

Transforming Services in Ontario for People who have a Developmental Disability

Preliminary Discussion Paper

Brant Families' Responses to the Joint Developmental Services Sector Partnership Table

Submitted by:

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**Brant Families' Responses to:
Transforming Services in Ontario for People who have a Developmental Disability -
Preliminary Discussion Paper**

The Developmental Services agencies in Brant (Community Living Brant, Family Counselling Centre, Brantwood Centre, Children's Aid Society (Alternate Care Program), Lansdowne Children's Centre, and Contact Brant for Children's and Developmental Services) coordinated two family feedback sessions on November 4, 2004 to gather a response from Brant to the "Transforming Services in Ontario for People who have a Developmental Disability - Preliminary Discussion Paper". Over 40 family members and individuals with a developmental disability were involved in the feedback, including one written response. Families received services from the various agencies. This report includes all the feedback received, with no prioritization or debate.

This report is prepared for information and will be forwarded to the Joint Developmental Services Sector Partnership Table, as well as the Ministry of Community and Social Services/Ministry of Children and Youth Services (Wilma VanStaalduinen, Program Supervisor for Brant), families involved in the feedback sessions, and the Brant Developmental Service agencies. Several Brant parents will attend the Federation Day meeting in London on November 13, 2004, and Eleanor Moore (parent) was asked by the families to present the Brant families' feedback as the opportunity arises.

Transforming Services in Ontario for People who have a Developmental Disability - Preliminary Discussion Paper: **Questions for Discussion:**

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

- Government services and funding should be based on need; government, service providers, family and professionals should have input into a common assessment to establish need
- Government should ensure there is one place to call for all community services, with available information on all sectors
- Government should require accountability and standards from service providers
- Government should declare developmental services as essential services for workers – no right to strike
- Government should promote inclusion: Inclusion needs to be promoted in social clubs, churches, health care, education, etc.; families are scared government is downloading responsibilities and concerned who will pick up the slack?
- Government should ensure good programs within developmental service agencies need to be accessible
- Government should ensure schools/teachers pay more attention to people with disabilities being bullied and prevent this, have realistic expectations regarding curriculum goals for students with developmental disabilities and encourage these students

- Government should ensure cross-sector (e.g., education, health care, community services) inclusion, awareness, support and responsibility for developmental disabilities
- Government should ensure public education on developmental disabilities is on-going; people with disabilities get pushed around in society – social education is needed regarding developmental disabilities in all sectors of society, similar to ethnic awareness/racism
- Government must provide safe affordable housing for this sector; individuals with disabilities should be prioritized for affordable housing
- Government must ensure that transportation is affordable and reliable; transportation must be available;
- Government must ensure that safety is considered – adequate services are needed for the sake of safety
- Families should apply for services before needing them to allow for planning
- Families should contribute support as they are able – each family is different
- Families should encourage and show appreciation for support offered by community groups (e.g., churches, service clubs, etc.)
- Individuals should be able to ask for help to improve their quality of life
- Service providers must provide quality training and supervision, and be funded to do this
- Service providers must ensure cooperation between agencies providing services to the same individual; need improved communication between agencies with the individual supported as the focus
- Everyone needs to identify the “has to be’s” and this will mean the government has to improve funding

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

- Advocates are needed especially to assist through transitions; need an on-going agency/person responsible to connect people to services when needed; advocates need to be separate from service agencies; advocates other than family are needed to ensure quality of life and services for people with developmental disabilities throughout their life
- Need one place, like Contact Brant, for anyone to go to and get connected to all services (not just developmental services)
- Need people to help find jobs, like Supported Employment Program
- Inclusion needed through life: infancy to education to employment to aging – people with developmental disabilities have the same range of issues as the rest of the population, so the new structure must mirror the range of services for all of society
- Ability to keep the wages they earn, plus have ODSP for expenses due to disability; transportation to work is costly and medication required is expensive
- Everyone should have meaningful work and be able to keep their earnings; wages are the communities’ contribution to people with developmental disabilities and should be encouraged; ODSP reporting on income takes away motivation to earn money

- ODSP is not enough to live adequately; families have the financial responsibility through life as ODSP is not sufficient and this must change
- ODSP medical benefits should be available and not dependent on income eligibility as medical expenses/prescriptions/assistive devices are high for people with disabilities
- Need people to give a damn
- Peer and volunteer support is needed
- Fewer developmental service agencies and more flexibility with services; Brant has 2 agencies providing Special Services at Home (one for adults/one for children); create less Administration and more services; several respite agencies in Brant need to be combined
- Communication between agencies is necessary
- Require legislation to ensure that services are stable and secure, including declaring essential services so there are no labour disruptions
- Supports have to be flexible and change as required throughout life
- Train other sectors to support people with developmental disabilities so that as people age, they can receive appropriate community support
- Ensure people have appropriate support as they age so they can stay where they are
- Resources have to be sufficient so that planning for transition can take place instead of waiting for transition to occur and worrying what will happen
- Avoid crisis by planning – preventative and early intervention support rather than crisis support
- Need continuity of services and dollars through life – funding and services decrease for adults

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

- Skill building opportunities must be on-going and repetitive; more groups offered by agencies to continue educating, e.g., life skills, anger management, sex education classes, financial training, vocational training, social events
- Trained empathetic staff
- Parental/family support is important, e.g., central information, networking groups
- More funding needed for Special Services at Home, Supported Employment and Transition to work (Foundations program)
- Special Services at Home is needed, and need to support the funding to avoid turnover of workers, and attract workers based on need; worker for a child can't support individual as an adult because it is 2 different agencies (in Brant); wages are less for adult SSAH than for children's SSAH staff (in Brant)
- Supported Employment is a successful program; government should encourage employers to hire individuals with developmental disabilities
- ODSP is needed and must include medical benefits for everyone with a disability; should be more than a welfare level of funding

- Transition Program (Foundations Program) is important and need more 1-1 staffing opportunities
- Supported Living programs are important and need more 1-1 staffing opportunities; SL support is needed in-home for parents who keep their adult sons and daughters at home
- Need more residential opportunities
- Flexibility in funding is needed to ensure choices by the individual of services
- Dunn Building (Vocational Program) needs to be maintained
- Respite programs for all ages; respite needs to be more readily available and flexible to meet the needs of the families
- Community Activity Program and Day Program at Brantwood need to continue
- Build upon and improve current services: accommodation supports, day programs, disability pensions, medical coverage, transition supports
- All programs should be inclusive – a person with a developmental disability that also has other disabilities should be able to access any developmental service
- Transportation services need to be funded for the developmentally challenged population; less barriers to transportation services are needed
- Require Assistance for Children with Severe Disabilities funding for all children with developmental disabilities
- Health benefits must cover the additional expenses incurred from having a disability; people need more specialized health services
- Require more funding for Assistive Devices so that families can keep their sons and daughters at home
- Increase dental services as people with disabilities often aren't diligent in brushing their teeth
- Intensive Behavioural Intervention (IBI) should be expanded for all children with autism spectrum disorder; expand the age for support beyond age 6; don't limit IBI support to one or two years
- Programs that are identified as gaps and run through community fundraised dollars should be supported by the government (e.g., Crossing All Bridges, Every Kid Counts)

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

- Funding should be based on individual needs and goals; funding should be based on a life plan, not done “in the moment” – the life plan needs to be flexible and reviewed regularly
- Funding should be based on family need (not just monetary) including coping, extended family and community supports, need for parents to work, etc.
- Use quality of life measures and update frequently; funding should ensure an individual is happy, active, involved, accepted, has choices, healthy, etc.
- ODSP must be above a minimum standard of living; must be above welfare level and more closely align with the average person living in the community or at family's home; need regular cost of living increases

- ODSP must account for additional costs due to disability, including medication, teeth (people have trouble brushing their teeth and so have more problems), glasses, hearing aids, assistive devices
- Basic health care must be provided
- Enough funding (ODSP) so people can eat following Canada's Food Guide and be healthy
- ODSP must allow for entertainment and exercise opportunities to encourage social participation
- Everyone must have a safe, healthy environment to live in
- ODSP should be the same whether living at home or in a group home or institution
- Consider that people with developmental disabilities have specialized needs
- More rent subsidies are needed
- Don't use "means" testing; rather base on needs for support
- Parents' income shouldn't affect individual's ODSP

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

- Increased opportunities for social participation and healthy lifestyles
- Meaningful work, recognizing limitations (e.g., part-time work might be all that can a person can handle)
- Everyone needs to feel that they have done something of value each day
- Support for parents/families – recognize the added stress/coping required – provide respite so parents can socialize throughout life
- Need more specialized housing for specialized supports (e.g., Bethesda, homes for adults with Autism)
- In-home services need to have continuity: need to be based on "people first"
- More individualized housing (apartments, group homes)
- More assistance to help people live independently – increase ODSP and staffing
- Special Services at Home workers should get mileage costs covered
- Special Services at Home must be consistent and equitable; 2 agencies (in Brant) make the services different
- Most appropriate agency should administer developmental services rather than services being divided between agencies
- Need funding for accessibility (physical) to services for people with developmental disabilities; need support for communication challenges
- Need flexibility re: respite services – need to respond to parental needs for respite
- More inclusion for people with multiple disabilities – inclusion for all
- Need more information available about all services/help for parents with adult children at home; need one place to contact for services including building ramps, getting updates on services, etc.

- More help to equip houses for people to live at parents' home
- Better wages for staff in developmental services to attract qualified staff and deter turn-over

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

- Housing and in-home supports for people who have always lived at home – provide more support to parents
- Recognize everyone has different needs; individualize supports
- Funding is needed as the individual's needs change, and there should be flexibility to change as things change in their lives
- Ensure everyone can do what makes them happy: need self-directed supports
- Sustainable funding is necessary for services
- Education re: inclusion
- Social opportunities
- Adequate housing supports and appropriate by-laws that don't restrict housing for people with disabilities
- Provide a range of day programs for people: Dunn Building (Vocational Program), living skill programs, literacy supports, employment, etc.
- Extend funding for at-home services
- Services should be provided to all who need it; one point is needed to link people to all services
- All Ministries should communicate between each other and each should know and support what the other does
- One agency in each community to provide information and link to opportunities
- Publish a list of services available so that everyone is aware and has the same advantage
- Adequate healthcare including medical benefits

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?

- Act on these changes in a timely fashion (i.e., now!)
- All institutional funding should go to communities, with focus on supporting people living at home
- Need realistic funding when bringing people back to communities from institutions
- Provide funding to siblings/family members to provide care for individuals with disabilities
- ODSP reviews need empathetic and friendly staff; support to parents and individuals is required to prepare for reviews
- Municipal services need to ensure accessibility (e.g., curbs)
- Individualized supports are needed, not just "programs"
- Programs and supports need to be responsive as people age

- Ensure they are safe – especially when parents are gone
- Realize there is a problem, a deficiency, and provide support
- Need a plan cradle to grave – ensure a happy, healthy life
- Ensure no language or cultural barriers in developmental services

Respectfully submitted,

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