# **Response to Preliminary Discussion Paper: Transforming Services in Ontario for People who have a Developmental Disability – October 2004**

I thank you for allowing me to speak on behalf of Family Directed Alternatives. This is a small parent organization based in London that represents a smaller population within the developmental disability community as they all have family members who have high needs. What this means is that along with numerous developmental disabilities many also have medical, behavioural, communication and social issues that requires them to have 24-hour care. Some are mobile to a degree, but all are dependent on others for their care. As well these individuals need someone to advocate on their behalf and through me I would like to present on Family Directed Alternatives behalf their thoughts on this discussion paper.

When reading over this document these families continued to hear echoes of a long forgotten document from 1987, entitled Challenges and Opportunities resonating through. The buzzwords being used were slightly different and yet, at the same time, had an eerie similarity and again the promise of wonderful changes were being dangled in front of their noses. While Family Directed Alternatives applaud this government for finally recognizing the need for changes in an area that has been financially strained and overburdened in the last few years, these family members still remember long forgotten promises from past years.

With that said, this organization still believes that those representing the developmental disability community need to continue hoping that this time they will see positive change. The best way that they know how to do that is by giving your task force the necessary feedback that will help bring this province to new and better heights for all its citizens including our population.

When talking about the roles and responsibilities of different parts of society who help support individuals who have a developmental disability, one thing that must happen is that everyone needs to be on the same page. What they mean by this is quite simple. Throughout your document you talked about citizenship and how people with a developmental disability should have all the rights of other citizens to participate in their community. Secondly, you discuss how society needs to change their thinking from trying to “fit ” the person with a developmental disability ”into” the community but rather the community needs to remove all barriers so these individuals can participate fully in life around them.

However, neither of these two ideas is currently held by everyone within our society. This does not just refer to individuals within the community, but also for service providers, religious and non-religious organizations, as well as government officials and policy makers. There are many current government, as well as agency policies, that put stipulations and conditions that prevent our population from accessing certain programs that all other citizens have a right to use. An example of this is the fact that any other individual may continue their education after the age of 21, until their death, but the Education Act specifically denies our population the same rights.

Also, when programs or services are being created or re-structured those involved do not include a component that specifically addresses the supports necessary to include people with disabilities. An example of this would be when daycare spots or after-school programs are being created or restructured, these programs tend to limit or exclude the developmental population because the proper planning and supports have not been considered or budgeted in during the preliminary stages.

Finally, when existing or new programs that are specifically geared to this population are created, there are again stipulations that often prevent certain groups from within the developmental community from accessing these services. Many of the day programs that are currently being funded by the government have various stipulations that limit who can access these programs. In some cases only those who live at home are eligible while excluding those living in alternative living arrangements like group homes or people with behavioural or medical issues may also be denied service.

In order for the individual to receive seamless supports throughout their lives several things need to happen. First, as previously mentioned any planning stages for development or restructuring of programs and services needs to automatically have strategies set in place to address the varied needs of our population in order that they too may have access to these generic programs.

Second, there needs to be a wide variety of programs that have quick and expandable components. Creating programs for 10 people with no room for expansion except when someone either leaves the program or dies is no longer a viable option. We need to have programs that are available at the exact time our population requires them, with little or no waiting time.

Third, there needs to be a combination of two types of government funding. There has to be individualized dollars allotted to each person with a disability or their family in order for them to purchase either services or supports that will allow the individual to access existing services that meets their specific needs. Also, there still needs to be monies allocated to transfer payment agencies in order for them to still offer a base set of programs or services in which individuals can pick the best programs for their needs.

Finally in order for there to be seamless supports throughout the lives of people with developmental disabilities their needs to be a unified ownership, co-operation as well as long-term planning in order to anticipate future trends and needs of this diverse population, between all aspects of the government

When addressing the issue of what supports and services currently work well in the community I must say that with the limited amount of resources, with funding claw backs, limited spaces and shortage of well-paid, highly trained staff all these agencies have done exceptionally well to provide the services that are currently attempting to meet the needs of this population. Again, in keeping with the idea that communities need to fit the consumer and not vice a versa, as well as being prepared for the future, all of these agencies should be built on, as well as new and innovative ways of offering services needs to be examined further.

In regards of how a reasonable level of government funding for an individual should be determined it must first be noted that currently there exists a two-tier system. Those who have money attached to them, which in most cases are individuals who have already been moved from institutions into the community and those who do not have money attached to them, which are mostly made up of individuals that remained at home with their parents. It is our belief that each individual with a developmental disability requires that amount of money which will ensure him/her the best quality of life, provides for their safety, is flexible as well as guarantees that person seamless points of transition. Also, if this government truly believes that the idea that rights of citizenship applies to this specific population as well, then shaping any funding based on family income would be counterproductive.

I believe that there are several priorities that this government needs to address. Firstly, as the last group of individuals are placed from institutions into the community, this government has to meet the needs of all those currently living either at home or in alternative living programs. You cannot expect those who are on or near the breaking point to continue with little or no supports. Family members have tried their up most to ensure that their children reach their full potential. But this has come at a great price and this government needs to assist us in making sure that our children live a full and enriched life regardless of where they are living or their exceptionalities.

Secondly, there needs to be a shift from just transfer agencies to a combination of both transfer and individual funding. This allows organizations to continue to operate and offer quality services at the same time allowing families or individuals to purchase other services or supports. Also, it allows for individuals to switch agencies if they feel that their needs can be better served by another program or group.

Thirdly, there needs to be a change in government and agency policies that currently restrict or eliminate the developmental population from accessing services and programs. There also needs to be co-ordinated future planning in order to make sure that there are programs available to those future users, with little or no interruption in services. Our population and their needs are forever changing and this needs to be reflected in any planning that is done.

Finally, I believe for any government to take on this task of assuring citizenship to people with developmental disabilities so they can experience a high quality of life within our society everyone must start looking at this issue as a group rather than a separate entity outside of generic programs, services and the general population. There also has to be a unilateral ownership by all branches of the government if there is to be a seamless transition.

The mission statement of Family Directed Alternatives is that “we believe that all individuals have the right to a dignified and fulfilling life that includes trust, mutually supporting relationships and a sense of community that honours and respects individual choices. It is our fervent hope that this government and those involved in the task force shares this philosophy and will implement the required supports needed for this to happen.

Respectfully,

On Behalf Of Family Directed Alternatives

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