



Opportunities Mississauga for 21 Plus

Caregivers Planning and Action Agenda



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Introduction: People with disabilities and those who love and care for them have distinctly personal and individual needs and goals. Systems of care are designed for some defined range of services and also as means to control costs. Therefore there will always be individual needs that a service system does not meet.

The recent survey conducted by OM21+ has identified some of those needs. Although there is a distinctive and individual aspect to those needs there are also some patterns. These patterns are described later in the report as an agenda of service improvements and changes that a significant number of caregivers in Mississauga want.

It should be noted that the list of desired changes is broad and comprehensive. Not every item has majority support - some were included on the basis of a single mention. This was done deliberately to reflect the reality that caregivers and people with disabilities have specialized needs. The items will be prioritized by caregivers at meetings.

The first section of this report provides a summary of the things caregivers told OM21+ that they want and need for their children beginning with a description of the Quality of Life long-term goals. This is followed by a chart summarizing short and medium-term goals (a more complete description of this is provided the Appendix).

The second section describes a planning and action process to work on these objectives.

The third section presents a short statistical profile of the families who participated in the survey.

Long-Term Goals

“Quality of life” means something different to every caregiver of, family of, and adult with a developmental disability. For some a sheltered environment with close supervision, appropriate stimulation and interaction with other people is ideal; for others, quality of living is achieved through volunteerism or work in a supported environment; for others still it is through completing post-secondary education and joining the mainstream workforce.

Whatever form quality of life takes, caregivers, families and those with disabilities deserve to know if their aspirations can be achieved and that the living arrangements that will provide happiness are in place. The characteristics therefore of a good life for adults with a developmental disability are:

- Appropriate support
- Physical and emotional well-being
- Friendship
- Realizing their full potential
- Right to full citizenship

Caregiver Planning and Action Agenda May 14 th , 2008		Long Term Goals A good life for adults with developmental disabilities Appropriate support • Physical and emotional well-being Friendship • Realizing their full potential Right to full citizenship	
		Short-Term Goals ←————→ Medium-Term Goals	
SSAH	<ul style="list-style-type: none"> Change Restrictions, enable: <ul style="list-style-type: none"> -carry over to next funding period -use towards professional services 	<ul style="list-style-type: none"> Increase funding commensurate with need 	
Residential	<ul style="list-style-type: none"> Immediate housing for urgent needs Immediate “transition” housing Right to self-determined models Once move has happened, caregiver support for visits home, better service at group homes 	<ul style="list-style-type: none"> “Transition” housing 5 – 15 years from now 	
Support Workers	<ul style="list-style-type: none"> Organized pool of “trustworthy” support workers 	<ul style="list-style-type: none"> Adequate funding = fair compensation 	
Overnight Respite	<ul style="list-style-type: none"> Increase CLM funding Expand summer camp offerings Emergency respite options Medical care at Oaklands Affordable in-home or out of home respite by support workers Respite options for “high-functioning” individuals 	<ul style="list-style-type: none"> Locate facilities in Mississauga 	
Before/After School Care	<ul style="list-style-type: none"> PLASP-style program Incentives for support workers 		
Day Activities	<ul style="list-style-type: none"> No wait after graduation Group participants by compatibility Gear activities to level and interest Equitable; affordable for 5 days/week 	<ul style="list-style-type: none"> All under one roof 	
Base Site	<ul style="list-style-type: none"> Equitable; affordable for 5 days/week Accept all requiring 1:1 care Waive 3-year commitment for those with Passport funding Subsidized community outings 		
Volunteer and Paid Work	<ul style="list-style-type: none"> Opportunities for meaningful volunteer and paid work 	<ul style="list-style-type: none"> Expand WSIB coverage No ODSP clawbacks 	
Post-Sec. Education	<ul style="list-style-type: none"> Expand beyond the current 20 spots per year at Humber College 		

Caregiver Planning and Action Agenda Continued		Long Term Goals A good life for adults with developmental disabilities Appropriate support • Physical and emotional well-being Friendship • Realizing their full potential Right to full citizenship	
		Short-Term Goals ←	→ Medium-Term Goals
Transportation	<ul style="list-style-type: none"> Expand Trans Help eligibility criteria Improve Trans Help service 	<ul style="list-style-type: none"> Affordable, wheelchair-accessible van service that meets a wide variety of needs 	
Social Opportunities	<ul style="list-style-type: none"> Evening and weekend options 		
Specialists	<ul style="list-style-type: none"> Individual support/advocacy for more or improved service 	<ul style="list-style-type: none"> Equitable, affordable, no-wait Mississauga-based service for all 	
Case Management	<ul style="list-style-type: none"> High-quality, consistent case managers 		
More Autism Services		<ul style="list-style-type: none"> Equitable, affordable, no-wait Mississauga-based service 	
Transition from High School	<ul style="list-style-type: none"> Prepare for transition process before graduation 		
Community Recreation Centre		<ul style="list-style-type: none"> Affordable, supported daytime/evening classes and programs 	
System-Wide Reforms	<ul style="list-style-type: none"> Accelerate Ministry of Community and Social Services promise to improve the funding application process by making “the application process in developmental services more consistent, fair and equitable across the province” Provide funds for implementation of innovative residential models Make information easily accessible and understandable to all 		

Next Steps

The first step is the May 14th meeting with caregivers to discuss the Caregivers Planning and Action Agenda and identify which of these issues are short, medium and long term priorities.

The second step will then be an action planning meeting. Interested caregivers will be invited to meet and plan with the Board of Directors of OM21+ an action campaign that can lead to success on the priority issues. The action planning meeting will be set for late May or early June.

The third step will be implementing the action plan. In support of the action plan we expect we will

- Provide advocacy support to parents around these issues
- Create working groups
- Develop a media and communications plan
- Reach out to involve more caregivers

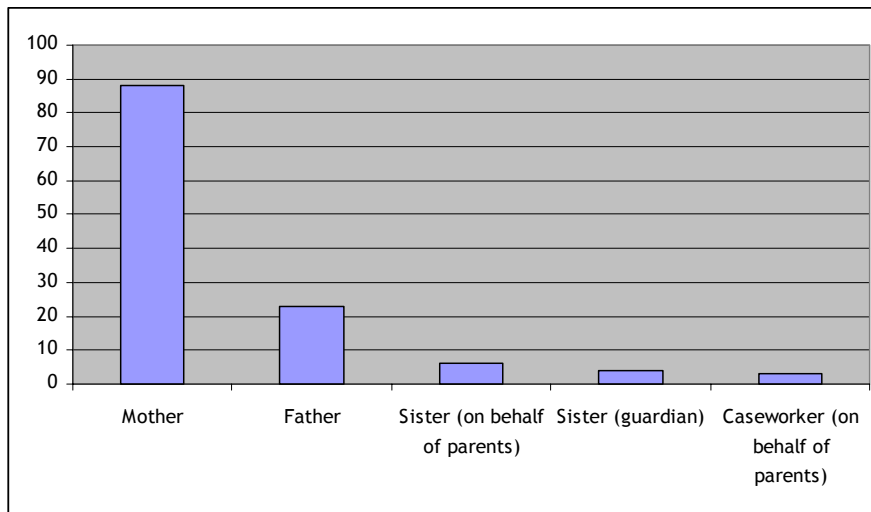
2007 Survey of Community Needs of Mississauga Youth and Adults with a Developmental Disability

123 self-administered surveys were completed by caregivers of a family member with a developmental disability either online or hard copy. 64 respondents participated in follow-up telephone interview.

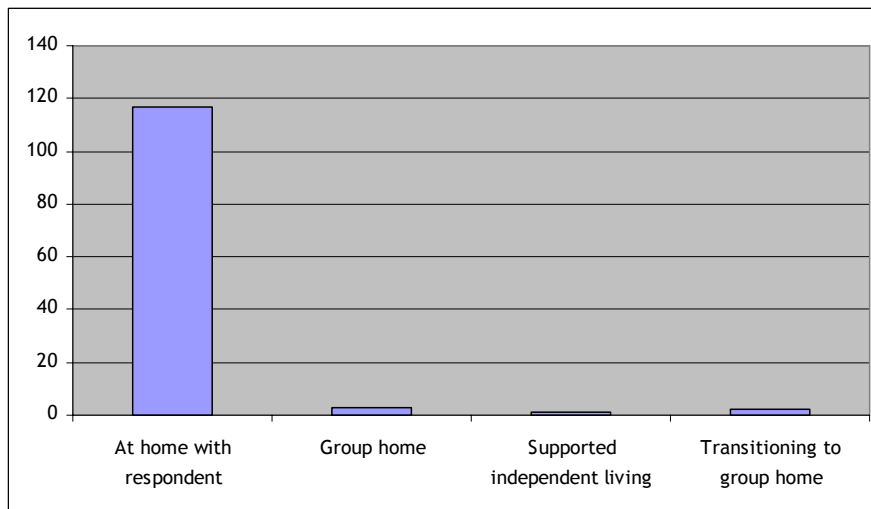
Below are some characteristics of the families surveyed:

91% of respondents reside in Mississauga

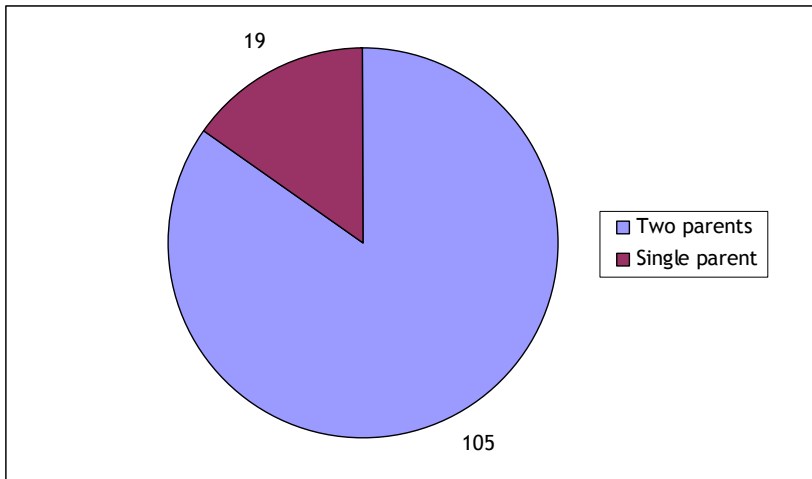
Respondent's relationship to family member



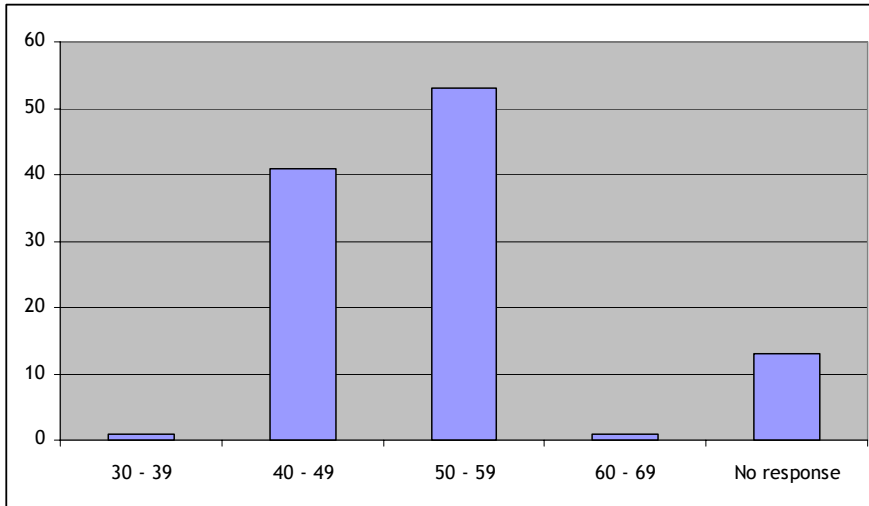
Family member's residence



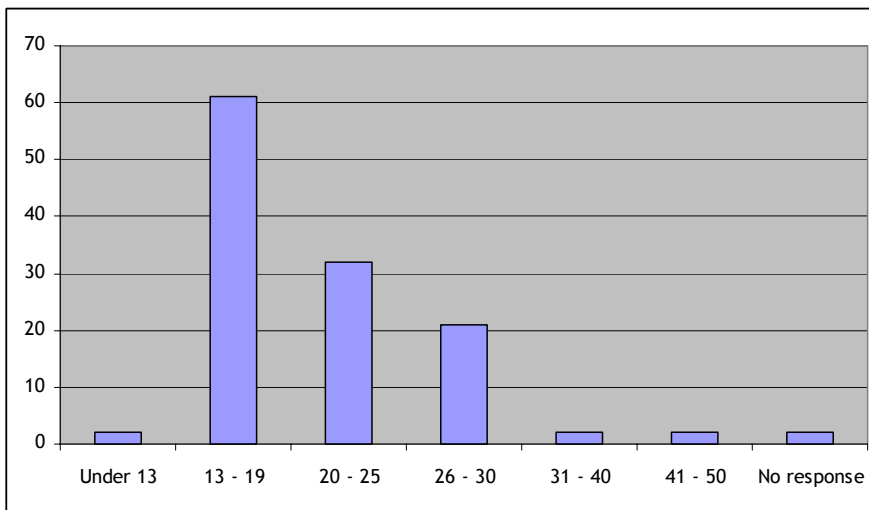
Household status of respondents



Age of caregivers



Age of family member



Appendix

Following are detailed descriptions of the recommendations captured in the Caregivers Planning and Action Agenda:

SSAH

- Change restrictions: be able to carry over funding to next funding period; enable it to be used towards professional services such as psychologists, speech therapists, etc.
- Increase funding to a level commensurate with need

Residential

- Immediate housing for some with urgent needs
- Immediate 'transition' housing for some
- Create options for transition to residential in next 5 - 15 years
- Right to self-determined residential models. For example, leave family home to loved one and community agency provides appropriate amount of support per week. Or, keep family member at home and receive funding directly - perhaps hire live-in help
- Once settled in residence: funds to hire support worker for visits home. Better managed group homes, better staff. Possibly accreditation

Support Workers

- Organized pool of *trustworthy* support workers. Police-checked, available when you need them, reliable, preferably living nearby. Some say education and experience are important - want someone who can handle challenging behaviour, plan activities, and advance skills, not just a glorified babysitter. Others say good people can be trained: their top priority is someone committed to the work, who does it because her or his 'heart is in it', not merely to earn pay
- To be effective, this resource must be accompanied by adequate funding. Good workers need fair compensation for the hard work

Overnight Respite

- Increase CLM funding
- Expand summer camp offerings; make service available all summer long
- Provide emergency respite money or facilities
- Oaklands should provide appropriate onsite medical care for service users who become ill during their stay, not require them to immediately return home
- Support workers to do affordable in-home or out-of-home overnight respite
- Locate respite facilities in Mississauga so day activities are not interrupted
- Respite options for "high-functioning" persons (currently, Oaklands may be inappropriate)

Before/After School Care

- PLASP style program or incentive for support workers to work these 'odd' hours - critical need for working single parents

Day Activities

- No wait between graduation and beginning day activities
- Group participants according to compatibility (such as personality, ability level and interests, possibly age and diagnosis)
- Gear activities to ability level and interests (e.g. taking walks and sensory stimulation vs. crafts, music, and drama). Offer ongoing learning (life skills, literacy, etc.) for those who want it
- Equitable: all people should receive up to 5 days/week of service
- Funding, such as Passport, should be at a level commensurate with cost of day programming
- All programs housed under one roof, not multiple agencies

Base Site

- Equitable: all people should receive up to 5 days/week of service at an affordable rate
- Not turn away from base site person that requires 1:1 care
- Not require 3 year commitment for those who pay with Passport funding
- Subsidized community outings
- Expand facilities (becoming crowded)

Volunteer Work/Paid Employment

- Opportunities for both should be widely available
- Work should be meaningful
- Expand Workplace Safety Insurance Board coverage
- End ODSP claw backs

Post-Secondary Education

- Expand beyond the current 20 spots per year at Humber College

Transportation

- Expand Trans Help eligibility criteria
- Improve Trans Help service
- Create an affordable wheelchair accessible van service that meets a wide variety of needs

Social Opportunities

- Create evening and weekend options
- Specialists (mental health, dual diagnosis, challenging behaviours, personal development, etc.)
- Individual support/advocacy to get more/right services
- Create equitable access, decrease waiting times, subsidize cost, and locate in Mississauga a full range of needed services (speech, language, behavioural, occupational, IBI/ABA, etc.) and therapy (psychologists, psychiatrists, etc.)

Case Management

- Case managers that stay with a family over time and support them ‘full circle.’ (e.g., help hire a support worker or educate about the formation of support circles). There should be regular check-ins by phone and occasional home visits. Case managers should have cross-sectoral knowledge (e.g., help family navigate other service systems like school and ODSP)

Dedicated Services for Autistic Persons

- Create equitable access, subsidize cost and locate in Mississauga services such as day programs, workshops, social groups, employment and independent living supports, counseling, etc.

Transition from High School

- Prepare for the transition process several years before graduation, (e.g., several times a week, family member attends co-op placement that will continue after graduation)

Community Recreation Centre

- Affordable, supported classes/instructors/programs for people with special needs. Daytime programs for adults and after school programs for youth (physical activities, cooking class, etc.)

System-Wide Reforms at Ministry of Community and Social Services level

- Accelerate promise to "make the application process in developmental services more consistent, fair, and equitable across the province." Ensure all funding applications and eligibility criteria are in layman's terms and easy to correctly interpret
- Release funds for implementation of promised innovative residential models (i.e., the right to self-determined living arrangements)
- Improve communication. Multilingual information; leave no one in the dark about services to which they are entitled; information about developmental services easy to find and understand

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