

The OASIS Response to “*Opportunities and Action, Transforming Supports in Ontario For People Who Have a Developmental Disability*”

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Context

In 2004, the Joint Developmental Services Sector Partnership Table released a consultation document, “*Transforming Services in Ontario for People who have a Developmental Disability*”. In response, OASIS undertook a process of gathering information and opinions on the future of the service system in Ontario and provided a formal response to the Ministry in late 2004. Additionally, OASIS members provided individual responses directly to the Ministry as did other organizations, associations, family and community members. Building on the feedback and perspectives provided through these and other forums, in May, 2006, the Ministry of Community and Social Services released the current paper “*Opportunities and Action, Transforming Supports in Ontario For People Who Have a Developmental Disability*.” Once again, OASIS convened a process to gather information and input from its members. This included written submissions from members and a one day information gathering session on June 14, 2006. This report reflects the themes and viewpoints coming out of that process and represents the position taken by the OASIS Board. Once again, individual OASIS members are also encouraged to respond directly to the Ministry to ensure that all perspectives are heard.

Major Themes

General Support

OASIS would like to compliment the Ministry for providing ample opportunity for input to the development of this policy direction. We are particularly supportive of the many different options to provide input over the past several years as this has given a voice to many individuals, families and community members who haven’t always been heard in the past. We will be providing comments and suggestions on possible improvements and these are provided within a context of general support for the directions outlined within the paper. We are fully supportive of the six principles underlying the framework including citizenship, fairness and equity,

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accessibility and portability, safety and security, accountability and sustainability. Our comments tend to reflect on concerns which we have with how these principles will be implemented and a few areas which we believe need to be addressed more completely.

Healthy Agency System

The paper emphasizes individual and family choice but makes limited comment on the need for a healthy agency system. Some families will choose to receive individual and direct funding and that is an important choice option. However, from the feedback received from existing users of service and experiences with Special Services at Home, many more individuals and families will be accessing services through agencies either by purchasing their services directly or by accessing existing programs. It is imperative to have a sound, stable agency system in place to allow families a real choice of how they want to be supported. The flavour of the paper is that agencies are not creative, innovative or responsive and that these characteristics will only be achieved through direct funding. While the level of innovation varies from one agency to another, most of the creative advances made in supporting individuals have come via agency resourcefulness and willingness to work with families and individuals to reach for their dreams and desires. In fact, in many cases, agencies wishing to support creative responses find their progress thwarted by rules and regulations, financial restrictions and government red tape.

Funding Flexibility

One area in which tremendous progress could be made is in funding flexibility. This is true both from an agency and a family point of view. When agencies attempt to be creative, they are often caught by the silos or program areas that they are funded through and find themselves unable to accommodate innovative responses because of the restrictions imposed through those funding streams. Currently, there are no incentives or rewards for good financial management or creativity. The paper indicates that funding will be more flexible but this will only be achievable if there is a restructuring of the current requirements and an acknowledgement that increased funding restrictions do not equate to improved accountability.

Families attempting to plan for the future are often caught and sometimes penalized by competing rules around things like trust funds, wills, ODSP restrictions, etc. We applaud the

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Ministry for identifying some of these issues and urge it to move forward assertively in bringing together the various levels of government to solve some of these long standing issues.

Intersecting Systems

In addition to funding flexibility, there are a number of other bureaucratic issues that stand in the way of transformation of the system. These include differences in philosophy and service delivery approaches between various ministries, varying levels of responsibility and ownership at different levels of government and competing sets of rules and requirements to meet different objectives. One example is the conflict between a desire for full inclusion and participation in community life like all other citizens and requirements of building and fire codes which define some people’s homes essentially as small institutions. Another example is the difficulty faced by individuals at transition times in their lives as they move from one system to another. We are very supportive of the Ministry’s stated desire to break down some of the issues between ministries and urge the Ministry to take a lead in moving forward in this area. We would be pleased to be involved in this work and are well positioned to identify additional areas requiring coordination.

Resources

It is important to note that even with all of the flexibility imaginable and no concerns with systems in conflict, more resources will be required to adequately support individuals and families. The paper focuses on the allocation and reallocation of funds, equity of funding, and portability and flexibility of funds but there is no acknowledgement that there needs to be additional investment by the government. The lack of appropriate resources has been compounded over the years by pay equity and other employer requirements. We are asking that the long-range plan for the next ten years and beyond include funding commitments which will begin to address some of the inadequacies that currently exist within the system.

Quality of Service and Accountability

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We would agree that quality of service and accountability are intricately linked and of high importance as we move forward with any system transformation. Many member agencies have considered accreditation or are in the process of working toward it and OASIS would support an accreditation system for all agencies. What is less clear is how accountability and quality of service will be achieved in direct funding situations. When individuals are purchasing services from agencies, that contractual arrangement will need to include standards, expectations, etc. We would welcome the Ministry’s initiatives to develop comparable systems of accountability for funds flowing directly to individuals and families.

Inclusion

We are in agreement that we need to do more to ensure that individuals with developmental disabilities have the opportunity to live as full citizens in our communities. Although we may have moved public opinion and awareness and have tools like the *Accessibility for Ontarians with Disabilities Act, 2005*, there remain many barriers to successful inclusion. We are endeavouring to build more and stronger bridges with the broader community. Jointly, we need to continue to seize opportunities to assist in public awareness, attitudinal shifts and media messaging.

Other General Comments

Generally, the approaches outlined in the paper do not reflect rural realities and are more in keeping with a sophisticated and well resourced system. Exercising choice is only an option when choices actually exist in the community and this is dependent on a number of factors including population size, infrastructure and historical development. Additionally, faith, culture (including the deaf community) and language are components of the lives of individuals which need to receive more emphasis. As Ontario becomes increasingly multicultural and diverse, the existence of options related to these factors will become more and more important.

We understand that there is another process in place to review and make recommendations related to single point of access. Our primary concern with both the access mechanism and the independent planning function is that too many resources may be diverted to these functions and away from actual supports. It is important to strive for a balance between providing

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sufficient resources to ensure that these functions are supportive and do not create a bottle neck for the system and having well resourced access mechanisms to an under-resourced service delivery system. We have found that a cooperative approach has been most effective both administratively and financially.

We welcome the opportunity to provide examples of creative approaches taken in various communities and encourage the Ministry to continue to provide mechanisms for the sharing of best practices. As an association, we are committed to stimulating continuous learning and improvement. Through the process of gathering information to inform this response, we had the opportunity to share examples of interesting efforts taking place in different communities and we are committed to finding a way to more formally share best practices and creative ideas.

Specific Feedback

Support for Inclusion and Community Engagement

Although many advances have been made in the inclusion of individuals with developmental disabilities in the community, many barriers still exist. Some of these barriers are physical such as accessibility to community venues and transportation issues. Progress has been made with the retrofitting of many existing buildings and community venues and new public buildings are being constructed with access in mind. Less progress has been made on the transportation issues, especially in more rural areas.

Other barriers are financial. Many families have also had to deal with expensive medical issues or have sustained additional financial strain in meeting the needs of their son or daughter. Individuals with additional needs such as interpreter services often receive no funding for these supports and/or are unable to access them in the community. Individuals with developmental disabilities remain under represented in the workforce and pension levels provide for basic needs but don't necessarily allow for additional costs which may be associated with involvement in community activities and events. Funding levels for agencies don't always allow staffing resources which enable individuals to be supported in all of the community activities that they might like. Salary levels within agencies make recruitment and retention of qualified staff difficult

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and the resulting staff shortages and turnover levels limit the building of natural supports within the community.

Some of the barriers are attitudinal with varied public perception of individuals with developmental disabilities, their rights, their gifts and their involvement in the community. Inclusion of all children in the school system is resulting in a change of attitude among young members of society but there is still work that needs to be done with the broader community. Research has shown that social marketing can be successful in altering attitudes and we would recommend that the Ministry take a lead in creating a Province wide campaign focusing on inclusion. Although a campaign would be helpful, it is also important to recognize that public education and community development are ongoing activities which need to be resourced adequately.

In addition to the public education efforts required for the whole community, we have recognized that our roles are changing from simply direct service providers to bridge builders with the community. This change in role is one which is essential in creating welcoming communities. Staff in agencies need assistance and training support in developing these new skills and salary levels need to be attractive to individuals who possess these capabilities. Also, educational institutions need to alter their curriculum to include this skill set in the learning outcomes of our future professionals.

Respite for Caregivers

As noted in the paper, the system of respite is somewhat confusing for families attempting to access service. The Special Services at Home model has been very effective for many families, especially as it has changed to reflect more accurately, the individual and specific needs of families. The types of respite available need to further evolve to include prolonged out of home respite for families dealing with emergencies and crisis situations. It is acknowledged that good respite is good prevention for many families. However, respite is often inappropriately offered as a solution to families who clearly ask for and need longer term residential placement. Additionally, for those families with a family member with complex care requirements, availability of respite services is very limited.

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As in other services, a whole range of respite options needs to be available for individuals and their families including in home, out of home, short term, long term, centre based, emergency, planned, etc. Although there should be options and choices, we would agree that the system needs to be more organized and coordinated to ensure that families have the information necessary to make informed choices. As in other forms of service, people can be very creative but are often stymied by the various rules, policies and procedures associated with the various funding streams and programs. While the paper outlines a planned redesign of the respite system which we would support, it does not address the need for additional resources. No matter how the system is streamlined and what efficiencies are achieved, there simply are not enough resources available to adequately support families.

Residential Supports

Agencies currently provide a wide range of residential supports but those options are often limited by the funding streams through which dollars flow. Many families and agencies have developed very creative solutions but are often thwarted because of the various rules, policies and procedures. The paper indicates that the Ministry will explore the use of provincial funds by families and individuals to ensure that there is maximum flexibility. This approach also needs to be taken with the funds which flow through the transfer payment system.

The paper identifies that the Ministry will work with other ministries and levels of government to identify and address tax issues. We believe there are a number of additional issues which need to be addressed with these other partners including building and fire codes, zoning concerns, development of new ways of working jointly with Ministry of Health and Long Term Care, and development of additional subsidized housing units and increased flexibility in their rules and requirements. We urge the Ministry to show leadership in ensuring that municipalities follow current legislation as found in *The Ontarians with Disabilities Act*, *The Planning Act* and *The Human Rights Code* in regard to discrimination and that they develop and interpret zoning and fire code requirements in a way which builds inclusive communities.

While being supportive of the idea that families be encouraged to look at a number of home ownership and housing options, we would also express caution that this be done within a longer range plan which can be sustained through change. We have encountered situations in which creative solutions were developed which subsequently fell apart when needs changed and

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agencies have then been called on to patch together emergency responses. While it is important for all parties to be creative in arranging housing, there must be an acknowledgement that for some individuals, 24 hour supports will be required.

Home ownership and the various housing options is a very complex topic with significant impacts on taxes, future pension eligibility, etc. In order to assist families in exploring this area, we would encourage the Ministry to create an easily understood “how to” manual which outlines the ramifications of the various options. In addition, a system of sharing of good ideas and best practices across the Province needs to be developed.

The paper puts a great emphasis on the role of families in planning for and supporting their family member and while we agree that families do have an important role, it is also necessary to highlight the role of the individual themselves. Historically, agencies have at times played a supportive and mediating role when the wishes of individuals did not align with the wishes of their family members. We encourage the Ministry to be mindful in seeking a balance between the active engagement of families and the protection of the interests of the individual. Individuals sometimes need to have ready access to a third party advocate and to be assisted in accessing those services when appropriate.

Transition Across Life Stages

The paper outlines a number of the challenges faced by individuals as they move from school age to adulthood and coordinated planning is identified as a means to address those concerns. We would agree that earlier planning and cross sector case management would be helpful. However, planning in the absence of options will not solve the problem. There must be additional options available for young people leaving the school system. We applaud the government’s investments in this area and would encourage the Ministry to continue to introduce additional resources.

As noted elsewhere in this paper, there are significant differences in philosophy and service delivery approaches between various ministries and these create challenges as individuals move between these systems. In the past, there has sometimes been an unwillingness to work collaboratively and we support the directions outlined in the paper to bring together the Ministry of Education (including the Provincial Schools Branch), the Ministry of Children and Youth, the

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Ministry of Health and Long Term Care and the Ministry of Community and Social Services to develop protocols and stronger working relationships. We would like to add the Ministry of Training, Colleges and Universities to the list as we believe that there can be some changes made in that sector which would encourage more individuals with developmental disabilities to pursue post-secondary education and training.

Employment opportunities for individuals with developmental disabilities remain scarce. There has been some success in media campaigns in educating potential employers regarding supported employment. However, this is an area that could benefit from additional attention.

For adults becoming seniors, the paper notes that options need to exist for individuals depending on their wishes, health, interests, etc. While it is important that all seniors have access to long term care supports, we must guard against inappropriate placements into long term care facilities. Once again, it is imperative that there be a strong commitment within the Ministry of Community and Social Services, the Ministry of Health and Long Term Care and the service system to find creative ways to support people appropriately.

In order for any of these transitions to be seamless, flexible funding approaches have to be adopted. Portability of funding, which is one of the six underlying principles needs to be applied to moves across systems in addition to physical moves.

Supports for People with Specialized Needs

Specialized supports have received a significant amount of attention from the Ministry over the past year and we are supportive of this attention. It is imperative to have resources in place to deal with crisis situations when they are happening and it is important to build a system that allows for interventions prior to them escalating to crisis level. The Networks of Specialized Care should build on existing resources and be a system that is understandable and accessible.

A collaborative approach with the Ministry of Health and Long Term Care in the provision of psychiatric supports for people with specialized needs is essential. We have many examples of the health care system not taking responsibility for the mental health needs of individuals with a dual diagnosis. Even when we have highly trained and qualified staff in place, they need to be supported by professionals within the health care system.

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In addition to specialized needs associated with behavioural concerns and dual diagnosis, there are also a range of individuals with special communication needs. It is important to include these individuals as plans for services are move forward.

As noted in the section under respite, some families with family members with complex care requirements are being offered respite when what they really need is specialized long term solutions. This requires additional resources.

The paper acknowledges the difficulty in recruiting and retaining qualified individuals to work in this area. In addition to the suggestion that members of the networks will have responsibility to promote recruitment and retention, we believe that the Ministry should take the lead with the Ministry of Training, Colleges and Universities to explore new diploma and degree options leading to the training of additional professionals.

As is noted elsewhere, key to the success of specialized supports will be a collaborative working relationship between the various ministries and service sectors.

Taxes, Wills, Disability Savings Plans

We are very supportive of any steps that can be taken to recognize the contributions made by families and to allow them to plan for their family member. As one example, it would help if payments made by families for resources in support of their adult children could be deducted from income for tax purposes. While the Ministry has committed to working with the Ministry of Finance and the federal government, there are changes which could be made to its internal programs like ODSP which could significantly contribute to this outcome.

Quality Supports and Services

We believe that quality and accountability are closely linked and are therefore supportive of the development of standards and of systems of monitoring quality. Families and individuals supported need to be assisted in having a voice in those developments and in the process of assessing quality.

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As an agency based organization, we are supportive of accreditation provided it can be achieved in an affordable manner. A system of accreditation will ensure that agency services are delivered at an appropriate standard and families receiving direct funding may feel more comfortable when purchasing services and supports from an accredited agency. When families wish to purchase services from agencies, there will need to be a contract developed which clearly spells out standards and expectations. If a family chooses to purchase service from someone other than an agency, there will still need to be a system of accountability in place with respect to the expending of public funds. However, it isn't as clear how the issue of quality assurance will be addressed. This is an area that needs considerable discussion prior to any move to direct funding. We would recommend that the Ministry develop a clear system of accountability before moving to a wide spread system of direct funding.