



# **Autism Ontario's Response to the MCSS Opportunities and Action Document**

**June 30, 2006**

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### **1a. What makes it hard for a person with a developmental disability to be active and included in the community?**

Regardless of functioning levels, people with a developmental disability on the autism spectrum face significant barriers to participating in the mainstream of Ontario life. All people with ASD have problems in the essentially human behaviours of social interaction, of communicating ideas and feelings, of imagination and of relating to others. To actively participate in community it is essential that support plans be based on individual patterns of strengths and limitations with the emphasis being placed on an individual's STRENGTHS. Clearly this is a heterogeneous group with unique and diverse needs therefore personalized approaches with independent planning and facilitation is required.

Attitudinal barriers and barriers created by policies or practices of government, community agencies or school boards have the greatest impact on people with a developmental disability/ autism spectrum disorder and their families. Things other people take for granted, such as appropriate education, employment and leisure activities and independent housing for adults remain elusive for many people with a DD or ASD and also for their family members.

Work also needs to continue in order to change society's attitude. We know that education and awareness changes people's way of thinking and responding and should be increased. This is especially true of the very unique needs of individuals with ASD that both service providers and the community at large need to be aware of. Poor attitudes result from a lack of information. Communities also learn, if all kinds of people are present and belong, not isolated and segregated. To do this individuals and families need to be supported, as appropriate for each individual, so they can participate in the community as respected citizens.

### **1b. What would make it easier to be active and included? Who can make these changes happen and how might they go about it?**

A lead role needs to be taken by government and agencies to ensure there is more awareness of the special needs of individuals with developmental disabilities, especially ASD. The urgent need for careful planning and expansion of a wide range of services and supports for individuals with ASD and their families must be addressed. Transitions are especially challenging for people with ASD. Long-term planning and flexible resource allocation aimed at known areas of difficulty, like the move from school to work, would go a long way to keep stress minimal. The key here is to have **FLEXIBLE funding**, whether it flows to families, individuals or agencies, to enable them to have/provide supports when they are needed, with the proviso that they can be reduced or re-allocated when the

need diminishes. The system needs to be more responsive to changes in a person with a DD or ASD which includes:

- life long planning and coordination- best provided by one's family supported in the process by an independent facilitator and agencies- and the funding to properly do this
- a central registry of government/service provider services and programs which ensures accurate information and an easily accessible seamless transition
- stable, annual, predictable funding based upon needs rather than diagnosis
- additional flexible, portable funding for emergency or crisis situations
- accessible, equitable services
- additional resources mandated for agencies to reduce waiting lists
- need for various types of housing options or living arrangements
- vocational opportunities, either paid or unpaid, and vocational support services
- appropriate funding and services for aging people with a DD or ASD: ODSP ends at 65
- inter-ministerial approach with collaboration between ministries/departments: Health, Education, Citizenship, MCYS, Developmental Services, Mental Health, Housing, Transportation etc.
- community capacity building that is flexible, collaborative and innovative including partnering with local community groups

### **1c. What do you see as the role of the various players in making it easier for people to be included in their community?**

Autism Ontario embraces the diversity of people with ASD and at the very core of our philosophy is the belief that no single program, treatment or support will benefit all individuals with ASD or a DD. These individuals, because of the unique nature of ASD and the lack of adequate or welcoming programs, may not venture forth in the community. Many parts of society can play a role in supporting these people including:

- **Individuals** with ASD of all ages, interests and modes of communication may be self advocates. They need to be valued for who they are with recognition of their full human rights as citizens. The recommendation of what is "best" or "most effective" should be determined by those people directly involved- the individual with a DD or ASD, to the extent possible, and their parents or family members, medical practitioners, educators and service providers.
- **Families** may play a crucial role in planning and communication and often understand the person best. They advocate for the citizenship of their loved one with a DD or ASD, find the best help available and work as part of the team to support their loved one and enrich and enhance their lives.

- **Government** has the central but shared responsibility to enable **ALL** individuals to be full citizens in society– including our most vulnerable citizens. Help to families enables all family members to participate more fully as citizens.

Inter-ministerial collaboration/accountability is essential particularly in:

- Expansion of community connectivity supports- independent facilitators/planners
  - Better planning for a person’s whole life, either linked to existing and respected service providers, or through an independent group which provides planning services that are available to individuals not directly linked to a particular community-based service
  - Expansion of mental health supports
  - Funding that is portable, stable and based on each individual’s person centered plan
  - Funding to develop more physicians trained in DD and ASD for ongoing medical supports, supervision of medication and other health care needs
  - Funding to enhance training of educators /developmental service workers about ASD
  - Identifying how many people are affected, where they are living and under what conditions
  - Better training for educators at colleges and university levels so that individuals with ASD have better skills to cope as adults with adult responsibilities and opportunities
  - Better incentives for people to choose education and a career in developmental services
  - Providing transparent ongoing evaluation of existing and new programs to determine effectiveness and public accountability
  - Providing enhanced support for organizations/agencies with a proven track record in providing effective, individualized supports to people with ASD (such as Autism Ontario, Kerry’s Place Autism Services, Geneva Centre, Woodview Manor) and utilizing this expertise to improve education, awareness, training and evaluation as listed above.
- **Service Providers-** Need to be supported financially to provide appropriate and ASD-specialized services in collaboration with the individual and family. Service providers should be provided the resources to develop specialized supports which address the needs of individuals rather than being funded to provide generic services to which individuals need to fit into. There should be funds for person-centered/person-directed planning and people specifically trained to do this.
  - **Others** (businesses, faith based communities, cultural organizations, service clubs, volunteer groups, police etc.)- have a role to recognize the value of all people and permit and promote acceptance within their settings. These groups may also:
    - provide community education & awareness opportunities, embrace, encourage and commit to community involvement which reduce attitudinal barriers
    - provide opportunities to participate in the community in which they are located

- address accessibility needs
- ensure non-discriminatory hiring practices
- provide fair wages

**1d. Do you know of any examples of successful partnerships among some or all of these players that others could learn from?**

There are a number of examples of positive collaboration between MCSS funded agencies, psychiatric hospitals, and professionals that have worked very well in support of specific individuals. Some good examples are:

Windsor-Essex Brokerage Supports – Families and individuals experience the choice of independent and unencumbered facilitation and planning, making key decisions about their lives. Government, agencies, families, and People First work in collaboration.

Kerry's Place Autism Services and the Centre for Addiction and Mental Health have worked together to develop protocols re individuals with ASD, along with families, case managers and Community Living.

Opening Doors (Hamilton Family Network) – is a Foundations funded project where young people are supported as they begin to plan for graduation from secondary school to have the same choices and opportunities as their classmates e.g. post secondary education, part time jobs, volunteering. An independent facilitator assists families and individuals to develop plans, make connections in the community, support situations to be successful etc.

Kerry's Place Autism Services has partnered with Brampton/Caledon Community Living to help a young person with difficulties with police over loud behaviour. They have also helped train staff of Brampton/Caledon CL and the local police to educate them both on ASD.

**1e. Are there particular cultural considerations that you know about that will need to be addressed appropriately in plans for including people fully in the community?**

Awareness of cultural issues ensures better support and may help lessen communication challenges and barriers. An example of a best practice in this area is the Community Liaison department of the York Region District School Board which is dedicated to deal with cultural challenges such as: proper language etiquette, mixing of genders in community outings, unsuitability of community & recreational venues and religious issues. Translators may also be required to include people fully in the community.

## **Respite for Caregivers**

### **2a. What types of relief (“respite”) from caregiving responsibilities are most needed by families?**

Short, medium and long term respite are all required at various times particularly:

- Specialized Supports- comprehensive/clinical(psychiatry), group and/or individualized direct support- day, residential, employment, respite supports, training centre, accessible transportation
- Meaningful day supports/employment--individuals who are no longer in a structured school setting represent a wide range of interests, abilities and needs.
- Special Services at Home (SSAH) is the most successful model in place currently for good general relief but there are waiting lists, not enough funds and quality issues with some employee’s training. In some areas of the province some people with ASD (Asperger Syndrome) are excluded by their diagnosis from receiving services because their impairment is seen as less severe. There are also challenges with money running out in some communities or difficulty finding and retaining support workers due to inadequate remuneration. Individual/families should be able to choose and train appropriate support workers so perhaps there needs to be enhanced Special Needs at Home funding for this specialized training.

### **2b. What would you like to see in the “best possible” system of family relief? What would be offered? How would it work?**

A range of respite options need to be fully funded, accessible, predictable, stable, local and individualized. Innovative, flexible and portable respite supports are desperately needed by families with an individual with ASD. Longer term specialized relief with a "treatment component" is particularly needed when a family gets to the point that it cannot cope and needs more than general relief. Specialized relief is also needed so families of adult children can take vacations, or get away for an evening or week-end. There should be a common application and equity in the system.

### **2c. What currently prevents families from getting the relief they need?**

Lack of funding, inequity across province (particularly individuals with Asperger Syndrome), lack of suitably trained relief workers, onerous application forms, cultural differences, feelings of guilt or lack of trust in another’s ability to care for their individual, lack of transportation, inappropriate mix of individuals being served together; i.e. 1 female with 4 males, children with adults.

## **How would you suggest that these challenges be overcome?**

- Increase funding and decrease waiting lists
- Eliminate inequity based on diagnosis (Asperger Syndrome issue- a definition problem leads to an access problem)
- Increase community capacity to provide specialized respite via training/mentoring by specialized agencies with appropriate background and expertise. Collaborate with service clubs, faith based organizations, community colleges etc. to train respite workers and volunteers.

## **2d. Are there special needs – emergency situations, for example – that require something different from the standard respite approach? What is different and how can these needs be met?**

Emergency situations require immediate response, within hours rather than days or weeks. There needs to be an added level of flexibility and responsiveness for such situations that arise and families need to know that such an emergency respite exists since such higher pressure needs can be particularly evident in individuals with ASD and their families. These needs can be met by increasing community capacity through recruitment, training and mentoring of specially trained workers and partnering with existing agencies. Good examples that currently exist are Griffin Centre in Toronto and Service System Response in York region.

A different approach from standard respite could be to develop a buddy system to come in and take the individual out for an outing. To accomplish this, local community linkages and training must be developed through advertisement at local volunteer bureaus, service clubs and religious organizations. A surrogate family could come in at vacation times or take the person to their home. Both approaches would involve training which could be done by partnering with existing agencies, DSW programs at community colleges, local YMCAs, etc.

## **1.3 Partnerships with Families on Residential Supports**

### **Key Questions**

### **3a. What can the ministry do to better support individual choice of how and where to live – within or outside of existing ministry-supported arrangements?**

Ask the individuals who require and would benefit from residential supports what they feel they need to be successful participants in society. Ask them to describe whom they feel they would like to live with.

Separate funding for support and funding for housing--fund individuals not "beds". Allow more flexibility in how families can use housing funds. Break down the current barriers. Families that have been trying to develop more creative options for years have been met with huge resistance from MCSS and agency staff. Case Management and Service Coordination is required for vulnerable families.

There is a need for more creative housing or living arrangements which might include variations on the following scenarios:

- families who may want to secure a home by placing the down payment and partnering with an agency where the direct funding from the ministry would flow to the agency to pay the mortgage. If families are doing this on their own, the funding from the ministry would have to be adequate to cover mortgage payments, maintenance expenses and the staffing component.
- Parents might give up house or place it in a trust for the individual, secure another living mate, who would be most compatible to the individual, selected by individual and/or family, and the ministry could fund operating expense. First and foremost planning should be done through perspective of person with ASD.

**3b. Do you know of any examples of successful partnerships among families, agencies, community groups and government in creating new kinds of living arrangements? Please describe what is happening and what makes it work.**

Kerry's Place Autism Services, TreAdd, Woodview Manor, HAADD- Homes for Adults with Autism & PDD, Individualized Funding Coalition, St. Francis Advocates, Christian Horizons and Harmony Centre for Community Living.

**3c. What barriers must be removed or incentives provided to individuals, families or agencies to encourage the creation of innovative residential options? (Think about funding, legislation, social assistance or other programs)**

The biggest current barriers to encourage innovative residential options are lack of funding, lack of opportunity and long waiting lists (not months but many YEARS). Due to privacy legislation it is difficult for families to share their stories about creative housing options. What monies will be provided for differing housing alternatives? How uniform are the guidelines from region to region? Is the funding uniform across regions? Will there be more options than the group home model? If buying a house will there be assistance with the capital or just operating expenses? Who will decide who will reside in the accommodation? Will hard-to-serve cases be included in the housing mix?

The best incentive to provide would be individualized funding that flows to families and/or agencies based on a person-centered plan. Positive, creative solutions are extremely necessary to suit the specific needs of each individual.

### **3d. What supports need to be in place to help protect the safety and security of vulnerable people living on their own?**

Support circles, along with an independent facilitator/planner linked with agencies and community would play a part in protecting the safety and security of vulnerable people. There needs to be reasonable, measurable criteria (outcome based) established to ensure the safety and security of these individuals that are monitored independently of who is paying, or providing service. There also needs to be an independent "right review process" to ensure that individual rights are protected – i.e. there is a balance between rights, risks and responsibilities. An example is Accreditation Ontario who sets standards for the quality of life re: health & safety, intimate relationships, appropriate behaviour of self and staff etc. There also needs to be community based training for people in community who are emergency responders so there is a greater sensitivity to folks with ASD so that situations are not exacerbated. A great resource is the Dennis Debbault website <http://www.autismriskmanagement.com/>

### **3e. What improvements could be made to existing choices?**

- ❖ **Group Homes?**
- ❖ **Supported Independent Living?**
- ❖ **The Family Home Program?**

The above categories should always be available but funding should be based on an individual's need. There should be creative, flexible and responsive living options based on an individual's person-centered plan. These living options should have the ability to change over time as the needs of the individual also change over time. People should not be locked into unsuitable living situations. The person's perspective needs to be foremost when choices are made re: accommodations, room mates etc.

## **1.4 Transition across Life Stages**

### **Key Questions**

#### **4a. What information and support would be of most help to individuals and families as they plan for the transition from school to adult supports?**

Transitions are especially challenging for people with ASD. Long-term planning and flexible resource allocation aimed at known areas of difficulty, like the move from school to work, would go a long way to keep stress minimal. The key here is to have FLEXIBLE person-directed and person-centered planning and funding, whether it flows to families, individuals or agencies, to enable them to

have/provide supports when they are needed, with the proviso that they can be reduced or re-allocated as when the needs of the individual change. The system needs to be more responsive to changes in a person with a DD or ASD which includes:

- life long planning and coordination- best provided by one's family supported in the process by agencies or an independent facilitator who has proper training and knowledge There should be a monitoring mechanism to ensure planning has been implemented.
- stable, predictable funding based upon needs
- flexible funding (i.e. funding that can be readily accessed when needed for particularly difficult periods and then returned to previous levels
- accessible services
- resources for agencies so that there are no waiting lists
- need for housing (of various types)
- vocational opportunities and vocational support services
- services for aging people with a DD or ASD
- inter-ministerial approach with collaboration between ministries/departments: Health, Education, Citizenship, MCYS, Developmental Services, Mental Health, Housing, Transportation etc.

Accurate information should be easily accessible from government/ service provider agencies/ educators to make transitions smoother and to let families know what is available from all ministry sectors. Guidelines should be developed re: acceptable funding, housing, employment, recreation etc.

#### **4b. What programs and supports need to be in place for seniors who have a developmental disability?**

There needs to be specialized access to geriatric support. For those that choose to move into a seniors home specialized support and education must be provided. Nursing health requirements, homemaking, availability of transportation, assisted devices, day programming—do we know how many people are out there who need these services?

#### **Optional Detailed Questions**

#### **4c. Who should be involved in planning transitions from school to adult support?**

##### **Individual, family, school staff, community staff**

Life long planning and coordination- best provided by one's family and supported an independent planner with suitable expertise, local agencies and community. There should also be an inter-ministerial approach with collaboration between ministries/departments: Health, Education, Citizenship, MCYS, Developmental Services, Mental Health, Housing, Transportation etc

**4d. What existing services for seniors are available to people with a developmental disability (whether they live with family, on their own or in government-funded residential supports)?**

**4e. Do you know of any examples of successful partnerships among individuals, families, schools, community organizations and governments to support life transitions that others could learn from? Please describe what is happening and what makes it work.**

Successful partnerships work well when there are progressive people with trusting relationships who have the best interests of the individual at heart. Specialized Autism Consultants have often played a central role as a facilitator, mediator and person with specialized knowledge. Some examples are from Kerry's Place Autism Services who have been contracted by the Simcoe School board to help with the transition from school to life and has partnered with VITA to help with sexuality issues of individuals with ASD. Opportunities Mississauga for 21 Plus provides meaningful daytime activities, learning opportunities and recreational options for individuals with a DD to participate in and transition into when school finishes.

## **1.5 Supports for People with Specialized Needs**

### **Key Questions**

**5a. What are the gaps between what is required by people with specialized needs and what is provided?**

Specialized services do not exist equally across the province especially for individuals with ASD and dual diagnosis. Long-term planning and flexible resource allocation aimed at known areas of difficulty, like the move from school to work, would go a long way to keep stress minimal. The key here is to have FLEXIBLE

funding, whether it flows to families, individuals or agencies, to enable them to have/provide supports when they are needed, with the proviso that they can be reduced or re-allocated when the need diminishes. It would also be helpful if there was a central source of accurate information and better collaboration between families/ government/ independent planners/service provider agencies and educators particularly about specialized service providers.

People are denied access to various ministry funded services and supports based on their primary diagnosis and/or age. Speech and Language Pathologists, Communication Assistants, Augmentative and Alternative Communication technology and devices, Occupational Therapists, Behaviour

Therapists, Psychologists and Multidisciplinary Team Assessments over the age of 6 are typically accessed only by families of individuals with ASD with sufficient private resources.

### **5b. What suggestions do you have as to how best to close these gaps?**

Examine "best practices" where things are working better than in other areas, and use these to build capacity elsewhere. Find ways of sharing expertise across regions through specialized training, mentoring and video conferencing.

More funding of independent planners and facilitators would help. If individual's lives are better because of choice, control, direct funding, portability, etc, they may not exhibit as much challenging behaviour.

Allocate ministry funded resources, services and supports based on the need of the individual rather than their diagnosis or age.

### **Optional Detailed Question**

### **5c. How can the specialized services recently introduced by the ministry best work together with the core service system?**

Same as 5B

## **1.6 Taxes, Wills, Disability Savings Plans**

### **Key Questions**

### **6a. What changes are needed to help families cope financially as they care at home for their family member with a disability?**

Make it feasible through taxation incentives for families to give their home, or to buy a home for their individual with a DD or ASD.

Make it more possible for parents to "income split" for taxation purposes when one stays at home to support their dependent with a disability.

Allow more tax deductions for all disability related expenses.

The concept of registered savings plans is good. Remove existing ODSP barriers to using wills and trusts to support people with developmental disabilities – i.e. eliminate the need for setting up a Hensen Trust.

**6b. What changes would help families who want to make long-term plans to support their family members with a disability?**

Help with planning support, and alter legislation as above, to facilitate the process, and make it worthwhile. Simplify, simplify, simplify.

**Optional Detailed Question**

**6c. What are the best ways to get people the information they need about wills, trusts and other plans to support their family member with a disability?**

A single point of access system, perhaps through Community Care Access Centres supported by accurate, up-to-date information on a government website would enable people to more effectively arrange their financial affairs in support of their family member with a disability. Community planning tables, community service provider agencies, and the education system at the high school level would have knowledge that this information database is available.

Sharing of and reference to information already produced and readily available in the private sector should be available through existing government channels. An example is the book and CD 'Removing the Mystery – An Estate Planning Guide for Families of People with Disabilities', produced by the Ontario Federation for Cerebral Palsy, Graeme Treeby author.

**1.7 Quality Supports and Services**

**Key Questions**

**7a. What role should individuals and their families play in setting quality standards for supports delivered by agencies, and for supports purchased elsewhere?**

Families should have a process, through the Person Centered Planning Process to help the individual establish their goals with their expected outcomes. Standards of supports must be included. MCSS should formally establish outcome-based quality measures, along with ways of assessing them. These are inherent in the Council of Quality and Leadership Canada: Outcome Based Performance Measures.

## **7b. How can individuals and their families contribute to the continual improvement of the quality of services and supports provided?**

- Individuals must have the right to discuss their services and supports, to the best of their ability. 'Nothing about me, without me'.
- Individuals need the opportunity to choose who will support them in facilitation planning, which needs to be unencumbered with frequent review.
- Their families may have information to assist in this process and be included in all planning.
- Individuals need to be advised of the accountability process of the service provider and the appeal process should they disagree.
- Their families also need to be advised of these processes.
- Funding for on-going in-service and staff training for support workers.
- Families should be invited to share information about all useful professional services used in the individual's past.

### **Optional Detailed Question**

## **7c. What needs to be put in place to monitor the quality of supports and services provided to individuals and their families (through agencies, or purchased directly from elsewhere) against agreed standards?**

Compliance review processes such as exist now, along with formally adopting objective measures such as the Outcome Based Performance Measurement Processes outlined in block 6, above.

Independent assessment processes.

### **WHAT ELSE WOULD YOU LIKE TO SAY:**

The whole process has to be easier to access than it currently is.

More attention should be given not just to the "spirit of Person Centre Planning" but to properly implement the totality of the goals and objectives set out in the Person Centre Plan and be more adequately funded by the service providers. There should also be more transparency and accountability by government as to how funding for individual funding is calculated.

What protection mechanisms are currently in place for vulnerable (especially non-verbal) adults in residential services? Who has access to these mechanisms? How are they accessed? What are the systemic flaws? How can they be identified then addressed? Is there an ombudsman for our most

vulnerable adults placed in residential service systems?

Is there a strategic plan for a flexible, sustainable and outcome-oriented **adult** welfare service delivery system?

MCSS requires documentation through Occurrence/Incident and Body Checklist Reports to be filed with them upon any injury, assault or abuse. What tracking system for these reports is in place? Who monitors the tracking system? What follow up is mandated? By whom? To whom? Who holds the transparency and accountability pieces?

Family/designate notification within 24 hours of occurrence is a requirement of some service providers. Is this mandated by the ministry, or has this particular provider chosen this as their 'best practice'? If not ministry- mandated, why not?

People with disabilities living in ministry funded residential services do not have the option of whom to share their home with.

Is peer abuse and assault in group homes frequent, rampant or merely a few isolated incidents? Does anyone know? How is this tracked?

The Ministry of Children and Youth Services (MCYS) has recently circulated "*Linking Child Welfare and the Children's Service System in Ontario: A Policy Framework for Communities*" to organizations across all sectors serving children and families.

Is there a comparable document from MCSS, or is 'Opportunities and Action' it?

Although we welcome the opportunity to provide input this process has been very time consuming. Our wish is that after all of this time and consultation there will be a meaningful link between public input and the final outcome and our system will truly be transformed.

Thank you.

**Autism Ontario**