

# RESPONSES TO MCSS TRANSFORMATION QUESTIONS

by a man in his 30s who has Autistic Disorder, June 2006

*(his responses are printed here in italics)*

## 1.1 Support for Inclusion and Community Engagement

Individuals, families, agencies and government need to work together to strengthen the voice of people who have a developmental disability – and make it easier for them to participate fully as citizens in their communities.

### Key Questions

1a. What makes it hard for a person with a developmental disability to be active and included in the community?

*I have an excellent life in my own home now and a circle of voluntary friends who care about me, and spend time and share interests with me. My home is in a good neighbourhood, where I have lived nine years. People have got used to me and watch out for me. I used to deliver the community newspaper till the business changed to delivering from vans. When I visited every house, my neighbours could see how I make a contribution. It feels different when I visit some other neighbourhoods or cities.*

*-I used to be in a group home but I hated being away from my family and true friends and only with staff who did not believe in my abilities, or that I had thoughts and feelings. They took me to crowded noisy places which upset me.*

*-It makes a big difference to be out in the community with true friends rather than staff. Certainly, it is better than when staff have several disabled people tagging along.*

*-When people stare at me, it makes me feel terrible. I may start to act weird because I am frustrated that I cannot explain to them that I am smart and like many of the same things they do.*

*-So the hardest thing is seeing and feeling that people do not understand that we are persons with a right to live here too. I do my best to show them, but we need help to get the message out for other people who are disabled. Could the government run messages on TV and in the newspaper to help everyone understand and be more positive about people who are different in some ways because of their disabilities.*

*-One thing that helps me a lot is that I have a service dog who is properly trained and licensed. She helps me a lot. Holding her improves my sense of balance, and makes it easier for me to cope with noises and crowds. I call her my friendmaker, as she attracts nice people to be interested in me and not afraid of me.*

*-I want to be able to move about our community more independently and safely with my dog. We have been testing a good locating technology device called the Columba and hope it become possible to use this all the time in Ontario.*

1b. What would make it easier to be active and included? Who can make these changes happen and how might they go about it?

*-Being recognized and treated as a person first, and not just seeing my disabilities, and judging by appearance and not lumping me with others who have the same diagnosis.*

*-Listening to me in the ways I communicate*

*-Recognizing my family and friends as the people who understand me best and who stick with me.*

*-Perhaps the Government could put out some positive messages about the abilities and gifts of people who live with disabilities, to help more people become understanding and welcoming*

*-Supporting locating technology systems, so I can move more freely and safely around my community.*

1c. What do you see as the role of the various players in making it easier for people to be included in their community? Think about:

- Individuals who have a developmental disability
- Their families
- Agencies who support people who have a developmental disability
- Other community organizations (voluntary organizations, schools, business, faith/culture organizations)
- Governments (federal, provincial, municipal)

*No agencies support me--just my family and friends.*

*I have really tried to use community swimming pools and recreation facilities and churches. But I am very intuitive and can tell that most people are not comfortable with me. Sometimes they look to me that they are so kind in letting me come into their buildings.*

*Governments could take a lead by broadcasting messages that are more positive--perhaps using good stories about people with disabilities who have made good lives, with help of families and friends.*

1d. Do you know of any examples of successful partnerships among some or all of these players that others could learn from? Please describe what is happening and what makes it work.

*I know there are some projects and people who talk about values and rights.*

*But I don't know of any project where inclusion really happens well in all parts of a disabled person's life.*

*There are just bits and pieces which show that it's worth trying harder.*

*Parts of my life are very good in this way, thanks to my circle of friends and my dog.*

1e. Are there particular cultural considerations that you know about that will need to be addressed appropriately in plans for including people fully in the community?

*In my case, a big factor is that I do not speak with my voice but use AAC technology to type. I need people to support me, physically and emotionally, in expressing my thoughts and choices. With support, I am very expressive and even compose poetry.*

*I think there are a lot of people who cannot use their voices, but could still express their thoughts if provided with proper support.*

## 1.2 Respite for Caregivers

There are good supports available now (called "respite" supports) to give families brief breaks from caring for an individual who has a developmental disability. But the system is very complicated and could be made simpler and more effective.

2a. What types of relief ("respite") from caregiving responsibilities are most needed by families?

*I have my own home, where I am supported a lot by my parents (who have their own home) and by others.*

*I do need other people in my home at all times--not to do everything for me, but to encourage me to do all I can for myself. I have serious health problems, and need a special diet, and care with my sleep routines as I can have seizures.*

*It is expensive to think of caregivers other than my parents. But more important than the cost is finding the right people who believe in me and do everything right for my health and safety.*

*My parents and friends talk about all these things with me, and really listen to me.*

*It would be good if my caregivers could have two kinds of breaks sometimes:*

*1. Times when they go away and some temporary carers come into my home to support me. They would have to be trained first, to know how to support me and keep me healthy..*

*2. Times when I go away for a few days, so the house can have some repairs and painting. What I would really like would be nice people who would also be paid for their time and care, who would take me somewhere special. I love travel, especially by train.*

*I do not want to go to a group home or a respite camp, as I always get ill there.*

2b. What would you like to see in the "best possible" system of family relief? What would be offered? How would it work?

*Sorry, I answered this in the last space.*

*I don't think there is only one best sort of family relief.*

*It may be different for every person.*

*What is most helpful is having the power to use some funds in the way that helps each person best.*

2c. What currently prevents families from getting the relief they need? How would you suggest that these challenges be overcome?

*Good respite is costly. But more important is finding the right people who can provide respite.*

*I think more caregivers need to be properly trained and qualified.*

*For anyone to care properly for me, they would have to have had a trial period first, learning everything while my parents are here. My diet and everything, but specially to respect me and listen to my communication.*

2d. Are there special needs – emergency situations, for example – that require something different from the standard respite approach? What is different and how can these needs be met?

*Because of my hyper sensitivities to everything and my high anxiety in an emergency, I should not go anywhere else away from my home. I am extremely anxious in a hospital or doctor's office.*

*If I were injured, or something happened to my parents, it would be an emergency. But I should be supported to stay in my own home.*

*Some people I know, like my circle of friends, could help to reassure me.*

### 1.3 Partnerships with Families on Residential Supports

We need to explore how ministries and families can best collaborate to support individuals' living arrangements outside the family home. For example, some families may wish to use their own resources to provide a home for a family member outside the family home. We also need to work to remove some of the barriers that currently exist. There may be other, innovative options – perhaps involving partnerships among governments and voluntary organizations.

3a. What can the ministry do to better support individual choice of how and where to live – within or outside of existing ministry-supported arrangements?

*I have a different kind of home than the Government usually supports for people with disabilities. I did live in a group home for a while 16 years ago, but I hated it. Having my own home for 9 years has made a huge difference to my life which is excellent now.*

*The most important thing is to listen seriously to me. I knew what I was talking about when I said I must live in my own home.*

*It was hard for us, as it was a new idea then for the Government. My parents paid for my home and have worked very hard to make it right for my needs. Fortunately my circle of friends, and the housing trust that now owns my home in trust for me, and our lawyers and other supporters, have understood and helped.*

*I hope that by being a pioneer, I am making it easier for other persons with a disability to have their own homes and better lives.*

*The home has to be right for the person. So people like me, with family and friends, should have the right to make the best plans. I hope that the Government will provide better help than in the past.*

3b. Do you know of any examples of successful partnerships among families, agencies, community groups and government in creating new kinds of living arrangements? Please describe what is happening and what makes it work.

*I think the arrangement I have with the housing trust that maintains my home in trust for me, is successful. Other families and agencies ask us how we do it. I think the Government is now more interested in this kind of home, as we have proved it works.*

*It's very important to have proper agreements with everyone, so my rights are respected for ever.*

*My housing trust is dedicated to making it possible for people like me to have our own homes, and to live the way we want to, sharing with who we want.*

*My aroha entity (the incorporated core of my circle of friends) is also involved to guarantee that I will be well supported always.*

## 1.4 Transition across Life Stages

Examples of life transitions are when a young person leaves school or when an adult becomes a senior citizen. Making the adjustment to different support needs and different sources of support can be difficult. We need to find better ways to help individuals and families plan for these transitions in advance, and make them successfully.

4a. What information and support would be of most help to individuals and families as they plan for the transition from school to adult supports?

*When I was a teenager, everyone said I had to go to a group home by the time I was 21. I did, and it may have been OK as a group home, but I hated it. Nobody asked me what I really wanted. I didn't have reliable communication support then—just sign language and a pic wallet. I hated being away from my parents and family and frustrated that nobody was listening to me. The staff put me on medication which made me feel far worse. I didn't choose the people I lived with, or the support staff. I still feel angry and upset whenever I think about that time. So I think that teenagers should be helped to express their dreams. Family and friends should really listen and then help those dreams to happen. Teenagers and their families should know that they can create a good life that is right for each person.*

4b. What programs and supports need to be in place for seniors who have a developmental disability?

*I am still much younger than 65. But I have thought a lot about my parents dying and know that my circle of friends and my incorporated aroha are very important. I hope that I can go on living in my own home, with all the things that are important and good. I know about an older man rather like me in Vancouver who died earlier this year after some time with brain cancer. His parents were already dead, but his great circle of friends helped him to stay in his own home till the end. I do not want to move into a hospital or nursing home. I think our lives should be supported to become good now; then they will be better in future.*

4c. Who should be involved in planning transitions from school to adult support?

*I think the person, with family and friends, are most important. Other people can let them know what options may be possible.*

## 1.5 Supports for People with Specialized Needs

Special supports, beyond those available through community mental health and counselling services, are needed when people who have a developmental disability face mental health and/or behaviour issues. The ministry has recently put special

supports in place for these individuals (called specialized services), but there are still gaps between what is needed and what is provided.

5a. What are the gaps between what is required by people with specialized needs and what is provided?

*I have a lot of special needs:*

*--for support to communicate reliably and to continue to learn*

*--for advice on my health swings and extreme sensitivities to just about everything*

*--for help with my difficulties with movement and balance--sometimes in perpetual motion, sometimes frozen and stuck*

*In the past, people thought I had behaviour problems, and I do get really down in the hard times when my health is poor. But having medication only makes everything far worse.*

*Professionals who really help someone like me are not found in every city. Family doctors don't want to be bothered with us.*

5b. What suggestions do you have as to how best to close these gaps?

*So my parents and close friends reach people who really understand and can help. Now, and more in the future, they need to be able to use some special funds to get the right help. People like me need direct funding, to be used as necessary for my health and quality of life.*

## 1.6 Taxes, Wills, Disability Savings Plans

While all parents have a legal responsibility to support their children until they turn 18, many parents who have a family member with a developmental disability continue to provide financial support throughout their adult years. Instead of contributing towards university tuition costs, as they might for a son or daughter who does not have a disability, one parent may stay out of the workforce to provide support at home and to provide transportation to work or volunteer activities in the community. There is an opportunity to get the provincial and federal tax systems working together more effectively to help address the additional financial costs faced by caregivers. This includes exploring the possibility of creating a registered savings plan for people with disabilities (similar to registered education savings plans). Families are also looking for changes in how they can use wills and trust funds to support a family member.

*My parents spend all their lives supporting me. They actually care for me in my own home, which is good preparation for the future, and much better for me as my home revolves around me and my life is excellent.*

*But it is more complicated for them, as they also have to look after their own home.*

*My parents bought my home for me and gave it to a housing trust so I can always live here.*

6a. What changes are needed to help families cope financially as they care at home for their family member with a disability?

*For the past nine years, my mother has camped in my home every night. For all that time and before that, she spent most of her energy caring and planning the best other supports for me.*

*I worry that she has no time for herself.*

*My parents say they are glad to support me. But it means that they have less for themselves*

*They have also planned for the future, to give me the best chance to stay in my home and have a good life. They still worry about the extra costs when they are too ill or old to support me directly.*

6b. What changes would help families who want to make long-term plans to support their family members with a disability?

*Families should be encouraged to invest in a home for their person with a disability.*

*Perhaps there could be grants or tax credits to help.*

*Circles of friends can help parents feel better about the long-term future. Trusted friends can keep good supports going after parents get too old and die.*

## 1.7 Quality Supports and Services

There is an opportunity to involve people receiving supports and services and their families in setting acceptable quality standards, and developing ways to improve the quality of services and supports provided to them.

7a. What role should individuals and their families play in setting quality standards for supports delivered by agencies, and for supports purchased elsewhere?

*A person with a disability must be centrally involved—“Nothing about me without me!”*

*I must be supported by family and community friends who understand and care.*

*I have an incorporated aroha entity, with the main purpose of setting standards and maintaining my quality of life.*

*An independent planner/facilitator can help a person and family to decide the most important goals and to measure progress.*

7b. How can individuals and their families contribute to the continual improvement of the quality of services and supports provided?

*Everyone involved in my life agrees to goals for continuous quality improvement and ways of reviewing progress. By deep listening to me, and by sharing time and interests with me, my circle of friends and incorporated aroha are in the best position to monitor my quality of life and see ways of improving it.*

*I am glad that the Government is trying to improve the supports for persons with a disability. I wish more people had a good life like mine. I think my parents and friends and my own determination have been more important than any services provided by agencies.*