with developmental delays, while others represented agencies assisting those experiencing homelessness or at risk of homelessness. Information was sought from agencies providing assistance to homeless and at risk individuals in order to gain some perspective on why individuals with developmental delays are using their services.

Twenty-one interviews were conducted via telephone, in person or via e-mail. Eight survey tools were developed and used to capture information from a very diverse stakeholder group.

2.2 The Literature Review

The literature review focused on materials provided by key informants about the current status of developmentally delayed services in Ontario. Several websites were also reviewed seeking information about developmental services, tools to

support community collaboration in influencing change, and studies about or services for individuals who are homeless and developmentally delayed.

A secondary literature review about housing options used the results of searches previously undertaken by one of the consultants. That review informed the development of a document on housing options contained in Appendix B of the attachment.

2. 3 Roundtable Meeting

Families with developmentally delayed members, and family member organizations and work groups, similar to any stakeholder group wishing to affect change, require a solid understanding of the existing sector capacity and associated challenges. A discussion paper containing such information was developed and previewed with family member organization representatives at an evening roundtable meeting on September 20th, 2005. The final version of: *“The Role of Family Members in Transforming Policies and Services for Individuals with Developmental Delays in the City of Ottawa: A Discussion Paper*, contains input from the roundtable process and is attached to this covering report.

3. FINDINGS AND OUTCOMES

3.1 Housing and Supports for Adult Children with Developmental Delays Living at Home

The roundtable meeting concerning developmental services provided an opportunity for invited participants and the investigating consultants to dialogue about:

- ✓ Existing issues and gaps;
- ✓ Desired changes in policy and services;
- ✓ Key developments and opportunities at the federal, provincial and municipal level;
- ✓ Possible actions to influence change; and
- ✓ Next steps for those in attendance.

According to participants, this was the first time family member organizations had come together to discuss the developmental services sector and possible actions.

The possibility of forming an alliance of family member organizations and work groups was explored and unanimously supported by participants. The potential of linking with service providers effectively was also discussed. Providing informed input into the developmental services sector planning process emerged as an immediate and time sensitive goal.

At the end of the Roundtable meeting participants reflected on the process and commented:

- The CCBT has lit a fuse that we now need to follow through on.
- We need to develop community capacity across the city.
- This provides an opportunity to comment on the developmental services [planning] process.
- We need to look at addressing other issues besides housing.
- We, as aging parents, need funding support to help us organize and apply pressure where needed in transforming developmental services.
- We need additional assistance to help us get coordinated. Strong facilitation is needed.
- This was a great learning experience. The numbers [those not receiving services] are frightening. If organized, we can make a difference.
- Scared but encouraged as this had been a long time in coming.
- I hope that families can come together and support each other to work together.
- This document should be circulated to all developmental service agencies and their boards

Representatives of the Families Matter Cooperative agreed to receive the final version of the discussion paper, and the names and contact information of those in attendance, for the purpose of organizing subsequent meetings about the proposed alliance. Skilled and neutral facilitation was identified by all as the critical requirement to achieving a collaborative partnership amongst diverse family member organizations.

3.2 Individuals who are Developmentally Delayed & Homeless

It was beyond the capacity of this project to capture sufficient data from informants to understand what proportion of individuals who are homeless in Ottawa, are also developmentally delayed. A rigorous literature search about developmental delays/disabilities and intellectual disabilities (including causes, solutions and incidence) was also beyond the scope of this project. A limited internet search was undertaken.

Three key findings emerged from the information collected:

- There is evidence of the existence of individuals in Ottawa who are developmentally delayed and homeless;
- Some individuals who are developmentally delayed and homeless in other cities are receiving specialized services; and
- Homeless children are at high risk of developmental delays.

3.2.1 Literature Review

A limited number of documents available on the web indicate that some agencies in Canada, the United Kingdom² and Australia are assisting individuals who are developmentally delayed and homeless. The small listing of search results may indicate that this is either an understudied or unrecognized phenomenon, or not considered of sufficient magnitude to warrant multiple studies.

Staff of the Street Health Nursing Foundation at Regent Park Community Health Centre and Surrey Place Centre in Toronto³ documented their findings over 3 years in conducting a drop in, support group for women with developmental disabilities who are poor, homeless and socially marginalized. They described participants as coming from a different culture and sharing increased vulnerabilities not experienced by their other homeless clients.

An Australian document⁴ provided more detail about the vulnerability of individuals who are developmentally delayed and homeless:

- They are victims of financial, emotional, and sexual abuse as their desire for friends and relationships leaves them open to exploitation.
- They are isolated due to poverty, low self esteem, and previous experiences that make them afraid to connect with others.
- They have difficulty negotiating the steps to access community services. When these individuals do access services they are often banned for exploiting provided services or lying to get services.
- Discrimination routinely denies them access to accommodation, employment and recreation. When accommodation and services are lost, their lives are so stressful that their mental health is affected.

² Homeless Persons who are Intellectually Disabled, Frail, Aged and Transient, 1993. U.K. Paterson, K.E.

³ Community Women's Circle: A Partnership Program Developed to Connect and Serve Homeless, Poor and Socially Marginalized Women with Developmental Disabilities. Cheryl Bedard, Caroll Drummond, Josie Ricciardi, and Fiona Husband. Journal On Developmental Disabilities, Volume 10, Number 1, 2003

⁴ Particularly Vulnerable: An Outreach Model for Supporting Young People with a Learning Difficulty/Intellectual Disability Who are Homeless. Sarah MacDonald, Mischelle Surawski. At Risk Resource and Outreach Service, QLD. Australia

Two American documents raised concern about the impact of homelessness on child development. One stated homeless children are at high risk of developmental delays⁵. A second⁶ noted that one-half of the homeless children studied were developmentally delayed, compared to 16 percent of poor but housed children.

3.2.2 Key Informants

Key informants within the developmental services sector were unable to describe any incidences of absolute homelessness within their client groups. However, information provided about the plight of 8 individuals who remain hospitalized due to the lack of specialized housing they required, provided an example of hidden homeless.

One key informant indicated that individuals with developmental delays who are homeless have mental health issues and therefore were served through mental health services. He also said that mental health services were not adequate to serve dually diagnosed⁷ individuals. Another key informant commented that a senior provincial representative told him that there were no developmentally delayed individuals who are homeless. Statistics provided by the province about ODSP recipients in Ottawa, and contained in the attachment to this report, appear to support this viewpoint. It documents that no individuals with developmental delays, and receiving ODSP, are homeless. Yet, one developmental service agency previously had an outreach worker who assisted those with developmental delays using Ottawa shelters. That position was eliminated several years ago due to budget cuts.

A different story emerges from informants at agencies providing services to homeless individuals, or to individuals who are dually diagnosed.

Their comments, which follow, confirm a situation where some individuals are developmentally delayed and homeless in Ottawa:

- Individuals with developmental delays are currently over-represented in the shelters (i.e. they perceive that even one client with a developmental delay in a shelter for homeless individuals is one too many). Their pathway into homelessness is usually the result of sporadic school attendance - hence undiagnosed, or an older individual who is mildly retarded/high functioning and lacked formal assessment as it was not available when they were in school. This problem remains under detected in the shelter population as long as the person is quiet and does not cause

⁵ Otitis Media and Early Development in a High Risk Pediatric Population. Ray Grant, Lourdes Lynch PhD, Peter Sherman MD, Irwin Redlener. U.S.

⁶ Equity and Opportunity: Addressing the Needs of Homeless Students. John H. Holloway, Educational Leadership, Volume 60 Number 4, January 2003, Pages 89-90

⁷ Refers to individuals who are developmentally delayed and mentally ill

too much trouble. It's often not clear how these people get lost from developmental services since they are such poor historians.

- Individuals who are homeless have come to the attention of the Dual Diagnosis Consultation Unit at the Royal Ottawa Hospital (ROH).
- Some individuals who are homeless and mentally ill, and assisted by the ROH Psychiatric Outreach Team, are then diagnosed as being developmentally delayed.
- There is a big crack in the developmental sector regarding services for those with dual diagnosis according to one informant.
- 10% of the clients housed and receiving mental health support from one agency are dually diagnosed. Another agency assisting those at risk of homelessness currently houses 4 or 5 residents who are most likely mildly retarded. The informant noted that they have all kinds of complications in their lives but they thrive there because their needs are being met.
- There is no screening tool that front line workers in the homeless sector can use to identify those with developmental delays. Training frontline workers around '*community function*' may be useful in helping identify those who are homeless and developmentally delayed. This may provide an opportunity to bring them to the attention of appropriate professionals.
- One informant estimated having had 15-20 individuals with diagnosed developmental delays accessing that agency's day services in the last 7 years. One was described as living with an elderly and ill brother and just now being diagnosed. Concern was expressed he may become lost in the homeless sector before other arrangements can be made. Another informant was aware of 5-10 individuals in the past year seeking help with housing. Some individuals wanted to leave their parent's home and appeared to have no avenues of assistance. Others were involved with Service Coordination. Many lived on their own, and some called a rooming house "home". One man who was being abused was able to receive alternate housing as a result of assistance by a housing worker with a mandate to assist low income and homeless individuals.
- Gaining access to services and programs for the developmentally delayed for our homeless clients has been very difficult according to one informant. There has been extreme reluctance to extend services to those with addictions.

- One informant described a situation in which she became involved with an individual moved to Ottawa from Rideau Regional who had become homeless.
- One agency has provided services for those who were diagnosed as developmentally delayed but kicked out of developmental delay services due to violence and addictions. The agency has also assisted those who appear developmentally delayed but have never been diagnosed.
- One informant stated she had not had any success in obtaining resources for clients from the developmental service sector. She was also not aware of any housing which is accessible for this population once they have become homeless.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1 Housing and Supports for Adult Children with Developmental Delays Living at Home

The provincial government is working to transform developmental services in Ontario. Regional consultations about the proposed plan are expected this fall.

By funding this project, the CCBT is providing a timely opportunity for families with developmentally delayed individuals to organize and provide a consolidated voice to the provincial government about what is needed by families in Ottawa.

The attached discussion paper provides information that can help families develop a well informed position. The Families Matter Cooperative is willing to schedule meetings with family member organizations as a follow-up to the September roundtable meeting. However, neutral facilitation of those meetings is needed to establish areas of consensus and to prepare for evidence-based dialogue with local service providers and eventually the province.

Circulation of the complete report to the developmental services sector may stimulate productive discussion between families and service providers. Agreement between families and service providers on some aspects of what is needed locally can only strengthen messages delivered during the consultation process. This in turn can affect the final blueprint directing how developmental services will be provided in Ontario in the future and ultimately prevent or end homelessness for some.

Beyond influencing policies, there is a real desire amongst family member organizations to establish models of housing and supports that leverage the resources of families, government and providers. They seek collaborative working relationships with developmental service agencies and governments to move this agenda forward. Current attempts by families and family member organizations, working in isolation or with agencies, are not succeeding.

4.1.1 Recommendations

1. Consider making additional short term funding available to assist with the start-up, organization, and facilitation of an alliance of family member organizations.
2. Request that the City of Ottawa facilitate discussions between all levels of government, the new alliance of family member organizations and developmental service agencies - for the purpose of identifying and/or creating opportunities where family resources can enhance housing solutions for individuals with developmental delays.
3. Circulate this report and its attachment within the developmental services sector.

4.2 Individuals who are Developmentally Delayed and Homeless

Information gathered for this project confirms the existence of individuals who are developmentally delayed and homeless. The magnitude of the situation and a complete understanding of their pathways into and possible pathways out of homelessness remain outstanding items of investigation.

This report and its attached discussion paper contain information that may prove useful to agencies, planners and government officials in a variety of sectors regarding the needs of those with developmental delays. Circulation to sectors such as those responsible for mental health services and addictions treatment may encourage those sectors to seek avenues of input into the developmental services sector planning process regarding ways to eliminate inter-sectoral gaps.

4.2.1 Recommendations

1. The CCBT consider a research project to further investigate the incidence of homelessness amongst those who are developmentally delayed.

2. Agencies providing services to the homeless ensure that front line staff receive awareness training around issues of developmental disabilities including key indicators of disabilities and community agencies for referral.
3. Circulate this report and its attachment to sectors that, purposefully or by default, provide services to individuals with developmental delays who are homeless or at risk of homelessness.

Attachment 1

Role of Family Members in Transforming Policies and Services for Individuals with Developmental Delays in the City of Ottawa: Discussion Paper



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Forward

This discussion paper was developed for family members of adults with developmental disabilities and other stakeholders seeking to enhance services and supports (particularly housing services) for individuals with developmental delays. It provides a common foundation for dialogue and working together to influence change.

A roundtable meeting on September 20, 2005, provided family members representing various interests and organizations an opportunity to begin such dialogue. Those attending determined that an Alliance of Organizations provided the best structure to support collaborative energy.

The key goals of the Alliance will be to:

- Influence the policies and direction of government with an initial focus on the transformation agenda currently being undertaken by the provincial government;
- Work together to develop appropriate family driven models of housing, services and supports for adults with developmental disabilities whose needs are not currently being addressed.

The anticipated membership of the Alliance will be: members of existing family member groups seeking change in services and supports for adults with developmental disabilities; and Board members and members of Developmental Services Agencies in Ottawa.

To move forward in establishing the Alliance, Roundtable participants identified the need to:

- Determine which individual or groups would assume initial responsibility for forming the alliance;
- Identify a respected chair of the alliance and neutral facilitation support;
- Identify what organization could provide a secretariat function for the new Alliance; and
- Pull together an initial meeting of the range of organizations who could participate in the alliance.

While the final discussion paper was to be sent to all participants in the Roundtable, it was agreed that Families Matter Cooperative would officially receive the document and accept responsibility for organizing the first meeting of the Alliance.

It was also agreed that the report should be widely circulated to developmental services organizations, staff in the City of Ottawa and the provincial government. It was recognized that many stakeholders are keen to see family members actively engaged in creating a developmental services system that works with and for their loved ones.

In addition to the formation of the Alliance, participants in the Roundtable discussion came to an agreement on their approach to working with Developmental Services Agencies. Participants

acknowledged the challenges that agencies experience in a climate of restraint and limited resources. Where there may be differences of opinion on service models and resource utilization, the real challenge for all interested stakeholders is to enhance resources to respond to those who currently do not have access to services. Families and developmental services agencies have a common goal of seeking to ensure that adults with developmental disabilities have a secure future and that they can optimize their quality of life.

We are pleased to have been instrumental in supporting family members to establish a platform for moving forward together to make a difference. This initiative appears to have taken place at just the right time. The province has embarked on a transformation agenda and family members in Ottawa are seeking a new approach to working together to influence change.

We wish you well as you strive to meet the needs of your loved ones.

Bonnie and Pamela

1.0 Introduction

The first draft of this discussion paper was developed to support discussion and shared analysis amongst family members who agreed to participate in a roundtable discussion about the housing and associated supports needed for adults with developmental delays living within the City of Ottawa. Those invited were family members or existing family group representatives actively working to influence how housing and supports are provided. Names and organizations were identified by those interviewed for this project.

It was the intention in planning the roundtable that parents/family members develop a shared understanding of the potential for working together to influence change given a common understanding of issues and potential opportunities. This final version of the discussion paper is intended to provide a foundation for further dialogue

The discussion paper provides information about:

- Existing service capacity and associated challenges;
- Desired changes in policy and services;
- Key developments at the federal and provincial level;
- Possible actions to influence change;
- Opportunities to build on; and,
- The conditions or supports to enable parents/family members to successfully influence change.

The questions raised in the discussion book were intended to stimulate thinking of family members engaged in the Roundtable Discussion. They will continue to serve that purpose as others become engaged in influencing change in the Developmental Services System.

Some of the additional information gathered through the Roundtable Discussion has been incorporated into the discussion paper.

A final report along with this discussion paper will be submitted to the Community Capacity Building Team (CCBT) of the City of Ottawa with recommendations for future action.

2.0 Background

The Community Capacity Building Team (CCBT) of the City of Ottawa is developing a comprehensive Community Action Plan on Homelessness in Ottawa. Adults with developmental delays are one of the areas that are being explored. This priority was identified through consultations with a number of key stakeholders concerning the CCBT project. It has also been the subject of brief discussions at CCBT meetings and an ad hoc Roundtable meeting. The focus has been on the urgent situation of aging parents still caring for adult children with developmental delays at home and the potential this creates for homelessness.

The CCBT has identified the need to better understand the needs of adults with DD in terms of homelessness and stimulate action to influence change. The CCBT has recognized that while various individuals and groups working in an ad hoc fashion have attempted to advance the subject and to advocate for the affected adults; there appears to be no effective unified centre or group effectively defining the issues and advocating with a plan.

The CCBT recognizes that adults with developmental delays who are in crisis obtain services on an urgent basis but that the challenge appears to lie in determining a course of action for those on the edge of a crisis, those at risk of falling between the cracks – the hidden demand.

The CCBT determined that facilitation was needed to bring the pieces of the picture together and to develop a momentum amongst parental stakeholders, in particular. A consulting team was hired to determine a course of action with stakeholders.

source: Terms of reference for the Consulting Assignment & key informant interviews

3.0 Process

The process has been largely directed toward establishing a foundation from which key stakeholders can work together toward change if they so choose.

Twenty one interviews were conducted with a number of key stakeholders representing parents/family members, housing and support service providers, provincial government representatives and local and provincial associations. Appendix A outlines the list of people interviewed.

A review of relevant background documents was also conducted to provide the necessary baseline of information.

The discussion document was prepared in advance of the roundtable to guide the discussion that evening but also to serve as a baseline for further discussion.

4.0 Profile of the Adult population with Developmental Disabilities

The population of adults with developmental disabilities is diverse. Adults and their families have diverse needs and interests as reflected by their:

- Varying levels of ability or disability;
- Varying levels of parent/family ability to provide support to the adult with the developmental delay;
- Varying levels of family income which can be dedicated to supporting their son/daughter in the long-term;
- Different preferences in the services/supports desired; and
- Varying access to existing housing and the associated services/supports within the current system given long waiting lists.

4.1 Estimated Prevalence of Adults with Developmental Disabilities in Ottawa

The actual prevalence of adults with developmental disabilities in Ottawa is unknown. Consideration has been given to possible indicators.

Estimated Prevalence using Census Statistics – 2001

It is estimated that approximately 1% of the population of Ontario has a developmental disability. Using that as a guideline, Census Statistics from 2001 would indicate that there are approximately 5779 adults with developmental disabilities in Ottawa. This estimate needs to be considered with some caution. The rate may be higher given that larger cities often attract residents with needs that are not being met within rural communities. The number may also be lower given that adults with developmental disabilities frequently have a shorter life span than others. There are likely fewer people with developmental disabilities in the older cohorts.

Estimated Prevalence using ODSP Data – 2005

A profile of ODSP recipients indicates that there are 2,124 adults with developmental disabilities receiving ODSP in Ottawa. A detailed profile is provided in Appendix E.

Not all adults with developmental disabilities are recipients of ODSP. There are a range of possible reasons for that including: some are not aware of possible entitlement; some families do not seek assistance; some adults with developmental disabilities have not been diagnosed – often as a result of early drop out from school; and some adults are considered ineligible.

Estimated Prevalence – Adults with DD Census Statistics - 2001		
Age Grouping	# Adults -Ottawa	Estimated # Adults with DD - Ottawa
20-24 years	53,680	536
25-29 years	56,010	560
30-34 years	59,435	594
35-39 years	68,925	689
40-44 years	67,290	672
45-49 years	60,030	600
50-54 years	54,890	548
55-59 years	39,370	393
60-64 years	29,860	298
65-74 years	48,010	480
75 +	40,890	409
Total		5779

5.0 Profile of Existing Services

Services Coordination des Services maintains an inventory of existing services. Their information indicates that there are 15 developmental services organizations offering services for adults with developmental disabilities. Ten of these organizations provide residential services, nine provide day supports, three provide transportation and two engage in community outreach activities.

Developmental Service Agencies Serving Adults in Ottawa						
Organization	Residential	Day Supports	Respite	Transportation	Community Outreach	Other
Association pour L'Intégration Sociale	X	X	X	X		X
Christian Horizons	X	X				
Citizen Advocacy						X Various Advocacy Programs
Canadian Mental Health Association						X Dual Diagnosis Service (Brokerage Service)
Innovative Community Services	X					
L'Arche	X	X				
Ottawa Carleton Association for Persons with Developmental Disabilities	X	X	X	X	X	
Ottawa Carleton Lifeskills	X	X				
Ottawa Foyer Partage	X	X				
Ottawa Rotary Home			X			
Service Coordination des Services	X Funds Only	X	X Funds Only	X		X Worker Bank
St. Stephen's Residence	X					
Tamir						
Total Communication Environment	X	X	X		X	
Y's Owl Maclure		X				

5.1 Residential Options

There are several residential options available to adults with developmental disabilities: group homes, supported independent living, time share, and family home. Developmental Service Agencies have a combined capacity to serve 733 adults.

Residential Services for Adults with Developmental Disabilities in Ottawa				
Organization	Group Homes	Supported Independent Living	Other	Actual Capacity
Association pour L'Intégration Sociale	26 (26%)	27 (27%)	47 (47%)	100
Christian Horizons	59 (87%)	9 (13%)	0 (0%)	68
Innovative Community Services	6 (100%)			6
L'Arche	27 (27%)	1 (1%)		28
Ottawa Carleton Association for Persons with Developmental Disabilities	90 (35%)	120 (47%)	47 (18%) time share- 2; family home-34; apartment -11	257
Ottawa Carleton Lifeskills	50 (54%)	18 (20%)	24 (26%)	92
Ottawa Foyer Partage	9 (100%)	0 (0%)	0 (0%)	9
Service Coordination des Services	42 (57%)	0 (0%)	32 (43%)	74
St. Stephen's Residence	6 (100%)	0 (0%)	0 (0%)	6
Tamir	29 (83%)	6 (17%)	0 (0%)	35
Total Communication Environment	57 (98%)	0 (0%)	1 (2%)	58
TOTAL CAPACITY				733

5.2 Capacity Relative to Demand

Service Coordination des Services maintains a community registry of people with developmental disabilities who require service. The community registry identifies what level of service people require. Appendix F shows how many people require what level of service for how many hours. As of September 15, 2005 there are 519 people seeking services: 77 people waiting for Level 1 service; 214 waiting for Level 2 service; and 228 waiting for level 4 services. Level 3 service identifies people who are being served but desire a change.

Not all adults with developmental disabilities who desire/require service are expected to be identified on the community registry. In some cases families are not ready to identify a need for support – some have been identified as families with parents who are aging and resistant to planning.

Using the ODSP data of 2,124 as an indicator of prevalence it would suggest that there are sufficient residential supports in the Ottawa system to serve 33% of adults with developmental disabilities. Using Census Statistics as an indicator it would suggest that there are sufficient residential services to accommodate 12.6%. The real number is likely somewhere in between. Given the diversity of adults with developmental disabilities this does not mean that residential options are required for all of those people but it would suggest that the current level of residential options is insufficient.

6.0 Vision

In speaking with key informants and reviewing the literature, there appears to be significant congruence in the vision of what family member groups, associations and providers are seeking for people with a developmental disability.

Responses to the vision put forward in the Preliminary Discussion Paper on October 2004 by the Joint Developmental Services Sector Partnership Table have been positive.

Is there agreement with the vision that has been put forward?

“Persons with disabilities participate as full citizens in all aspects of Canadian society. With commitment from all segments of society, persons who have a developmental disability will maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation.”

(adapted from In Unison: A Canadian Approach to Disability Issues (1998) “

Developing a vision is the 1st step in uniting people towards a common purpose.

A successful vision:

- gives a sense of the future
- guides decision making and strategy
- creates a shared purpose
- provides guidelines that determine behaviour
- inspires emotion
- connects to values

The 2nd step is to determine the group's role or mission in working towards that vision. Determining how the group will conduct itself, based on its values, is the 3rd step.

7.0 Gaps in Services and Supports

In exploring gaps in service and challenges, key characteristics of the system desired by families have been identified. The characteristics are largely congruent with comments by agency and government informants, and key documents of associations of providers and family groups.

Families are seeking...

- A range of different services and supports across a continuum that reflects varying interests, abilities, personal/family choice and enables people to participate fully within the community
- Life long planning and support that builds on people's strengths, abilities and interests as they change over a life span
- Fair and adequate access to services, supports and funding
- High quality services that are evaluated, based on best practice and support the vision of inclusion
- Access to specialized services - medical, behavioural
- Recognition, respect and support for the families role

Through key informant interviews a number of gaps in service related to housing and the associated supports were identified. Given that this initiative is not intended to be a comprehensive review of services and supports the gaps identified provide a foundation for discussion.

7.1 Continuum of Services/Supports

- People seek choice in their housing options. Different people would like to have access to different housing arrangements that match their interests and abilities. Appendix B outlines possible options.
- As developmental services evolve from an institutional focus and a community-based approach to a citizen oriented approach, the expectations of adults with developmental delays and their families have changed. Demand for housing options that permit greater integration opportunities is evident. There is a perception amongst parents that this requires a paradigm shift for providers.
- Some families seek a shift to an individualized funding model which will enable them to purchase the services and the supports they require/desire from existing service agencies or other providers. Families indicate that an individualized funding model will provide maximum choice, enable them to customize supports, pool resources and create new solutions to housing.
- Some families perceive that the move to a single point of access results in families having less control and choice of services for their son/daughter. They would like more direct connections to providers. For example parents seek input into the compatibility & interests of individuals who move into group homes.

Questions to reflect on...

Are there other gaps related to housing and associated supports that have not been identified?

What types of housing and supports do we need more of or less of in Ottawa; and, what evidence supports this?

The Province has made a commitment to transform services for developmentally delayed individuals. Representatives say it will address the inequity of resources, increase flexibility and make it fair for all families.

What benchmarks do families want to have in place to monitor if this is happening?

7.2 Fair and Adequate Access to Services, Supports and Funding

- Many individuals and their families are not receiving the services and supports they need now. Families seek to reduce/eliminate waiting lists. Access to housing and associated supports and day programs are the key issues.
- The rationing of the system results in some families receiving service and others with similar challenges and issues not receiving any support/services. This inequity has created considerable frustration particularly for parents who are aging and are feeling more desperate to establish a suitable living arrangement for their son/daughter.
- Access to Services at Home funding is also rationed so some families do not have access to the funds they need while sons/daughters live at home.
- Individuals with the greatest need receive priority service. While people want those in need to be served, families perceive that this crisis approach actually costs the system more in the long run.
- Many families have and continue to be willing and able to assume financial responsibility for their son/daughter yet there are limited mechanisms for parents to contribute funds in a secure manner eg. tax shelters, housing equity.
- Capital funding does not appear to be as much of an issue as operating funds
- Funding is needed to address the range of support needs. Federal-provincial housing agreements do not take into account supportive housing needs. Families have different opinions about what the system should be expected to contribute to support their son/daughter and what they can be expected to contribute.
- Families seek increased funding levels in ODSP so individuals have more resources to enable them to choose housing options.
- Recent policy changes now allow basement bedrooms in group homes where health and safety requirements are met. Unfortunately restrictive municipal by-laws can increase the costs of housing stock forcing new building into the suburbs. Increased transportation costs are one of the outcomes.
- Francophones have relatively reduced access to day programs offered in French when compared to that available to the English speaking population .

7.3 High Quality Services

- Families seek an enhanced focus on evaluation of services to determine what services are meeting client needs and are directed toward supporting inclusion. Families would support funding mechanisms that offer preferential funding to service and support options geared toward inclusion.
- Families want to ensure existing limited resources are being used effectively.

Questions to reflect on...

What models of housing and associated support in other sectors (such as provided to those with mental illness) should be considered for use in the developmentally delayed sector?

Housing with nonprofit housing providers such as Nepean Housing and a partnership between a Cornwall non-profit housing provider and the local Kinsmen Club were mentioned as innovative approaches to housing those with developmental delays. Can these models provide any new information about effective housing options?

7.4 Life long Planning and Support

- Families are seeking enhanced flexibility from providers and a move toward individualized person-centred planning. They would like providers to be more flexible, responsive and willing to listen to the uniqueness of individual family situations.
- There is a perception that a more individualized approach will ensure people get as much support as they need but not more support than is actually required/desired. Interest was expressed in the CMHA model of providing flexible support for people with mental health issues. There is a perception that considerable resources are dedicated to assessment and diagnosis that does not translate to access to concrete services. At the same time there is a need for long-term planning for people to accommodate changing needs.

7.5 Specialized Services

- People with behaviour challenges are sometimes accommodated in group settings such as group homes which do not have the staff to meet their needs. The behaviours have a negative effect on the living experience of other clients. Families seek appropriate housing models for people with behavioural issues.
- Services are set up in silos and some services such as medical services are not accessible to people with developmental disabilities. This can limit people's options for living arrangements given certain supports are needed.
- Some people with developmental delays are using shelters and services for the homeless. Their needs have not been addressed. Others such as those developing dementias associated with aging are inappropriately housed and lack access to more appropriate housing and supports for seniors. Other individuals who are developmentally delayed and mentally ill remain hospitalized because their housing needs cannot be met.

7.6 Recognition, Respect and Support for the Families role

- Families seek the opportunity to be actively engaged in decisions related to their son/daughter. Some families are willing to be intensively involved in planning and in some cases providing care.
- Families seek family oriented case management and to be recognized as integral to their loved one's life and an essential resource in conjunction with system funded services and supports.

Questions to reflect on...

Is there a clear understanding of what is needed? Can agencies undertaking assessment and diagnosis of individuals with developmental delays produce reports about what is needed in Ottawa and what is not available?

What are the avenues for person- centred planning currently available?

Is there agreement that services are needed from other sectors such as health, long term care, education, housing to adequately meet needs and make best use of resources?

What role can or should families play when their assistance is not welcomed by their family member?

8.0 System Capacity Challenges

Interviews with providers and government representatives and a review of core documents⁸ written by provider groups allowed for the identification of key system capacity challenges. Reduced or constrained revenue coupled with increased demand has created a situation in which providers have:

- Limited flexibility to respond to new situations and demands;
- Decreased opportunities to expand programs and services;
- Reduced programs; and
- Enhanced focus on people who are more at risk/vulnerable.

8.1 Reduced/Constrained Revenue

Revenue challenges that have been identified include:

- Operating expenditures have exceeded revenues. Cuts in budgets in 1994-95, 0% increases for 10 years, and a limited 0.5% increase in 2004 have stressed agency budgets.
- The \$75 million made available province-wide for salary enhancements did help to ease staffing pressures however salaries continue to be low and the sector has experienced a loss of trained staff.
- To avoid operating deficits a number of strategies have been used to manage staffing costs including reductions in management and administrative capacity, movement toward more part-time staff and clustering of clients to reduce staffing needs.
- Agencies, particularly older agencies, have older infrastructure. Balancing budgets by reducing or deferring expenditures on replacements, repairs and maintenance means housing stock continues to deteriorate.
- Agencies have limited operating expenditures resulting in more limited travel and outings for clients and reduced/not increased food and household supply budgets; and
- More responsibility for clothing and personal needs of individuals is passed onto family members.

Questions to reflect on...

*Are recent funding announcements sufficient to provide more housing and associated supports to the number now needing them?
(See Appendix D)*

⁸ Eakin, L., and Thelander, M. for Metro Agencies Representatives Council, *Beyond Numbers: The Implications of Financial Restraints and Changing Needs on Developmental Services*, February 2005

Reena, *Successfully Transforming Services in Ontario: The Social Policy challenges involved in expanding the continuum of care for people with developmental disabilities*, date – unknown

8.2 Increased Demand for Service

At the same time as revenues have been constrained service demands are increasing:

- Given the aging of the population there are increasing demands for staffing for overnight awake periods, in home daytime coverage for clients who can not attend day programs, incidental day time coverage for medical appointments, support to hospitalized residents or residents newly transferred to long term care settings, and training as resident's health deteriorates related to lifting, medications, care needs; and
- Demand for more flexibility in service and support options from families and clients.
- Closure of Rideau Regional and the movement of approximately 270 individuals to the Ottawa area by 2009 is described as a major balancing act. Funding is attached to that process to negate any impact on the existing system, however, providers remain concerned.

8.3 Recommendations to Enhance Organizational Capacity

Providers have identified a number of ways to enhance the capacity of the developmental services sector:

- Restore system capacity to ensure it has response capability, flexibility to reconfigure services and better support people in service, develop elder care services, and strengthen staffing resources.
- Restore financial health to developmental services to address issues related to competitive compensation, global budgeting, predictable multi-year funding and flexible funding which covers the actual cost of service for individuals;
- Strengthen planning capacity and develop multi-year plans based on sound planning data;
- Support and promote inter-system planning with other sectors such as social housing, community health and long-term care; and
- Streamline and simplify Ministry accountability measures.

Questions to reflect on...

Provincial funding has been designated to transition individuals from Rideau Regional to community living in Ottawa. Can this funding and any unused operational funding from Rideau Regional be used to benefit all individuals with developmental delays in Ottawa?

What will be the impact on non-profit service agencies should individualized funding be implemented?

8.4 Implications of Proposed shift to more Individualized Funding

While providers appear to support a shift to more choice in services and supports that enable inclusion, some cautions have been identified related to the possible direction toward a more individualized funding model.

- Need for a new system/infrastructure to effectively monitor accountability, funding allocations, risk management and service standards.
- Need for some stability in agency funding revenues to give them confidence that they can provide the necessary services while balancing budgets
- Guidelines be established so intensive and costly services continue to be provided in a group setting to achieve economies of scale while individual funding be directed toward families/individuals with low support needs and lower risk
- Adequate funding be made available within the system while it transitions.
- Desire for transfer payment agencies to remain the cornerstone of the developmental service system.

Questions to reflect on...

How can the existence of non profit agencies be safeguarded to ensure they are able to support individuals with developmental delays when their families no longer can?

9.0 Key Provincial Developments related to the Developmental Services Sector

Completed

March 2004	Provincial government announces \$24 million in capital and operating funding for 44 housing projects in 27 communities across Ontario. Focus – adults with DD living with aging parents and adults with changing and multiple needs.
September 2004	Provincial government launches review of the province's developmental services system. \$110 million allocated toward strengthening community-based services including \$70 million to create places for adults with developmental disabilities who will be leaving provincially operated institutions.
October 2004	Joint Developmental Services Sector Partnership Table ⁹ releases Preliminary Discussion Paper <i>Transforming Services in Ontario for People who have a Developmental Disability</i>
November 2004	Provincial government announces \$22 million (part of previously announced \$110 million) to enhance supports for people with a developmental disability in the community and the community agencies that support them. Funding targeted toward Special Services at Home, transition supports for young adults and increase to base funding for sector.
May 2005	Provincial government announces \$18 million in capital funding over next 2 years and \$20 million in operating funding over the next five years in the Home of Your Own Initiative, which will create 390 new spaces for adults with developmental disability including 90 specialized spaces for individuals with high care needs, 55 group home spaces and 245 supported independent living/family home spaces. Funding is in addition to \$70 million announced for individuals leaving provincially-operated institutions.
May 2005	Provincial government announces creation of four regionally based networks with a mandate to strengthen community-based services for individuals who require specialized care. The intended focus is individuals who have a developmental disability and also have to deal with mental health issues and challenging behaviours. Networks will benefit people leaving institutions and people already living in the community.
December '04 to May 2005	Policy Forums held on Residential Options, Funding for Developmental Services and Strengthening and Supporting Families.
August 2005	Memorandum of agreement signed to allocated \$402 million in federal and provincial housing funding to build 5,320 homes and 5000 new rent supplements. People who require supportive housing are eligible for capital subsidies but no new support (operating) dollars were made available. There are no plans to coordinate the new supply, rent supplements and support dollars. (Michael Shapcott, Homelessness and Housing Network of Ontario).

Pending

October/ November 2005	Province government is writing the Transition Plan which will go to the Joint Developmental Services Sector Partnership Table for input and then out across the province in late October 2005 for consultation. Agencies will need to identify constituents for this consultation. Ottawa is expected to have 2 meetings in English and one in French.
2006	Results of Consultation will be rolled up to create final Transformation Plan to be presented to provincial cabinet for approval and legislation.

⁹ Membership includes , OASIS, People First MARC, Christian Horizons, Family Alliance Ontario, Community Living Ontario
 Role of Family members in Transforming policies and Services for Individuals with Developmental Delays – City of Ottawa
 Prepared by Bonnie Dinning, Health and Social Services Consulting, and Pamela Smit, Veradus Consulting

9.1 Key City Developments Related to the Developmental Services Sector

According to the City of Ottawa Housing Branch, many details about the Federal/Ontario Affordable Housing Program noted in section 9 remain outstanding. The program, however, is expected to permit applications from groups wishing to serve constituencies with special needs like those with developmental disabilities. The program will also make available up to 5,000 housing allowances across the province to address households with rental assistance. \$24m for 500 units province wide was recently released which must be spent by March 31, 2006.

The City has committed, through its *Action Ottawa* affordable housing development program, to encourage proposals from all groups wishing to build affordable housing. The City has planned 2 calls for proposals to develop housing in the near future.¹⁰

- The first has already been announced in response to the initial wave of Affordable Housing funding from the province. It will be of interest to those with proposals already developed for rental properties of at least 7 units.
- A second RFP is expected in January 2006. Any units funded under this call will come out of Ottawa's total unit allocation of 305 units.

The City is undertaking the development of a City Housing Strategy¹¹. An initial component of this work was the completion of a housing demand-supply analysis which included an analysis of housing for persons with developmental delays. The results of this research have yet to be released.

The City administers the Strong Communities Rent Supplement Program¹² which subsidizes tenants in rental accommodation by providing a rental subsidy on a rent-geared-to-income basis. Under the supportive stream of the program which was launched last year, the allocation of units set aside for Developmentally Delayed tenants here in Ottawa has been 100% absorbed. The City is not expecting additional funding to be made available from the Province at this time.

The City Housing Branch is offering a training session this fall called "**LEARNING ABOUT DEVELOPMENT: TRAINING AND SUPPORT FOR ORGANIZATIONS WANTING TO CREATE AFFORDABLE HOUSING**"¹³. This intensive "Development 101" training program is for organizations (community organizations, service agencies, and non-profit & supportive housing providers) that are committed to creating new housing, but are new to the development process. The program will introduce senior staff and volunteer Board members to all the components of the development process: how to create a strong development team, developing land, securing financing and other funds, NIMBY and other issues.

¹⁰ City contact regarding housing development RFPs is Janet Kreda 580-2424, ext.44154.

¹¹ City contact for the City of Housing Strategy report is Elizabeth Dandy 580-2424, ext. 43139.

¹² City Rent Supplement Office can be reached at 733-6354.

¹³ To register contact Carol Couture at 613-580-2424 ext 43086. This program was almost full as of Sept 15/05.

10.0 Opportunities to Build on

There are a number of initiatives that have evolved over the past two years that could potentially offer some direction and opportunity to build on. Some of these initiatives have been agency led and some are family led. The initiatives that have been identified are current. It should be noted that there have been many attempts over the past 10-15 years by families working together and by families working with providers to address concerns.

10.1 Family Led

Families Matter Cooperative is developing a website. They are creating a virtual resource outlining government legislation, services/supports available, efforts of families to influence change etc. They seek to be an umbrella group to support families to work together toward change. They have identified housing as a major issue and hope to create a housing cooperative. They currently have 10-12 members and have a general meeting planned for September 2005.

Six families have submitted a proposal to the Government of Ontario for two apartments for their sons and daughters. The proposal includes a plan to economize support services.

Lifetime Networks Ottawa is offering a Special Services at Home Workshop. Forty families will examine how to make the funding work in their own unique situation. An associated group of families has worked on a housing initiative "A Place to Call Home".

LiveWorkPlay is seeking to secure property for a housing development.

10.2 Agency Led

The McFarlane Share Equity Model was developed by Stewart and Associates working with OCAPDD as the lead agency. The model is based on the premise that some families have and are prepared to put forward funds for housing as shareholders. Pre-development funding was provided by CMHC. The model has yet to be piloted despite the expressed interest of families in Ottawa who have the financial resources to contribute and who have sons/daughters who are relatively high functioning and require more limited supports. The major block to the initiative is the need for a government body to underwrite the financial risk for families and the sponsoring agency. Families also seek a model of governance that gives families some input into the planning and management of the project.

Some efforts are underway to leverage existing housing resources. Infill suites are being created within existing residences which allows for expansion within existing capacity without significant

Questions to reflect on...

What other opportunities are there to build on that have not been identified here?

What is the status of the housing initiative associated with Lifetime Networks?

If families are prepared to use their own resources for equity in housing, how can that equity be insured?

additional costs including staffing. Organizations planning these changes do not need to address NIMBY which can consume a considerable amount of time.

Developmental Service Providers have established a Capacity Enhancement Committee for the City of Ottawa. They are examining how to develop enhanced capacity across the system. Three working groups have been established: Property Committee to address issues related to building codes, permits and bylaws; Human Resources Committee to address issues related to staffing and training needs; and Community Planning Table to address issues related to coordinated planning and facilitating movement of clients within the system.

Executive Directors of Developmental Service Agencies in Ottawa meet monthly. Their focus is on systemic advocacy (e.g wage disparity, policy, shifting funding needs, impact of closure of Rideau Regional and overall impact on city health and recreational services).

Questions to reflect on...

Can family groups access the results of the capacity identification exercise providers are currently undertaking on behalf of the province? Might this information assist families in seeking funding to support collaboration from funding bodies such as the United Way, Trillium, etc?

11.0 Possible Actions

Key informants identified a number of possible actions that family members and other key stakeholders could undertake to influence change. Appendix C provides a listing of websites with helpful information.

1. Develop a vision and priorities for change in the developmental services sector in Ottawa.
2. Participate in provincial consultations related to transforming the developmental service system.
3. Develop an understanding of the range of housing models, best practices and economics. Some generic information has been provided in a report by Bonnie Dinning in Appendix B.
4. Request that bureaucrats from federal, provincial and municipal governments work together to determine how contributions at all levels could be leveraged to provide a solution that combines housing funding with support services.
5. Advocate with provincial representatives for additional funding to create supports so that recently announced affordable housing funding can be used to create housing for those needing supports to live in the community
6. Develop an enhanced relationship with media. Collect stories from parents to help generate a greater awareness and understanding of what the needs are. Use the facts contained in this document as evidence of need.
7. Develop relationships with local politicians to engage someone to champion the issue locally and provincially.
8. Request support from a funding body or a developmental service organization to perform a secretariat function for families interested in working together toward change.
9. Provide training to develop skills in strategic planning and dialogue with agencies.
10. Develop a Council or Alliance of existing organizations and families not affiliated with existing groups that can work together to have a stronger unified voice.
11. Develop an understanding of some of the system capacity challenges so that advocacy is directed appropriately to providers or government.

Questions to reflect on...

Are there other actions that could be considered?

What are the criteria for deciding what actions to take?

Possible criteria:

- biggest impact
- timely
- likely to succeed
- families have the energy

How can family members become involved in local consultation about transforming developmental services?

What needs to be considered in the development of a vision and mission of any group evolving out of this roundtable?

12. Document positive and negative changes in individuals housed at home over time and their families.
13. Work with the developmental service sector to identify & evaluate ways family support and resources can enhance housing and associated supports, etc.
14. Establish a liaison from the Executive Directors Group of Developmental Services Agencies to link with any family led advocacy work. Executive Directors have identified the need for increased family advocacy and would be supportive.

Questions to reflect on...

What needs to be considered in developing values to guide how future members work together and with other contacts invested in shaping developmental services e.g. integrity, accuracy, respect, dedication,

For Consideration....

Effective collaboration requires:

- *Respecting differences between partners*
- *Appreciating other's contributions*
- *Developing existing relationships*
- *Building on the local informal relationships that already work*
- *Acknowledging that inequalities strain relationships*

Glouberman, S., Complex Health Care Relationships, Dialogue on Health Reform - Champlain District Health Council, March 2003

12.0 Conditions/Supports Required to Enable Collaboration

Key informants, particularly family members and parents, involved in previous initiatives to influence change have identified a number of conditions and supports required to enable effective collaboration amongst parents/family members and with agencies and government.

1. Current information about policies, proposed changes and government priorities.
2. Clear sense of purpose for mobilizing and clear agendas and desired outcomes for meetings.
3. Development of a clear vision and priorities for change amongst families before engaging providers (while there are some consistent messages there are many differences).
4. Recognition of unique situations and diverse interests and capacities. It is difficult for families to come to a shared vision. Families who work together toward change need to acknowledge that they want different services/supports and that advocacy for a continuum approach to services rather than one model of service would enable more people to speak with one voice.
5. Engage people who can take a system approach toward influencing change. Some families are fearful and are sometimes challenged to look beyond their own family given their desire to ensure that their son/daughter is well cared for. This fear can lead to an “us” and “them” relationship which may prevent successful collaboration.
6. Information about service delivery models and best practices.
7. Recognition that families require concrete support from agencies and government to work toward change. Specific supports such as meeting space, refreshments, parking, technical support for proposal development and facilitation were identified. Many parents are tired, burned out, overwhelmed and struggling to cope with the existing system. Others have been engaged in unsuccessful attempts at change and are reluctant to embark on another process without support.
8. Recognition and appreciation by government and agencies of the significant value of the contributions families make toward changing policies and services.
9. Build on relationships. Many families know each other, connect socially and work together collaboratively.

Questions to reflect on...

Are there other conditions/supports needed to enable collaboration?

Are any of the conditions/supports here already in place?

13.0 Factors Influencing the Success of Collaboration

The University of Wisconsin–Cooperative Extension outlines the factors influencing the success of collaboration based on work by Mattessich & Monsey (1992) in *Evaluating Collaboratives* (1998).

Factors Related to the Environment

- History of collaboration exists in the community
- Collaborative group is seen as a leader in the community
- Favourable political and social climate exists for support of the collaborative

Factors related to Membership Characteristics

- Mutual respect, understanding and trust exists among members
- There is an appropriate and representative cross-section of members
- Members see collaboration in their self-interest - benefits exceeds costs
- Members are able to compromise

Factors related to Process/Structure

- Members share a stake in the process and outcome of the collaborative
- Layers of decision-making - all levels of each organization participate
- Flexibility – varied forms and functions are allowed
- Clear roles and policy guidelines exist
- Adaptability to major changes in the environment

Factors related to communication

- Open and frequent communication between members and the outside
- Established formal and informal communication links

Factors related to purpose

- Goals and objectives are both clear to members and obtainable
- A shared vision and mission exists for the collaborative
- A unique purpose exists for the collaborative different from each organization

Factors related to Resource

- Sufficient funds exist or are expected for functioning of the collaborative
- A skilled convener in the collaborative has respect and legitimacy

14.0 Key Questions Considered at the Roundtable

1. Are you interested in working together to influence change?
2. How would you want to do that?
3. What opportunities can you build on?
4. What supports do you need to collaborate?
5. Are any of those supports currently in place? How can you get those supports in place?

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7. Family Alliance Ontario, *Response to the Discussion Paper on Transforming Developmental Services in Ontario*, November 2004
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11. Minister of Community and Social Services Sandra Papatello, Speaking Notes for OASIS 2005 Conference, May 2005
12. Ontario Agencies Supporting Individuals with Special Needs (OASIS), *Transforming Developmental Services in Ontario*, date unknown
13. Reena, *Successfully Transforming Services in Ontario: The Social Policy challenges involved in expanding the continuum of care for people with developmental disabilities*, date – unknown
14. Shapcott, M., Analysis of August 31, 2005 Federal-Ontario Housing Announcement, Homelessness and Housing Network of Ontario
15. Summary Report on Residential Options Policy Forum

Service Coordination

Appendix A

ORGANIZATIONAL REPRESENTATIVES COMPLETING INTERVIEWS	
Affiliation	Name of Representative
Centre 454	Mary Martha Hale, Executive Director
Citizen Advocacy	Brian Tardiff, Executive Director
City of Ottawa, Housing Branch	Ken Foulds, Manager Housing Policy and Programs
CMHA, Brokerage	Martha Marr , Coordinator
Community Capacity Building Team (CCBT)	Paddy Fuller
Community Capacity Building Team (CCBT)	George Brown
Downs Syndrome Association National Capital Region	Louise McGoey
Families Matter Cooperative	Marge McCabe
FASD Consultant	Dianna Fox
Housing Help	Trudy Sutton, Executive Director
Inner City Health Inc.	Wendy Muckle, Executive Director
Lifetime Networks Ottawa	Kathleen Jordan
(MCSS) Ministry of Community & Social Services Developmental Services Team	Ginette Desmarais, Program Supervisor, Eastern Region, MCSS/MCYS Shalan Gobeil, Program Supervisor, Eastern Region, MCSS/MCYS Pierre Sauvé, Program Supervisor, Eastern Region, MCSS/MCYS Corey Beard, Program Supervisor, Eastern Region, MCSS/MCYS Donna McInnis, Project Coordinator, Eastern Region, MCSS/MCYS
(MCSS) Ministry of Community and Social Services and CCBT	Linden Holmes, Program Supervisor
OASIS Provincial Partnership Table	George Braithwaite
OAPDD	David Ferguson, Executive Director
Options Bytown	Lorraine Bentley, Executive Director
Royal Ottawa Hospital - Dual Diagnosis Consultation Unit,	Dr. Susan Farrell, Psychologist
Salus – Community Development	Hilary Jocelyn , Manager-Community Development
Service Coordination	Luc Ouellette, Executive Director
Stewart & Associates	John McFarlane

Appendices

Role of Family members in Transforming policies and Services for Individuals with Developmental Delays – City of Ottawa
Prepared by Bonnie Dinning, Health and Social Services Consulting, and Pamela Smit, Veradus Consulting

PARTICIPANTS AT SEPTEMBER 20TH ROUNDTABLE ON THE ROLE OF FAMILY MEMBERS IN TRANSFORMING POLICIES AND SERVICES FOR INDIVIDUALS WITH DEVELOPMENTAL DELAYS IN THE CITY OF OTTAWA	
Affiliation	Name of Representative
OASIS Provincial Partnership Table	George Braithwaite
Community Capacity Building Team	George Brown
Families Matter Cooperative	Kryisia Pazdzior,
Families Matter Cooperative	Marge McCabe
Community Capacity Building Team	Paddy Fuller
Lifetime Networks Housing Group	Paul Francis
Faith & Light Group, L'Arche	Susan Wheatley
Downs Syndrome Association National Capital Region	Louise McGoey
LiveWorkPlay	Cathy Rodgers
LiveWorkPlay	Elaine Murphy
LiveWorkPlay	Doug Gage
LiveWorkPlay	Kathy Gage
Le Regroupement des partenaires francophones travaillant auprès des personnes vivant avec une déficience intellectuelle (ou un handicap de développement). web site: http://regroupementdespartenaires.ca/	Diane Desrochers

Appendices

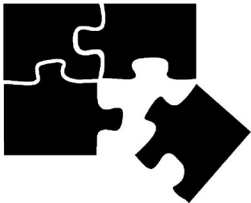
Role of Family members in Transforming policies and Services for Individuals with Developmental Delays – City of Ottawa
Prepared by Bonnie Dinning, Health and Social Services Consulting, and Pamela Smit, Veradus Consulting

Appendix B – Housing Options

Housing and Support Options for Individuals with Special Needs:

A Discussion Paper for Use by Families with Developmentally Delayed Family Members in Need of Housing

Prepared by:



L. Bonnie Dinning
Health and Social Services Consulting
Organizational Development

September, 2005

Appendices

Role of Family members in Transforming policies and Services for Individuals with Developmental Delays – City of Ottawa
Prepared by Bonnie Dinning, Health and Social Services Consulting, and Pamela Smit, Veradus Consulting

More than bricks and mortar is needed to make good housing a good place to live. It must be:

- *Affordable (you can pay for your housing and still have enough money to eat and have fun)*
- *Secure (you can stay as long as you want)*
- *Comfortable, safe and happy (you feel comfortable, safe and happy in your place)*
- *Good location (close to shops, places you like to go, etc.)*
- *Allows you to have rights (your right to have privacy, your own money, visitors, etc)*
- *Choice (so you can choose the sort of place that is best for you, and choose who you live with)*
- *Not stigmatizing or different (so people don't walk past and say "that house is especially for disabled people")*
- *Equitable, just and fair (everyone should have good housing. Housing should not be provided in a way that makes some people miss out)*
- *Allows you to have the support you want (no more/no less)*

A message from disabled individuals (Western Regional Housing Council, 1996)

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1. INTRODUCTION

Information about how to assess housing options is not readily available to families currently struggling to house their developmentally delayed family members.

Canada Mortgage and Housing Corporation (CMHC), Canada's national housing agency recently commissioned a study on housing for intellectually disabled adults. This research will identify housing needs and explore housing options for adults with intellectual disabilities. It will include an examination of: the availability of housing and support services, best practices, the role of parents of disabled adults, risks such as homelessness, housing requirements of people with multiple disabilities, and gaps in the availability of housing. Unfortunately this study may not be available in time for families to use when reviewing the Ontario Government's proposed plan for transforming services for people who have a developmental disability.

The following sections of this paper have been developed from studies about best practice¹⁴ housing for a variety of special needs groups; especially those who are mentally ill, involved in substance use, or homeless. Recent spotlights on the needs of such individuals have produced a significant amount of research on their housing needs. Much is applicable to any special needs group. It is also important to recognize the high incidence of mental illness and substance use, especially alcohol, amongst those with developmental delays, and the emerging recognition of individuals who are developmentally delayed and homeless.

Although not specifically about housing options for individuals with developmental delays, this paper hopefully provides information about the realm of generic housing and support possibilities families still caring for their developmentally delayed adult family members should consider, when either planning for their family member or collectively advocating for government funded options.

1.2 Definition of Supportive Housing

¹⁴ A concept referring to the best way of doing something.

Supportive housing, in its broadest definition, is public, private or non-profit housing linked with health and social services and tailored to the needs of the individuals being housed. It is frequently used as an umbrella term to cover a variety of housing and support combinations. (Glauber 1996, HRDC 2003, Corporation for Supportive Housing Website)

In Ontario, the term “supportive housing” is mainly used to describe housing with on site support.

1.3 Types of Support Services Linked to Housing

Support services provided regarding housing for special needs populations can range from 24 hour/7 day a week on-site support, to occasional support from off-site service providers. Supports may be provided by the same agency that does the property management or through partnerships with social and health service agencies. Supports can be tied to the individual, the housing site, or both. The support services required by special needs individuals typically fall into two broad categories- health related and personal support services. (Pleace 1995, Fitzpatrick et al 2000)

Health related services include assistance with physical tasks such as toileting and with treatment plans. Personal support services are more varied. They include assistance with:

- Daily living skills such as cooking, cleaning, and housekeeping responsibilities for personal and shared living spaces;
- Financial management skills such as budget planning for shared rent and grocery expenditures as well as personal expenses; and
- Social skills to ameliorate the isolation often experienced by those with special needs. If in a shared living arrangement, individuals most likely require additional support to interact socially, form relationships and comply with house rules such as those found in group homes.

2. HOUSING AND SUPPORT MODELS

The majority of individuals with special needs require stable, affordable housing plus supports to remain in the community. Their combined provision is a recognized best practice.

Reviewed research on models and consumer preference has yielded a range of approaches that are proven to work. Collectively they call for a variety of flexible models and recognize that the best combination of support and housing for any individual requires assessing that individual’s needs and circumstances (CAMH 2001, Pleace 1995, Regional/Municipal Working Group on Long Term

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Supportive Housing 1996, HUD 1995, Ministry of Municipal Affairs and Housing, Corporation of Supportive Housing, ONPHA website).

Different communities and countries use similar terms in different ways. The following descriptors of models reflect common usage and respect definitions already in use in Ontario. Institutional care is not included, as such housing for individuals with developmental delays will not be available in the near future.

2.1 Emergency Housing and Shelter

Although not normally considered a housing option, especially for individuals with developmental delays, service providers in the homeless sector are identifying such individuals within the client group passing through their doors.

2.1.1 Description

Such options provide accommodation for short periods of time. Sleeping arrangements may be in dormitories, or in shared or single bedrooms. Some shelters can accommodate families, or alternatively, families may be placed in motel rooms. According to one document, homeless children are at high risk of being developmentally delayed.

Included as emergency shelters are youth safe houses and transition houses for individuals fleeing abusive situations. Services (e.g. meals, medical aid, and social services, etc.) vary depending on the provider.

2.1.2 Assessment

Initial understandings of a solution to homelessness were often seen as the need to create emergency shelters. Considered a crisis intervention, the focus is one of safety and control not rehabilitation. Modern nations now understand that prevention and long-term approaches must replace reactive, emergency responses to homelessness. For the time being, progressive emergency shelters and companion outreach services provide a first encounter or intake opportunity that may be able to connect developmentally delayed and homeless individuals with appropriate support and hopefully housing.

2.2 Custodial Housing

2.2.1 Description

In this model, residents often share bedrooms and have little choice over roommates. Privacy is limited, there are few diversions and rules abound. The focus is care rather than rehabilitation. Examples include lodging, foster homes, and board & care arrangements.

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2.2.2 Assessment

At some point in the transition from institution to community living, it was commonly thought that some clients could not benefit from a rehabilitation focus. The result was placement in a custodial setting for a significant number of individuals. Reviewed studies, particularly in the field of mental illness, contradict this belief. For the most part, homes of this type do not provide care that is in line with current best practice evidence and consumer need, but potentially could with additional funding to provide appropriate support.

One study (Nelson et al 1999) theorized that older individuals with past life experiences in institutions or other undesirable living arrangements in the community may see their current quality of life in custodial housing as satisfactory relative to their experience and relative to younger residents who have not experienced similar conditions.

2.3 Transitional Housing

2.3.1 Description

Transitional housing is considered short-term accommodation (6 months to two years) while assistance is obtained to address problems such as physical and cognitive disabilities. Transitional housing units typically provide access to a mix of support services that enable residents to move towards self-sufficiency and permanent housing.

2.3.2 Assessment

Transitional housing may be an appropriate setting for those whose present circumstance requires targeted supportive services to regain stability and develop skills. However, for some, transitional housing represents one more unnecessary move and adjustment to new rules and regulations.

Potential residents of transitional housing require good assessment to determine if this is an appropriate housing step towards other longer term or permanent housing and support models. Two Canadian studies evaluating such housing found mixed results. Both stressed the need to provide subsidized permanent housing and transitional support services, not transitional housing, so that stable social connections and neighbourhood supports could be developed (Novac et al, 2004).

2.4 Supportive Housing

2.4.1 Description

Within Ontario, the term “supportive housing” typically connotes a situation where supports are linked to a specific accommodation unit and staff work on site supporting all who live there. The amount of time staff spend on-site depends on the level of assistance needed by the residents. Supportive housing includes group homes, and small rooming house settings, but can sometimes include low-support, self-contained apartments that are shared. The focus is on skills training and community integration. Residents may receive support from both on site staff and those that support them individually (portable support).

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2.4.2 Assessment

Several studies (Chipperfield et al 1990, Johnson 2001, CAMH 2001, Fitzpatrick et al 2000, Nelson 1999, Schwartz 2003, Anucha & Hulchanski 2003) show a number of positive impacts on consumers living in this model. They include a reduction in rates of rehospitalization, lessening of psychiatric symptoms, greater independence, and improved self-esteem, social skills and quality of life.

Disadvantages of this type of housing are related to residents' limited privacy, lack of power and control and limited if any choice over who lives with them. Problems with living companions are common and residents may be expected to move to a new level of housing when they do well. In essence, they lose their home.

2.5 Supported Housing

2.5.1 Description

Supported housing involves portable support tied to the individual not the housing site. In some instances this form of housing is considered permanent housing not a step within a continuum. Typically, supported housing has been identified with apartments, housing co-ops or other government funded social housing for people with low income. Use of support or participation in treatment is normally a prerequisite to accessing this type of housing. It may or may not involve shared living space. When living space is shared, roommates may not have control over who they live with. Supported housing can also include private market housing options.

2.5.2 Assessment

Studies on the impacts of supported housing for homeless people with serious mental illness show positive impacts on housing stability, reduction in hospitalization, greater satisfaction with housing, fewer housing problems, better housing quality, and better overall quality of life. Identified negative impacts include isolation and loneliness, and; little evidence of integration into the community through informal support systems, education, or work. The latter may speak to the need for access to supported socialization, supported education, and supported employment.

2.6 The “Housing First” Model

2.6.1 Description

Best known as the Pathways program in the U.S., this model is founded on the belief that housing is a basic human right for all individuals, regardless of disability. Homeless clients are offered immediate access to permanent independent housing of their choice before other services are offered.

Staff develop relationships with landlords and housing management companies in order to secure apartments for new clients and rent is guaranteed. Staff also serve as liaisons to ensure that apartment repairs and emergencies are dealt with adequately and in a timely manner. Once an individual is placed in housing, he or she is encouraged to participate in treatment, vocational and rehabilitative programs. Support can be likened to Ontario’s Assertive Community Treatment (ACT)¹⁵, however unlike ACT, Pathways allows clients to determine the type and intensity of services or refuse them entirely.

2.6.2 Assessment

Pathways to Housing and the Continuum of Care Model are participating in a randomized study comparing the two alternatives for housing homeless, dually diagnosed individuals¹⁶. The study examines housing stability, mental health, substance use, social support and networks, involvement in the criminal justice system and vocational rehabilitation outcomes.

Thus far, housing outcomes have been significantly better for the Pathways group. Contrary to the expectations of the continuum of care service delivery model, Pathways clients did not exhibit higher rates of psychiatric symptomatology or substance use. Experimental and control groups were also compared on treatment utilization, residential program costs, perceived choice in housing, and employment. Preliminary results strongly support a housing first approach for individuals who are homeless and dually diagnosed. The findings also challenge commonly held clinical beliefs regarding the correlation between psychiatric disability and competence. Housing first, combined with a harm reduction approach¹⁷ to mental health and substance abuse problems virtually eliminates the barriers of access to housing for people with dual diagnosis and reduces the likelihood of their relapse into homelessness.

¹⁵ Multi-disciplinary clinical teams providing intensive ongoing support and comprehensive treatment to those with mental illness living in the community

¹⁶ Refers to having a mental illness and also engaged in substance use/abuse. In Ontario, this is known as “Concurrent Disorder”

¹⁷ *“Harm reduction is a set of strategies and approaches aimed at reducing the risks and harmful effects associated with substance use, and addictive behaviours, for the person, the community and society as a whole. While helping users abstain from substances or addictive behaviours is one appropriate long-term goal for some, harm reduction strategies place the emphasis on the most immediate achievable and positive changes whether or not they are shown to reduce use”.*

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3. Philosophical Approaches to Housing and Support

The models described on the previous pages have evolved along 3 philosophical approaches to assisting special needs individuals with housing following modern society's rejection of institutional care.

3.1 The Medical Approach or “Mini Institution” in the Community

The guiding belief for the Medical Approach is that some patients or clients are too disabled to function in society. Only basic services are offered to meet their needs (e.g., food, shelter, and medication) and staff usually have limited training. This approach is common in the custodial model.

3.2 The Continuum of Care Approach

This approach is based on a ‘continuum’ paradigm in which different housing environments are available to residents. Each provides a different level of support that is rehabilitative or instructional in nature. Individuals are seen as requiring supervision and may be moved back and forth from one environment to another depending on need. The final stage of the continuum is reached when a resident either achieves independent living status or reaches his or her optimum level of development. Transitional and Supportive Housing are the mainstay of this approach. However, the continuum approach in relying on a variety of housing and support options fails to reach its potential in many communities as there are few communities capable of providing the quantity if not the array of models required for all client groups. A result may be individuals who remain stuck in inappropriate housing because the “next stage” is full or does not exist.

3.3 The Person-Centred Approach

The primary goal is to have individuals choose and settle in their own homes, and have them access resources with the assistance of supportive “relationships” as they see fit. This approach encourages tenants/citizens to be viewed by others as community members with “normal” tenancy and responsibilities rather than as residents/clients or patients. Although “normal” housing is encouraged, some might choose to reside in housing that is custodial or supportive in nature. The most common models used, however, are the Supported and Housing First models. This approach requires access to sufficient affordable housing stock and community services to be successful in any community.

(Pathways; HUD websites; CMHC, Applicability of a Continuum of Care Model to Address Homelessness, Social Data Research Ltd., 2002)

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4. HOW BEST TO PROVIDE HOUSING AND SUPPORT FOR INDIVIDUALS WITH SPECIAL NEEDS

The literature identifies the need for a range of housing and support options for special needs individuals as it is only after assessment of the specific needs of each individual that one housing and support model can be chosen over others. A hybrid approach to housing and supporting individuals with special needs is probably the best approach in any community. As such it merges aspects of the continuum of care and person centred approaches, and entails the following:

- A variety of housing and support model options is available in each community similar to that expected of a continuum of care approach; but the type of support becomes the changeable aspect not the location of “home”. Such an approach supports consumer choice and control over where and how they are housed and what supports they may or may not need;
- Assessment of the housing needs of special needs individuals is person centred in that it is directed by individual preferences or their designated decision-makers, not rehabilitation or learning needs;
- Housing and support options are continuously balanced and realigned in each community to meet the needs of its special needs populations. For the time being custodial models may need to remain an option as they are seen as home to some they currently house. However, research supports the phasing out of such options, especially for those with mental illness. Transitional housing also requires a review. Recently popular due to short term federal funding available to address homelessness, transitional housing has become a panacea due to a lack of other housing options.

(Chartrand et al 2002; Nelson et al 1998; Parkinson et al 1999; Ridgway & Zipple 1990; Glauber 1996)

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5. BENEFITS TO SOCIETY WHEN BEST PRACTICE HOUSING AND SUPPORTS ARE UTILIZED

Reviewed documents collectively point to multiple short and long term benefits to the individual and ultimately society when special needs individuals are appropriately housed and supported. These are summarized in 5.1 and 5.2.

5.1 Short Term Benefits

Decreased	Increased
<ul style="list-style-type: none"> • homelessness • use of emergency shelters • use of emergency services (ambulance, ER, Police) • Potential harm to resident (violence, overdosing, etc.) • crises (suicidal behaviour, severe psychological distress, etc) • substance abuse • episodes of hospitalization 	<ul style="list-style-type: none"> • awareness of needs • understanding of contributing factors (psychiatric disorder, etc) • awareness and motivation to improve life and to work towards goals • financial stability • health promotion behaviours (regular check ups, & medication use, etc) • formal and informal support and referral network • basic skills (hygiene, cooking, etc) • interest in recreational activities

5.2 Long Term Benefits

The ultimate long term outcomes are maintenance of stable housing, optimal health and improved quality of life.

Others include:

Decreased	Increased
<ul style="list-style-type: none"> • crisis situations 	<ul style="list-style-type: none"> • integration into the community • commitment to maintain safe, clean and sober living • maintenance of sobriety and/or abstinence • financial security • reliability in paying rent and of meeting resident obligations (keeping appointments, etc) • efforts towards meeting needs and goals • mental health and personal well-being • solid formal and informal support and referral networks • effective management of illnesses, conditions, issues (mental illness, etc) and/or improved health • increase in life skills, leisure and social activities

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Appendix C

Website Resource List

About Intellectual Disabilities:

Bibliography of articles on developmental disabilities <http://www.utoronto.ca/gol/bibliodd.htm>

CMHA - Dual Diagnosis

http://www.ontario.cmha.ca/content/about_mental_illness/dual_diagnosis.asp?cID=3307#section3310

Disability Research <http://www.ccsd.ca/drip/research/>

Disability Research Links <http://www.ccsd.ca/drip/links.htm>

Intellectual Disabilities and Health <http://www.intellectualdisability.info/home.htm>

International Journal of Disability, Community and rehabilitations <http://www.ijdc.ca/>

National Center for the Dissemination of Disability Research <http://www.ncddr.org/>

Roehrer Institute <http://www.roeher.ca/english/about/about.htm>

Legal Resources:

ARCH: A legal Resource Centre for Persons with Disabilities <http://www.archlegalclinic.ca/index.asp>

Tax Measures for Persons with Disabilities <http://www.disabilitytax.ca/main-e.html>

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Resources to Help Groups Organize Themselves:

Charity Village –source of information for volunteer organizations <http://www.charityvillage.com/CV/main.asp>

Community Tool Box <http://ctb.ku.edu/>

“Community for All” Tool Kit <http://thechp.syr.edu/toolkit/>

Non profit Good Practice Guide <http://www.npgoodpractice.org/>

Ontario Healthy Communities Tool Kit <http://www.healthycommunities.on.ca/publications/ICO/>

Perspectives on Partnerships <http://www.caledoninst.org/Publications/PDF/perspect%2Epdf>

Organizations to keep your Eye On:

(LNO) Lifetime Networks Ottawa <http://www.lifetimenetworks.ca/>

(PLAN) Planned Lifetime Advocacy Network <http://www.plan.ca/>

Canadian Association for Community Living <http://www.cacl.ca/>

Ontario Agencies Supporting Individuals with Special Needs <http://www.oasonline.ca/oasis.htm>

Ontario Association on Developmental Disabilities <http://www.oadd.org/>

Ontario Community Living <http://www.communitylivingontario.ca/index2.html>

The Council on Quality and Leadership (American) <http://www.thecouncil.org/>

Youth Involvement Ontario <http://www.communitylivingontario.ca/yio/index.html>

Ontario MCSS, Developmental Services

<http://www.mcass.gov.on.ca/CFCS/en/programs/SCS/DevelopmentalServices/Transformation/default.htm>

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Ministry of Community
and Social Services

Ministry of Children
and Youth Services

Eastern Region
10 Rideau Street, 7th floor
Ottawa ON K1N 9J1
Switchboard: (613) 234-1188
Fax: (613) 787-5283
Toll Free: 1-800-267-5111

Ministère des Services
sociaux et communautaires

Ministère des Services à l'enfance
et à la jeunesse

Région de l'Est
10, rue Rideau, 7^{ième} étage
Ottawa (Ontario) K1N 9J1
Réception centrale : (613) 234-1188
Télécopieur : (613) 787-5283
Sans Frais : 1-800-267-5111



August 12, 2005

MEMORANDUM TO: Executive Directors
Transfer Payment Agencies
Developmental Services

FROM: Susan Bihun
Regional Director

RE: **Allocation to the Eastern Region of Funding
Investments in Developmental Services**

Further to the Minister's announcement of May and July 2005 regarding new investments in developmental services, I am pleased to provide you with allotment summaries for the Eastern Region. These investments are in addition to the four-year \$110 million investment announced in September, 2004 for the Facilities Initiative.

The financial information provided in the attached chart refers to the Minister's Announcement in relation to:

- Home of Your Own Spaces including group home, supported independent living, family home spaces and specialized spaces)
- Special Services At Home
- Passport to Community Living
- Allocation to support At-Risk Individuals currently identified in services as a financial pressure
- 1.5% increase to agencies

Program Supervisors from the Eastern Regional Office will be meeting with service providers in the near future to provide you with more information and to discuss with you the implementation plan and the allotment for each of the communities.

Through these investments, the ministry is taking action to reduce current wait lists, expand services and improve client care across the developmental services sector.

Should you have any questions, please do not hesitate to contact your program supervisor.

Susan Bihun
Enclosure

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APPENDIX E

PROFILE OF ODSP RECIPIENTS WITH A DEVELOPMENTAL DISABILITY

JUNE 2005 CITY OF OTTAWA

Total Cases	2,124
Family Structure <ul style="list-style-type: none"> • Singles • Married • Without children • With children 	94% 6% 96% 4%
Client Age <ul style="list-style-type: none"> • Under 18 years • 18-21 years • 22-24 years • 25-34 years • 35-44 years • 45-54 years • 55-64 years • 65 years and older 	0% 9% 7% 23% 26% 23% 12% 0.4%
Gender <ul style="list-style-type: none"> • Female • Male 	42% 58%
Disability <ul style="list-style-type: none"> • Specific delays in development • Mild mental retardation • Other specified mental retardation • Unspecified mental retardation • Chromosomal abnormalities 	11% 37% 21% 19% 12%
Time on assistance <ul style="list-style-type: none"> • 0-35 months • 36-59 months 	14% 9%

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Total Cases	2,124
<ul style="list-style-type: none"> • 60-120 months • 121 months or more 	19% 58%
Highest level of Education Completed % with information <ul style="list-style-type: none"> • No education • At most grade 6 • Grade 7-11 • Grade 12-13 • Post secondary 	82.82% 31% 13% 28% 24% 5%
Employment and Income <ul style="list-style-type: none"> • Non-earners • Earners Average income	87% 13% \$546
Type of accommodation <ul style="list-style-type: none"> • Renting, not subsidized • Renting, subsidized • Owned home • Board and lodging • Chronic care, community resource centre, nursing home, non-aged home • DS- group living, apartment program • Domiciliary hostel, emergency hostel, transition home, homeless • others 	30% 14% 1% 36% 2% 16% 0% 0.5%

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APPENDIX F

Service Coordination des Services Community Registry Level 1, 2 and 4 Housing Needs by Language September 15, 2005

Levels of Service	Hours of Service Needed			
	24 hour	15-20 hours	8-14 hours	Up to 8 hours
Level 1 – English	44	11	5	2
Level 1 - French	5	5	3	2
Total	49	16	8	4
Level 2 - English	97	27	27	30
Level 2- French	17	7	5	4
Total	114	34	32	34
Level 4 – English	115	41	36	6
Level 4 – French	20	5	5	0
Total	135	46	41	6

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Categories of Service Need - Services Coordination de Services

Category 1	
Safety	<ul style="list-style-type: none"> a. safety of individual – abusive situation b. safety of individual – home alone and safety at risk c. safety of caregiver – is at risk because of individual. Caregiver is unable to intervene
Housing	Homelessness of individual or significant danger of losing housing within 2 working days
Financial	<ul style="list-style-type: none"> a. individual experiencing a financial breakdown (no income) b. caregiver experiencing a financial breakdown due to providing care for individual (loss of job, unable to work) c. shortage of basic necessities – food, clothing, transportation
Health	<ul style="list-style-type: none"> a. individual requires extraordinary medical intervention and caregiver is not able to assist. b. individual is not receiving adequate care because caregiver’s physical, psychological condition
Category 2	
Safety	<ul style="list-style-type: none"> a. individual not a risk but neglect issues such as substandard housing, poor nutrition, poor health care b. caregiver – safety not at risk but able to intervene
Housing	a. individual has been served notice that they will lose housing/placement
Financial	<ul style="list-style-type: none"> a. individual at risk of losing income b. caregiver at risk of losing income, employment due to caring for individual
Health	<ul style="list-style-type: none"> a. individual is requiring medical intervention and caregiver’s ability to assist is deteriorating b. caregiver’s health is deteriorating but still able to assist individual
Day	<ul style="list-style-type: none"> a. individual is at risk of losing day option or employment if follow-up services are not implemented b. individual has no day option and individual and/or caregiver is unsatisfied with the situation
Category 3	
Housing	<ul style="list-style-type: none"> a. individual has a placement and wants a change b. individual has a placement and family wants a change
Day	<ul style="list-style-type: none"> a. individual has a placement and wants a change b. individual has a placement and family wants a change
Category 4	
Day	<ul style="list-style-type: none"> a. individual; at home participating in some activities, wants to explore other options b. presently attending a day option and looking at long-range planning c. presently in school, wants to register and plan for services upon graduation (3 yrs or more)

Appendices

Role of Family members in Transforming policies and Services for Individuals with Developmental Delays – City of Ottawa
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