

Family Alliance Ontario

Response to the Discussion paper On Transforming Developmental Services in Ontario

Nov. 30, 2004

This response is derived from discussion and feedback from the families in the following participating family networks:

Windsor/Essex, Toronto, Chatham, Sarnia, London, St. Mary's, Hamilton, Kitchener/Cambridge/Guelph, Mississauga, Muskoka, Kingston, Thunder Bay, Ottawa, Durham, Markham/Unionville, Fort Erie, and Leeds/Grenville

The Family Alliance Ontario distributed the discussion paper throughout the province by sending it to all the Family Networks with memberships from 20 to 800 members, and its partners. Networks distributed the paper to their members who submitted written replies and /or met in discussion groups throughout Ontario. All responses were then sent to the Family Alliance Ontario where they have been listed in our response. No contribution was excluded.

The contributions of the family networks are consolidated and summarized under the following headings:

- 1. Values and Principles**
- 2. Process (system design and monitoring)**
- 3. System benefits**
- 4. System features**
- 5. Current system failures**

1. Values and Principles

We believe that people with developmental disabilities should be vital and integral members of our community life. This means that young people with disabilities grow up with their families and other children in their neighborhoods. It means that young people with disabilities attend the same schools and classrooms as the other kids. It means that all children grow up knowing that disability is part of human life and not grounds for being excluded and sent away from community life.

We believe all people should be everywhere and no one should be missing. No-one should be missing from our churches, schools, service clubs, sports teams, work places, recreational places, shopping malls, voting booths, movie theaters, etc.

People with disabilities should be living, learning, working, loving, shopping and having fun among us. They will be free to be with whom they wish and where they wish, doing things they want. Tolerance will not be enough; membership and belonging will.

People with disabilities should be recognized as full citizens and should be supported in ways that respect their right to decide what they want to do with their lives, and that allow them to make the choices and decisions that affect their lives.

Key issues

- These values and principles should be built into the legislation that governs supports and services
- ***“Nothing about me without me”***—people should not be controlled by the service system, the system should respond to what they want to do with their lives.
- Support systems should be built on people’s strengths and talents, not their shortcomings
- People should have legal rights to accountability from the government and service providers

- Supports and services should be required to promote full inclusion and participation, and to enable contribution
- The state should invest in people, not in services. The focus of the developmental services system should be on people and citizenship, not programs.
- The support system for people with disabilities should recognize, protect and enforce their human rights.
- Legislation is needed to promote full citizenship, allowing people to lead the lives they want to lead, instead of being treated as “clients”
- The system of supports should encourage individuals and families to innovate, to design custom solutions to fit their personal requirements
- The state should value family contributions and welcome family involvement in policy development
- The system of supports should recognize and solicit family expertise
- The system of supports and services should be universal and accessible as in health care. No means testing.
- The system of supports should preferentially fund forms of living that are valued by typical citizens society (typical homes, typical workplaces, typical lifestyles, typical social relationships)
- *“Self-Determination is a ten dollar word for choice...it is another word for freedom... a life filled with rising expectations, dignity, responsibility, and opportunity... a chance to live the dream.”* (Robert Williams)

2. Process (system design & monitoring)

Firstly, the design of a new transformed system for supporting people with developmental disabilities in Ontario must be founded on the formal lead and participation of the *primary* stakeholders, the people themselves and their families, because they are directly affected by the system, and because they have the most extensive personal experience and knowledge. Service providers are *secondary* stakeholders whose mandate is to respond to the requirements of primary stakeholders.

Secondly, because no such system design will ever be perfect, and because every system needs to be monitored and continually improved on an on-going basis, there is a requirement for on-going participation of people with disabilities and their families in planning, reviewing and improving the system at regional as well as provincial levels.

The involvement of people with disabilities and their families in supports that profoundly affect their lives is a simple consequence of the recognition of people as respected citizens rather than merely as clients of services.

Key issues

- People with disabilities and their families should be recognized as lead resources in driving policy. They should be recognized as the primary stakeholders at regional and provincial policy tables.
- The service system must be made accountable to individuals and their families through individualized funding that ties funding to people rather than to agencies.
- There need to be effective processes to make agencies and government respond to complaints about supports and services.
- There needs to be effective independent appeal mechanisms for individuals unhappy with the decisions of bureaucracies and agencies
- There is a need for independent consumer satisfaction surveys
- There is a need for an *Adult Advocacy Office* to protect the rights of vulnerable adults.

- The *Ministry of Community and Social Services* needs to be accountable to people with disabilities and their families, and to the public through regular (e.g. annual) open reporting of funding statistics, of how well it has met performance criteria, of consumer satisfaction surveys, etc.
- The government should fund demographic research to budget disability support funding on the basis of population statistics and needs.
- Independent, unencumbered (i.e. independent of service providers) planning and brokering should be funded (at arm's length).
- The developmental support system should be based on self-directed planning for all. It should allow people to design their own support system
- Advocacy groups should be funded (at arms length) to safeguard the rights of vulnerable citizens
- Service system must be fully accountable to person and family

3. System Benefits

The purpose of the disability support system is to serve people, not to maintain institutional services. This section addresses the personal outcomes/benefits that are expected in a system that is consistent with inclusion, participation and citizenship.

As citizens, people with developmental disabilities have the right to associate with whom they choose. People with disabilities have the right to choose what they want to do with their lives. Funders and service providers have no right to decide with whom and under what circumstances people with disabilities spend their time and lives.

People must have choice. Choice means the person makes the choice. It is not a response to a restricted offering by a third party. Having only one option – *“this program or nothing, take it or leave it”* -- means having no choice. Choice, in the current system, is a virtually meaningless concept. True choice means creating the best fit between what an individual needs and what is provided in response.

Choice means that segregation and congregation are not forced upon people. There are two ways that such exile is forced. First, the segregated option is the only choice offered. Second, in order for one person to have a segregated service, many others are required to participate. The choices of one individual should not impose or limit choices on others.

Key issues

- People have choice
- People enjoy self-determination: they are in control of decisions that affect their lives
- Portability: people can move, people can change service providers, people can take action to realize their dreams
- Self-directed: people have the option of self-directing their personal support system

- The support system is as flexible as can be, as requested by the individual or family
- People are supported to have lives enriched by friendships
- People have living arrangements that are typical and valued ...all citizens access to home of their own.
- People have adequate, reliable, and consistent supports
- People have fair access to supports
- People experience speedy responses to requests for supports
- People have the benefit of effective complaint and appeal mechanisms
- Family involvement is welcomed and promoted
- People's supports fit their personal plans for personal goals, post secondary education, job training, transportation, etc.

4. System Features

This section addresses the systems features that need to be implemented to provide the required benefits.

Individuals should have the authority, power and resources to control their own destinies. This includes planning for their own futures with their family, friends and advocates, and negotiating for funds, which will assist them in realizing their hopes for future. The decisions by individuals and their families must be supported, as they are the only ones who can assess the true need.

People with developmental disabilities should have the right to decide where they live and with whom they wish to live in typical community housing. The goal is to support people to live in community, not in cells of exclusion scattered throughout the community.

Institutional settings should not be among the range of “service options” available to people. Consistent with this, nursing homes, as yet another expression of the institutional approach, are not consistent with that vision.

The new system of supports and services must be more efficient in the use of resources. The current system dedicates massive amounts of money to services that do harm, services that do not respond to the real needs of individuals, and services that are not used. People with developmental disabilities, their families and allies, have no interest in such wastes of public monies.

Two fundamental shifts are required. First, decisions about what is important to fund should be left to the individuals who are to benefit. It is far better for people who care about their own futures to make such determinations than to leave such decisions to those who do not care. Second, a system that is initiated by people with disabilities being in control of their own funds will mean that only that which is needed will be purchased, and only that which is received will be paid for.

A system defined by the choices of individuals will be far more efficient. It will also rely on individuals, and those close to them, making sure they make good decisions for themselves, especially in terms of money they spend to secure what they need.

Efficiency also means taking advantage of the many sources of funding. A great deal of social services funding currently dedicated to housing costs and construction dedicated to institutional settings would better be replaced by individuals purchasing their own housing with insured, guaranteed mortgages and creating tax credits and rebates for family homes being renovated to suit family members with a disability.

Individualized funding must be attached to the individual and be portable to enable them to fulfill their role as citizens to live, work and move in Ontario.

Key systems features

- Funding is attached to individuals not to programs
- Universality/fairness: As in health care, everyone who is eligible is entitled to supports, not just those who happen to be first in line.
- The system is designed to provide speedy responses
- Non-institutionalized modes of service/supports are favored instead of institutional models. Supports based on individualized funding (such as Special Services at Home (SSAH) for example) should have equitable claim on government resources.
- Allocations are based on personal plans and community capacity, not on institutional benchmarks
- Assessments of support requirements are made by individual, family and friends
- The system must be fair. Funding for SSAH and other individualized supports should be annualized as other programs are.
- There should be a universal, single application form throughout the province, as opposed to program by program (“silos”) applications
- Income tax system should encourage contributions for disability related expenses through comprehensive tax credits.
- The system is designed to provide seamless responses to changing needs: cradle to grave, annualized, flexible, no program silos, accommodating life transitions

5. Current System Failures

Community programs for people with developmental disabilities are in a crisis. Today's crisis is the result of the transfer of institutional patterns of service development and delivery to community programs. It is time to give up the paradigm of programs and adopt a paradigm of support.

The current system in Ontario discriminates unfairly in favor of institutional models of service. Institutional practices in the community have created unacceptable and harmful control over the lives of people with developmental disabilities and their families.

Today, people with developmental disabilities are seen as people with problems that must be fixed. The system has created an array of special places where people are treated, cared for and trained for eventual life in the community. But, "eventual" means never. People with disabilities need support that respects them as individuals and citizens. The support should focus on assisting people to get on with life, to be in life, not separate from it in some isolated environment or program.

The answer to this crisis is to abandon the culture of institutions. We need to move away from practices that make people live in the community, but fail at making them part of the community. Services have ignored the riches of opportunity and support that community offers while depriving people of the satisfaction that comes from exercising choice.

The current service system discriminates unfairly against families. Thousands of people with developmental disabilities are living at home with their parents. Despite families' role as the largest single provider of support to people with disabilities, families are routinely ignored, not respected for their role, and under funded by services and the bureaucracy. Even though the families' capacity to provide care is subject to other family stressors and the aging of the caregivers, flexible support and respite is virtually non-existent in many parts of this province.

Families do not want more of the same. Families do not want to tinker with a broken system. They want a real transformation. Families do want a better future that offers choices and opportunities, choices that encompass where to live, where to work and with whom to spend time. There needs to be a

change in the way we think about meeting the needs of people with disabilities.

Families provide more support to people with disabilities than all of the formal components of the service system. Meeting the support needs of people living at home requires that we recognize and meet the support needs of their families.

We need to explicitly acknowledge the family's role as advocate, support coordinator and support provider. The person and their family must be driving the development of plans for the future. When the person moves out of the family home the family role must be encouraged to continue.

These issues need to be addressed with new policy and direction

- The current system is inflexible, based on programs not on individual needs. People who do not fit programs, or who do not like existing programs are not served.
- Funding is not portable, not tied to the person. The system is not responsive and not accountable to families or the people it is mandated to support.
- The institutional approach is the first resort and usually the only resort. People are forced to accept group homes and segregated programs in order to receive any form of support. More effective progressive alternatives are not funded.
- The current system threatens the viability of family-directed supports by discriminating unfairly against workers hired directly by families. Government funds higher wages and benefits for agency staff, and funds salary increases only for agency staff.
- The *Ministry of Community and Social Services* (MCSS) does not value supporting the family unit, nor does it value families' contributions and expertise, nor does it value families supporting their family members as decision makers
- Access Centers are a failure. People are treated like commodities where the service providers "bid" for them. The practice of forcing people into institutional programs violates their human rights. The

system of access centres is costly as well as harmful to the people it is mandated to serve.

- Ontario government has no data on how many people have disabilities in Ontario, on the kinds of supports they require. Funding is based on politics rather than on demographics.
- Ceilings on *Special Services at Home* funding discriminate unfairly against families, especially against those with the highest needs. Ceilings are not imposed on less effective institutional models. System serves agencies better than people.
- People are forced to live in group homes to qualify for supports. Group homes are not a valued way to live (no other segment of society lives in group homes). People who live in group homes are powerless and captive “clients”.
- System is not accountable to person and/or family. There is no formal complaint process, and no appeal process for people who are dissatisfied with services. The government does not support independent surveys to assess people’s level of satisfaction with the existing system.
- People with disabilities are being marginalized by segregated services. They are treated as second-class citizens. They are denied choice and portability.
- MCSS policy of favoring institutional models of service is a major barrier to full citizenship for people with disabilities
- The current system funds programs instead of people. The patchwork of programs in Ontario is chaotic, ineffective and unfair. A uniform approach to supporting individual plans is needed in Ontario. All support funding should come from one pot.
- The government has failed to respond to the strong demand for individualized funding.
- There is widespread dissatisfaction with quality of services that many agencies provide, but the system continues to fund those agencies, and fails to fund better alternatives. The people directly affected have no recourse.

- There are **no service standards** in Ontario. The government funds services but has no expectations of outcomes for inclusion, community involvement, social relationships, valued activities, personal development or accountability to the individual.
- ODSP income levels are far below poverty line. Still based on old welfare system mentality that refuses to invest in people.
- The government continues to allocate new funding to group homes every year even though people don't want them, with no funding for valued forms of accommodation.
- *What's Not Working*: Ombudsman's Office, case resolution, waiting lists, escalating costs of building group homes and day programs, private for-profit residential facilities, institutions large and small, a mental health system where people with developmental disabilities are trapped in psychiatric hospitals or homes for special care under the label of "dual diagnosis", group homes and day programs where people have isolated/segregated lives "in community", sheltered workshops, etc.
- *Issues around Ministry of Education not doing their part, pressuring families to segregate their children etc.* "warehousing" students. There is a need to give the Education act teeth when it comes to inclusion as being the first resort, and promoting full citizenship. Government policies are needed to promote inclusion, and those policies should be consistent across all Ministries, including *Education, Citizenship, and Social Services*.