



***Step by Step:
A Transitional Residential/Respite Program***

**A proposal from
*Opportunities Mississauga for 21+
and Christian Horizons***

March 2011

The proposal in brief:

- *Opportunities Mississauga for 21+ and Christian Horizons* propose creation of a home that will offer residential/respite services to 12 people for the cost normally associated with the provision of such services for 4 people in a traditional “group home.”
- The Mississauga residence would create vitally needed transitional experiences for young adults with developmental disabilities as well as extended respite opportunities for families who are at risk of “burn-out” after providing full-time support for several decades.
- The program would emerge through family/agency/government/community collaboration. The synergies inherent in this collaboration would multiply both the scale of the services that can be delivered through traditional funding arrangements and the quality of those services. The quantitative augmentation will be evident in two ways: through tripling the number of people served with the same funding supports and through community fund-raising that will provide the capital funds required for the purchase of long-term residences for individuals moving through the transitional process. In addition, the quality of services will be enhanced as energetic local outreach to faith communities, sports groups, and ethnic organizations (for example) yields social and recreational connections for the program’s participants.

Introduction:

Working together, *Opportunities Mississauga for 21+* and *Christian Horizons* propose the establishment of what might be called a “4 x 12” residential program for adults with developmental disabilities currently living with their families. A “4 x 12” residence would be one in which spaces for 4 individuals would actually be utilized by 12 individuals.

How would this be possible? By having three different groups of four adults access the program for one month in each calendar quarter: i.e., one month in the residence, two months in the family home; another month in the residence, another two months in the family home, etc.

We see this model as one that would make it possible for 12 individuals to gradually experience life away from their family home – sparing them the stress and even trauma that can come with a sudden and complete separation from their parents under crisis circumstances later in life. Of equal importance, the quarterly residential program would provide significant respite support to families struggling against “burnout” or nearing breaking points of stress and health problems.

If individuals were able to start accessing such a “transitional residence program” by their early-30s (for example), it would be easy to imagine a five or even ten-year period during which their families could remain primarily responsible for their care (with the individuals involved still living in the family home two-thirds of the time). Support dollars for the residence would thus go significantly further than would be the case in a more conventional program – while “quality of life” benefits would also be dramatically greater for the individuals and their families.

How will the program be established and how will it operate?

Step By Step will emerge from collaboration between families, an established service -providing agency, government, and the wider community of Mississauga. The synergies generated by such collaboration have the capacity to yield a whole that is much greater than the sum of its separate parts.

Detailed planning for the launch and operation of the “Step by Step” pilot project will be undertaken jointly by *Opportunities Mississauga (OM21)* and *Christian Horizons* (continuing extensive conceptualization discussions already held). The involvement of the Ministry of Community and Social Services in further detailed planning would also be both necessary and desirable.

Some important features of the initiative include:

- The capital costs for the purchase or retro-fitting of a permanent residential facility will be raised through *OM21* fund-raising, operating through an existing *Christian Horizons* non-profit housing corporation. (The rental of apartment, condominium, or townhouse space would be at least an initial option as the project gets off the ground and fund-raising proceeds.)

- Six individuals from *OM21* families would utilize the program and a further six individuals would be designated by the Residential Services Management Committee of the Peel Planning Group. (The six individuals from *OM21* families have long been included in the Peel “waiting list” for residential services: indeed, between them, the six have spent almost 100 years on the list.)
- Sufficient funds for the maintenance of the facility would be required from MCSS – with family resources mobilized as possible (through partial utilization of ODSP funding, for instance).
- Primary responsibility for the establishment and day-to-day operation of the facility will be undertaken by *Christian Horizons*.

Both *OM21* and the six *OM21* families will undertake a range of ongoing responsibilities for the *Step By Step* program:

The families, for example, will commit themselves to providing various kinds of support during the times their sons or daughters spend in the residence: e.g., regular visits and consultations regarding the design of appropriate transitional efforts involving staff and families.

The *OM21* organization, for its part, will pledge itself to:

- the development of community supports for the *Step By Step* facility, with an emphasis on outreach to faith communities, recreational groups, and ethnic organizations to arrange (in particular) social and recreational interaction with the larger community;
- participation in a “users” or “advisory committee” (comparable to the one created at *OM21*’s initiative for day activity programs launched in partnership with Community Living Mississauga);
- public relations and publicity efforts concerning the contributions made by this innovative government program;
- consultations with interested family organizations throughout Peel and in other communities across the province.

Further steps in the *Step By Step* process:

To be true to the spirit of this proposal, the *Step By Step* transitional/respite program should continue to evolve – as the residents and their families do. The working assumption here is that each of the individuals participating will move into a permanent residential setting or alternative arrangement at an appropriate time, generally within a three to five year period (with variations depending on particular needs and opportunities). As this movement to fuller independence and

community involvement takes place, new individuals (and their families) can take up the transitional spaces that become available.

The 3-5 year timeline envisioned for each individual's participation in this transitional residential/respite program meshes very well with the sequencing of the Ministry's "transformation" efforts. The establishment of the new "regional contact points," the administration of the "support intensity" survey process, the determination of resource allocations linked to support intensity determinations, etc.: these complex, but necessary steps will be shifting into their most active "front line" phase (with services being accessed by individuals with developmental disabilities) as those who have experienced the transitional program become ready for longer-term opportunities.

It might be added, as well, that the very nature of the transitional program will enhance the success potential of the transformation process. On one hand, there will be greater opportunities to observe the evolving abilities and needs of the participants – lending a dynamic element to support determination. On the other hand, as well, it is entirely conceivable that transitional experiences will allow some participants to "learn" and "grow" in ways that will reduce the level of supports required over the long-term.

With an eye to another dimension of the ongoing evolution of the *Step by Step* program, it should also be emphasized that fund-raising within the *OM21/Christian Horizons* non-profit housing corporation will play an important role in making it possible to build or purchase the additional homes required for the initial (and subsequent) *Step by Step* participants to move to full-time residential opportunities as those may be needed.

What's the reason for a new approach? What are its advantages?

The *Step By Step* concept took shape as people facing difficult circumstances sought to cope with severely limited services.

It would have been all too understandable if those worn down by literally decades of heavy responsibilities for family members with developmental disabilities had simply succumbed to depression. Like other organizations across the province, however, the more than 150 families represented by *OM21* decided to take seriously the urgings of the Ministry of Community and Social Services to think creatively about problems that had been defying solution. The McGuinty government's determination to provide real leadership in this area was both greatly appreciated and energizing.

OM21, for example, met with both Sandra Papatello and Madeleine Meilleur to applaud the provincial government's seriousness of intent regarding "transformation" of services. The family group then worked energetically to encourage a maximum degree of grassroots consultation, helping to organize two large Mississauga meetings for Parliamentary Assistant Ernie Parsons. This was followed up through the contribution of *OM21* feedback on Mr. Parsons' draft report – as well as invited testimony during Queens Park hearings on Bill 77. *OM21* has now also occupied a seat on the Ministry's Partnership Table for the past two years.

Throughout, OM21 has remained enthusiastically and vocally supportive of the provincial government's constructive efforts.

Within our grassroots organization itself, the Ministry's encouragement of "creative thinking" led to lengthy deliberations – deliberations in which pragmatic calculations soon meshed with idealistic visions. It was enormously important to our members to find that such seemingly different types of thinking could co-exist in a powerfully reinforcing way – and we want to outline key components of the two analytical and conceptual streams that have generated this proposal.

Pragmatic calculations: Families would obviously love to see Queens Park coffers opened to the point where the severe shortages of residential programs for adults with developmental disabilities would simply be eliminated. While this is a perfectly understandable wish, *OM21* families know it is just not going to happen: given competing demands in areas like health care and education, we can more realistically hope for progress rather than solutions that come in dramatic leaps. But progress can still offer meaningful results and satisfactions.

Ministry leaders have been clear about the budget problems they confront and have emphatically urged district offices, agencies, and families to think creatively about ways of using current and gradually expanding resources. *OM21* and *Christian Horizons* strongly believe the *Step By Step* proposal does exactly this. We want to launch a program that will make government dollars go three times farther than they would otherwise go: we are proposing a way to make resources that would ordinarily serve four individuals yield a quantitative and qualitative improvement of services for twelve individuals and families.

In addition to servicing a larger number of people, the initiative we propose would also respond to a greater variety of needs than is often the case with existing programs and templates. One key example of this is the way in which *Step By Step* would allow resources to simultaneously impact both residential and respite shortfalls in our community. Mississauga is strikingly lacking in respite programs for the families of individuals with developmental disabilities, for example. "House 5" at Central West Specialized Developmental Services (formerly Oaklands) has provided a periodic lifeline to many, to be sure, but huge population growth in the region has meant that space available in this one facility does not match the burgeoning needs – particularly since the Oakville-based facility serves several growing communities. And it should be added that that specific *Oakville* location creates problems for *Mississauga* families, e.g., in that those spending "respite" time there cannot access their usual community-based day activity, employment, or social opportunities.

Another way in which the *Step by Step* proposal would respond to a greater variety of needs is through its ability to allow attentiveness to individuals across the spectrum of developmental disabilities: where "Supported Independent Living" (SIL) arrangements have often been used as a way of aiding a larger number of individuals on residential waiting lists, for example, the *Step By Step* proposal would yield similarly larger numbers while meaningfully stretching the reach of designated resources to those less able to access services in the past. (And it would do so by way of per capita budgetary allocations that may in many cases be only modestly greater than

current SIL calculations – since individuals with higher support needs will require away-from-family support for only four months out of each year.)

Combining vision and quality with pragmatism: At no point in OM21’s deliberations regarding creative solutions to long-standing shortages of residential opportunities did pragmatic calculations concerning quantity overshadow attentiveness to quality. All of the brainstorming discussions which produced the plan, after all, were conducted by parents and siblings: was anyone likely to focus more consideration on the merits of programs (as opposed to their number) than the family members who had been giving so much of themselves for decades?

What became apparent over time was that quality of life concerns could be addressed in a practical fashion. In fact, greater progress could actually be made with respect to quality of life concerns precisely by way of pragmatic innovation.

A particularly clear example of this multifaceted dynamic is the way in which the *Step by Step* proposal allows for a genuine transition experience – one not usually possible in existing models of residential services.

The life histories of both individuals with developmental disabilities and their families often create unusual degrees of sensitivity and vulnerability: day to day experiences and relationships can be challenging – and the challenges can be especially intense. Under such circumstances, the process of encouraging a family member with developmental disabilities to move into a more independent life in the larger community can be fraught with special complications.

The benefits for adults with developmental disabilities:

Step By Step would allow a measured, literally “step by step” movement away from the long-time family home. The move would be both planned and gradual, two qualities of enormous potential value relative to common experiences to date.

As a result of planning, for example, the shock and dismay that can be associated with movement to a residential program under crisis circumstances could be minimized. In part this would be possible because serious illness or the death of parents would cease to be the trigger for the launch of a new life stage. As well, the transitional process would begin earlier in the life of the adult with developmental disabilities: the trauma of a major new experience is often going to be much greater at 50 than at 30 (for example).

The gradual character of *Step by Step* will also be one of its significant virtues – for multiple reasons:

- The pain and discomfort that can (again) come with transitions for vulnerable people can (again) be limited if there is an extended period of back-and-forth movement between the new and the familiar. This is a segment of the population (more than most) that would almost invariably be better off if it could gradually learn to swim – as opposed to being thrown into the deep end of the pool in a crisis atmosphere.

- Powerful further opportunities to minimize the potential trauma of a transition to residential experiences beyond the family home would emerge from the fact that parents would be young enough and well enough (alive enough!) to continue playing the kind of supportive role they had traditionally played in their child's life. It would be difficult to over-estimate the comforting impact of this particular *Step by Step* feature.
- Aside from their ability to make the move to residential independence more comfortable for the adult child with a developmental disability, parents who are younger and healthier can also multiply the growth opportunities available within the transition process. Family integration into the process – during the periods when the individual making the transition is living in the *Step by Step* facility as well as at the family home – would significantly enrich the learning/growing environment.
- The earlier start of a transitional residential program would also help to multiply growth opportunities and increase the likelihood of each individual living up to his or her full potential. For adults with developmental disabilities (as for almost any person) the ability to learn and adapt is likely to decline at least somewhat in more senior years. Beginning a transition away from the family home at an earlier age will make it far more likely that life skills and the ability to thrive in a more independent, community-oriented setting will be enhanced: dependent behaviours will not be as greatly entrenched and a door to a greater measure of real independence and citizenship will less likely be closed.

The benefits for families:

If *Step By Step* offers significant advantages to adults with developmental disabilities, the families of these individuals will also certainly benefit. Such families have often paid a heavy price as they have fulfilled their responsibilities toward children with developmental disabilities – and it is no small thing that an innovative program like *Step by Step* will allow important transitions for both families and adult children. Of greatest importance would be the lightening of emotional burdens: the sometimes paralyzing worries about how a vulnerable adult child will be taken care of if something happened to his or her parents; the agony (and the guilt) associated with not knowing how to play the natural parental role of preparing a child for independence – because programs and resources are limited. *Step By Step* would enable families to fulfill the responsibilities they desperately want to fulfill – by allowing them to plan and act before health problems overtake them. In addition, the gradual, transitional nature of *Step By Step* would spare the families as well as the adult children with developmental disabilities the wrenching experience of a sudden and complete move away from the family home at a later moment in life.