



Autism Society Ontario

Submission to
Transforming Services In Ontario for People who have a Developmental Disability
Preliminary Discussion Paper

November 30, 2004

Introduction

Autism Society Ontario welcomes the opportunity to provide feedback to the Joint Development Services Sector Partnership Table on their Preliminary Discussion paper ***Transforming Services in Ontario for People who have a Developmental Disability***. This document provides the findings from 4 different discussion groups that were held. The draft document created from these groups was also widely distributed amongst our provincial membership for input.

ASO is a leading source of information and referral on autism and one of the largest collective voices representing the autism community in Ontario. Members are connected through a volunteer network of 31 Chapters throughout the Province of Ontario. We are dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families, and the professionals with whom they interact. The Society and its chapters share common goals of providing information and education, supporting research, and advocating for programs and services for the autism community. Our vision is *Acceptance and opportunities for all individuals with Autism Spectrum Disorders* and the mission of the ASO is *To ensure that each individual with ASD is provided the means to achieve quality of life as a respected member of society.*

It is estimated that up to 70,000 people in Ontario today have some form of Autism Spectrum Disorder (ASD). It is one of the most common developmental disabilities with prevalence estimates as high as 1 in 165 people (Fombonne E. The Prevalence of Autism. JAMA 2003; 289(1):1-3). The number of people being diagnosed with ASD continues to increase dramatically yet most of the public, including many professionals in the medical, educational and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with ASD.

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. Unusual sensory processing and motor patterns are also seen in people with ASD and there is a wide and uneven expression of a range of ability levels among people with this Pervasive Developmental Disorder (DSMIV diagnostic terminology for ASD, American Psychiatric Association, 1994). Communication deficits range from mild to severe, with approximately one third of people with ASD remaining essentially non verbal throughout their lives. A majority of people with ASD have a significant level of cognitive impairment, although those with Asperger Syndrome have more normal levels of cognitive functioning but their executive functioning and adaptive functioning may be impaired. 40% of "higher functioning" people with ASD also have an anxiety or mood disorder, the most common being OCD and depression. Many people with ASD have co-morbid conditions including Epilepsy, Mental Retardation, Down Syndrome, Attention Deficit Hyperactivity Disorder or genetic disorders such as: Fragile X Syndrome, Landau-Kleffner Syndrome, William's Syndrome or Tourette Syndrome, along with higher rates of anxiety. These must all be considered in looking at the overall challenges of the person with ASD.

Clearly this is a heterogeneous group with unique and diverse needs. It is essential that intervention plans be based on individual patterns of strengths and limitations (Perry, A & Condillac, R. *Evidence-based Practices for Children and Adolescents with Autism Spectrum Disorders*. CMHO 2003:18). As the numbers of children diagnosed with ASD continues to increase, 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.

1. What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability (DD)?

ASO embraces the diversity of people with ASD and at the very core of ASO's philosophy is the belief that no single program, treatment or support will benefit all individuals with ASD or a DD. Likewise, many parts of society 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.
- **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:

- Providing enhanced support for organizations/agencies with a proven track record in providing effective, individualized supports to people with ASD.
 - Expansion of mental health supports
 - 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.
 - Funding to develop more physicians trained in DD and ASD for ongoing medical supports, supervision of medication and other health care needs
 - 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
 - Provide transparent evaluation of existing and new programs to determine effectiveness and public accountability
- **Service Providers-** provide appropriate services in collaboration with individual & family, should be used to support individuals rather than to provide services and there should be funds for person-centered/person-directed planning
 - **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 education & awareness to encourage community involvement and

- reduce attitudinal barriers
- provide opportunities to participate
- address accessibility needs
- ensure non-discriminatory hiring practises
- provide fair wages

2. What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?

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 expected 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.
- stable, base funding based upon needs
- predictable funding
- flexible funding (i.e. funding that can be readily accessed when needed for particularly difficult periods and then can be backed off
- 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

3. What supports and services that are currently available work well and should be built on for the future?

Studies show that individuals with autism respond well to a highly structured, specialized environment, tailored to their individual needs, whether it be through education, recreation or employment. A well designed approach may include some elements of communication therapy, social skill development, occupational therapy (which is also responsive to the unique sensory experiences of many individuals with ASD) and applied behaviour analysis, delivered by trained professionals in a consistent, comprehensive and coordinated manner. The more severe challenges of some people with ASD may be best addressed by a structured education and behaviour program, which contains one-on-one support or a small group environment. However, many other people with DD or ASD may be successful in a fully inclusive environment with appropriate support.

- Special services at Home (SSAH) - most successful 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) do not get service. Challenges that result in waiting lists for depleted local SSAH funds must not occur. There must be flexibility in being able to pay family members for services, so that they can spend quality time with their family member with DD or ASD. For example, if a sibling spends a day, as a caregiver, with an adult with DD or ASD, providing respite for older parents, the sibling should be able to be paid so that he/she can have the free time to spend with the sibling (some family members cannot afford NOT to work and thus do not have the time to take the sibling /family member for 1 or more days). Also need flexibility in being able to purchase other services (e.g. housecleaning, shopping, etc.) so that there is enough time to spend doing activities with the person with DD/ASD. It must be remembered that it is not easy, even for family members, to spend full days or weeks with a relative with DD or ASD, and family members should be appreciated for their gift of time.

- Ontario Disability Support Payment (ODSP) has a great capability but some aspects need reworking:
 - Income support has essentially been frozen since 1993. It needs to increase substantially to improve quality of life and to keep up with the increased costs of living (the recent 3% increase in ODSP was negligible, but an appreciated step in the right direction).
 - Create financial incentives for ODSP recipients to locate and secure paid employment
 - Work is a disincentive since individuals lose their benefits if they work to capacity. The well being of people with a DD or ASD would be greatly enhanced if there was no claw-back until a person reaches the poverty line threshold.
 - If a person consistently makes a certain amount of money then he/she risks losing not only the income portion but also the benefits portion of ODSP income supports.
 - There needs to be some separation between organizations that have come to depend on a person's ODSP to run their support services and the amount itself- \$112.00 is not enough. Perhaps a formula of some sort or percentage could be worked out.
 - Employment supports – may need to be ongoing and support not just seen as a stepping stone. Currently if support is provided the first time a person has worked (entry level position) and then they are able to advance and make more money they can't get new ODSP for job coaching to support the new venue and improve self. Training with support in a real job setting. Incentives to engage business community leaders regarding employment opportunities for individuals with ASD are strongly supported.
 - Flexibility
- Day programs- may work well for some but not enough available, not flexible enough in meeting ASD needs (social challenges). There should be a range of choices.
- Respite- needs expansion across the spectrum

4. How should a reasonable level of government funding for an individual be determined?

Sustainable funding from government funnelled through existing agencies allows for on-going support and accountability. The important thing to focus on is building a 'life' for the individual

with a DD/ ASD. This includes having a home, a place to engage in meaningful activity during the day including employment in the community, if appropriate, and a social network that provides friendship and support; in short, people with DD/ASD should enjoy full citizenship and so should their family members.

- Based on the lifelong, ever changing needs of the individual and family i.e. person centered planning
- Flexible funding with a range of choices. Funds should follow the individual (not be tied to the agency) and be especially accessible when particular difficulties arise.
- Needs assessment should be completed and criteria need to be established
- There should be training centers devoted to teaching people how to work with individuals with ASD especially to ease anxiety and prevent behaviour outbursts triggered, at times, by unskilled support personnel
- Pool of trained staff that families can access through individual agencies and families should be able to choose appropriate support workers
- Reasonable rate of pay/benefits with standards for individuals who support people with DD or ASD
- Reimbursement for actual extraordinary costs incurred to support a person with a DD in their home: incontinence supplies, laundry, equipment such as alarms, monitors, respite housekeeping
- Encourage parent group initiatives and partnerships with community agencies. This allows for valuable input and contribution of resources from families into arranging the lives of their family members

5. Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?

People of all abilities should have the rights and responsibilities inherent in full citizenship. This includes meaningful work, recreation, relationships, financial well-being and security, advocacy/support in times of need, education opportunities, timely access to appropriate medical care and transportation. All should be provided the opportunity to be valued as participating citizens and they could be helped to achieve this through:

- Individualized, person centered, lifelong approach to funding facilitated by an independent qualified person based on need (not diagnosis/label or age BUT the level of adaptive skill across whole spectrum and across all ages)
- Evidence based best practises following a sound research methodology
- Sufficiently flexible, easily accessible system, once needs are determined, with choices of individual supports and resources (current system not capable of being flexible in a timely way-especially not when a family or individual are in crisis.)
- Importance of the special needs of ASD person (very important considering the unique social challenges/environmental sensitivity)
- Decrease waiting lists and age restrictions
- Provincial coordination of training, supports and research
- Tax credit for extraordinary expenses borne by families of people with a DD/ ASD.
- Stop the “forms” process of re-applying annually. This is a lifelong condition yet diagnoses are repeatedly required annually and families have to pay for these assessments and they are time consuming and often humiliating
- Range of residential options
- Range of affordable, quality respite programs/opportunities

- Speech, language and communication services should be available in community settings based on need rather than diagnosis and age; currently those with a developmental disability over the age of 6 who are non-verbal but with an intent to communicate are prohibited from obtaining SLP services
- ADP-funded communication equipment, even when prescribed by their physician, is partially funded for those with a physical disability but denied to those who also have a developmental disability.
- Chronic underemployment of people with DD or ASD decreased
- Chronic unemployment by family member staying at home to care for their DD or ASD loved one- there should be compensation or a tax credit
- ANY expense incurred as a direct result of a developmental disability should be 100% tax deductible, not income-tested, no minimum or maximum defined benefit:
 - actual cost of incontinence supplies required > age 3 i.e.: latex gloves, incontinence pads, mattress covers, sterilizer
 - costs associated with prescribed devices; batteries, ear molds, visual supports
 - reimbursement for expenses over and above the 'neuro-typical' person:
 - prescribed medications where not covered by a major medical plan
 - transportation to medical, therapeutic appointments
 - enhanced recreation and leisure programs, social skills groups, transit training, family support.
- Core rehabilitation services (SLP, augmentative communication devices and writing aids, equipment, OT, PT)

6. What do you think are the priorities the government should address?

Families need the government to recognize their extreme dedication and love for their family member(s) affected by a DD and/or ASD and to support them in ways that enable family members to be full citizens, providing for their families and participating in community activities (including caring for elderly parents, volunteering, working outside the home, enjoying recreational activities, etc). It has to be recognized that parents and siblings do much of the education of professionals caring for their family members with DD/ASD and this is very stressful. Imagine how family members feel when they fail in their duty to inform about something they themselves do not understand.

- Reduce the burden on families – person- centered, lifelong planning facilitated independently- provide funds for case coordination
- Person-centered simplified approach to funding that reflects individual needs of person and family that is portable and equitable across the spectrum- entrust families with stable financial tools to purchase appropriate services and supports that will change over time- single point of entry to the system for funding
- Specialized Supports- comprehensive/clinical(psychiatry), group and/or individualized direct support- day, residential, employment, respite supports, training center, accessible transportation
- Funds for research- information on ASD numbers (*where are adults with ASD?*) and best practises (*identify services that are effective and create an inventory of examples across the province*. Measure quality of life and outcomes (accountability and criteria)
- More networking/communication at all levels- coordination of ministries and consistency of rules and delivery across province
- Better affordable housing- choices with support
- Support groups for families/adults with ASD in all communities

- ODSP regulations (*\$16,100 is considered poverty in Ontario today— the basic ODSP rate for a person living independently was \$11,160 before the recently announced 3 per cent increase. The rate is lower for adults still living with their families and those in group homes etc get only \$112 or so a month in pocket money (the rest being used for their room & board in the group home—close the gap!) & advocacy-income/employment supports*)
- Interagency cooperation, training and information sharing.
- Transition services for individuals and families
- Advocacy- to address the range of needs and array of supports for entire spectrum (*new funding for high needs rather than the broad spectrum; support faded out too quickly for higher functioning individuals*)
- Parents over 65 with adult children with a DD or ASD living at home- this is often a prescription for isolation and lack of meaningful daily activities
- Individuals who are no longer in a structure school setting-representing a wide range of interests, abilities and needs-- meaningful day supports/employment are needed
- Should not have to continually prove status
- Innovative ideas such as RESP concept applied to support planning for adults with DD/ASD
- Community capacity building that is flexible, collaborative and innovative

7. Is there anything else you would like to say about the ideas in this discussion paper or ideas not included in the paper that you feel are important?

Regardless of functioning levels, people with a DD or ASD face significant barriers to participating in the mainstream of Ontario life. 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. Attitudinal barriers and barriers created by policies or practises of government, community agencies or school boards have the greatest impact on people with a DD or ASD and their families. Work needs to continue in order to change society's attitude. We know that education and awareness changes people's way of thinking and responding.

- Clearer definition of "pervasive developmental disorder" and "developmental disorder"- inconsistent funding and support in various areas of the province based on differing interpretations of diagnosis and diagnostic terminology. All levels of the spectrum need support especially when social understanding is impaired.
- Concerns about non-helpful terminology that is used- "low functioning" "high functioning" should be omitted and should be replaced by the adaptive skill of the person and discussions centered around their strengths and abilities
- Lifelong nature of these disorders needs to be acknowledged
- Staff training in both government and service provider agencies is inconsistent and sometimes inappropriate. Minimum standards are required and need to be enforced
- Develop specialized supports for adults with ASD and DD, typical DD supports are not appropriate nor successful for individuals with ASD
- Restraint issues resulting because society/support staff does not understand the nature of complex behaviour. It is essential that there is adequate training in approved crisis prevention and management methods that maximize safety and focus on completely eliminating the need for restraint and encourage the use of the least intrusive methods.

- Justice system needs to understand the needs of people with a DD, limited or unusual communication styles, behavioural differences, unusual sensory responses in community settings.
- Having a child with autism can have a devastating impact on parent's mental health. In fact, family stress research has repeatedly demonstrated that parents (especially mothers) of individuals with autism experience greater stress, depression and mental health difficulties than parents of other types of disabilities or no disability. (in Perry, A, 2003. Bristol, Gallagher & Schopler, 1988; Dunn Burbine, Bowen & Tantleff-Dunn, 2001; Dyson, 1997; Konstantareas,1991;Sanders& Morgan,1997.)

Appendix A

ASO Resource Materials submitted with this document:

- 1) ASO Website- www.autismsociety.on.ca
- 2) *In Our Own Words*- booklet & video – *Adults with Autism or Aspergers*
- 3) Toonie for Autism Day educational materials and videos
 - 2004 Education Package
 - Meet My Brother (video)
 - A Chance to be Me (video)
- 4) ASO Manuals:
 - Children Diagnosed with Autism: What to Expect and Where to Get Help- Strategies and Information for Ontario Families and Care Providers
 - Navigating the Special Education Systems in Ontario (2nd edition) A Handbook for Parents of Children with Autism Spectrum Disorder
- 5) Our Most Vulnerable Citizens (ASO Publication 1991)
- 6) Supporting Adults with ASD meeting reports 2004
- 7) ODA submission March 2004
- 8) ASO report to OHRC on Education 2002
- 9) ASO report to Minister of Finance, 2004