

## ***GSA's Roles as a Housing Trust***

*Guelph Services for the Autistic (GSA) has functioned as a Housing Trust since 1997. Its mission and main focus are to help adults with high support needs because of the complex challenges of Autism to have their own homes and to be included with respect in our communities. GSA has pioneered ways of encouraging self-advocacy and coordinating private and public resources and the efforts of families and friends. Elements of a good whole life include reliable self-expression and self-directed planning, direct individualized funding, and a sustainable continuum of support. Adults assisted in this way to have their own homes are GSA's "active members", other supporting friends being "associate members". Because other families and organizations are interested in the path pioneered by GSA, we compiled a guide to its various agreements and procedures as possible models.*

*Trust is the vital quality in GSA's role for our active members and their families and friends. The primary role of directors of the GSA Board is to be good trustees for the well-being of our vulnerable citizens and of the funds that support their good lives. In its primary function as a Housing Trust, GSA's roles and responsibilities are carefully defined in legal agreements.*

### ***What is a Housing Trust?***

Guelph Services for the Autistic uses the term with two levels of meaning. One is the sum of the formal and informal relationships of trust around each person when an agreement is made to support lifelong occupancy in their own home. Such an agreement is legally defined and subject to several conditions.

The term is also used for the mission and focus of the charitable not-for-profit corporation that has embraced the vision, mission and function of making these agreements with individual persons and may support several vulnerable persons in homes of their own.

The term Housing Trust has been used to mean a fund or mechanism for creating affordable housing in municipalities and regions all over the world, with several safeguards—usually involving public funding. We share that general function, but with a special emphasis on supporting a person with a disability (Autism in our case) to have his or her own home. Our use of the term also involves more shades of meaning of "trust"—so that persons and their families can trust that good arrangements, made in advance, will be carried out. Trust is involved among more partners with more safeguards for the person's well-being.

Guelph Services for the Autistic (GSA) is a charitable, not-for-profit organization, incorporated in Ontario since 1980, that reorganized itself in 1997 as a Housing Trust. GSA's mission is to help adults with severe Autism to live good whole self-directed lives in their own homes, supported by people they choose, and included in their communities.

GSA is concerned that all supports in a person's life are well planned and co-ordinated to form the basis for a good whole life. For each person with whom GSA makes a commitment to support in a home of their own, there must be assurances that all the costs of occupancy will be covered. So far, this has meant a commitment by the person with family to contribute private funds for the capital costs of the home and to negotiate any

support dollars for which the person may be eligible. The finances of each person's plan are kept in separate bank accounts. GSA's relationship with each person is defined in distinct agreements. GSA must do everything possible to protect the person's home for their lifelong occupancy. This is such a serious process that GSA discourages family groups from acting hastily to purchase a property to be the home of a vulnerable person until decision-making and an Aroha are in place.

Each person supported by GSA must have an Aroha, an incorporated entity with directors representing the circle of friends, to be responsible for most aspects of personal support including supported decision-making. An Aroha (like a Microboard) is valuable now and vital in the longer term to sustain the person's good whole life. GSA depends on each person's Aroha to take responsibility for support workers and caregivers and the co-ordination of everyday life to ensure successful occupancy. An Aroha should be active before a family group begins to buy a house.

GSA has not been a transfer payment agency and does not seek regular government funds. All GSA work has been done by volunteers; there are no paid staff. This might change in future with an increase in the number of people supported in their own homes by GSA.

To encourage vulnerable persons and the families and friends to plan well, GSA has also organized events or sheltered various projects and information services that support its mission. The Bridges Communication Group with GSA support is dedicated to helping adults who cannot use their voices to express themselves reliably in alternative ways. Since 2000 the OAARSN website and Listservs have offered encouragement and information sharing and promoted positive and respectful approaches in supporting adults with Autism.

GSA's bylaws are similar in many ways to those of any charitable not-for-profit corporation in Ontario that supports human and social services. There are two distinctive features that ensure that the interests of adults with Autism are always of central importance in the board's decisions.

One is in the membership structure. "Active members" are persons with Autism who are signatories to a current and binding Occupancy Agreement with GSA. "Associate members" are persons who wish to support GSA, usually because they are family members or friends of a person with Autism. Another feature of GSA's constitution is the election of up to four GSA directors directly by "active" members.

More generally, it is important that directors and prospective directors of the GSA Board are trustees for the good, whole sustainable lives of our adults with Autism. Directors of a Housing Trust should be:

- Sensitive to the values and spirit of GSA, in relation to people who are vulnerable because of disability-- including the presumption of competence, the right to communicate and to direct one's own life, and the insight that a person's good whole life must be grounded in their own priorities and choices and in support by family and friends.
- Reliable and trustworthy members of the community so they can be responsible trustees for the long-term interests of adults with high and complex support needs, and for the house properties maintained by the Housing Trust.
- Well connected with the community and thus with helpful resources relevant to administering and maintaining a home, and who offer community connections to increase our effectiveness.

- Aware of the legal requirements of being a director of a not-for-profit corporation with registered charitable status.

### ***Why and how did GSA develop as a Housing Trust?***

From first incorporating in 1980, GSA's founding members were looking ahead. Their sons and daughters, then in their early teens, had quite severe symptoms of Autism. Autism was defined much more narrowly than it would be from the late 1990s, and numbers were small. There were no local services and even special education was not yet mandatory. Some of our young people had to live away from their homes or commute long distances to get any Government-funded programs designed for their needs.

As a voluntary advocacy and support group, GSA worked through several generations of proposals for adolescent and adult residential services. We spoke up for persons with Autism and organized meetings and proposals on innovative ways of supporting them. From 1991, we collaborated with our regional neighbours in the incorporation of Waterloo-Wellington Autism Services (WWAS). Together we planned for three successive pilot projects over the next four years—a pair of group homes, development of Autism information and resources, and an experiment in “enhanced supported employment”. Some Government funds were obtained for the second and third of these until the end of 1995.

A combination of factors in the mid-1990s influenced GSA's sense of purpose. The Ontario Government was closing the institutions or “facilities” that had housed about 50,000 people with developmental disabilities since 1870. Incentive funding was offered to agencies to accept people being “re-patriated” to their home communities, usually to accommodation in group homes. In the same period, governments at all levels were cutting off social housing funds that had supported some earlier innovative projects.

A high proportion of the last to leave the institutions were probably adults with the symptoms of Autism who had not been formally diagnosed. We were very aware that our friends with Autism did not fit comfortably into institutions or group homes. They did not thrive in group living environments. Their special needs were inadequately understood and the staff seemed to treat them as challenging and barely manageable only with physical or chemical restraints. Their families were too often excluded from their lives. We felt there had to be a better way, in which vulnerable persons would be supported to express their thoughts and choices and their families would be respected and included.

But there were also signs of hope. People with Autism severe enough to prevent them from using their voices, when given the opportunity to use Augmentative or Alternative Communication (AAC), were beginning to show that they could both understand what was going on around them and express their thoughts and feelings reliably.

Progressive ideas of tailoring supports to the individual person and building community resources to include them were gaining ground. Individualized funding, pioneered in British Columbia and later adopted as official government policy in Alberta, was being discussed in Ontario. Workshops on these new approaches were offered by Homes for Adults with Autism and Pervasive Developmental Disorders (HAADD) in Toronto in 1996. With others who advocated alternatives to the traditional services and more choice for persons with

disabilities, we were associated in early meetings of the Individualized Funding Coalition for Ontario (IFCO) and have continued to be connected.

GSA's re-orientation in 1997 was focused by the urgent needs of one person. "Anthony" (let us call him) lived with quite severe symptoms of Autism and had endured some very unhappy experiences of group living. His parents were his only family in North America. The tragedy of his twin sister's accidental death concentrated the minds of his parents and friends to help him to build a new life of quality and respect. Though he could not speak with his voice, Anthony was able to express himself with Supported Typing (a form of Augmentative and Alternative Communication) to ask consistently for "a home of my own" in his home city, among other key elements of a good whole life.

Pioneering models of "one's own home" for a person with a significant disability were known to us. We were inspired by the individual home and life developed around Catherine Schaefer by her family in Winnipeg in the 1980s. A little later, the NABORS project in Toronto (Neighbours Allied for Better Opportunities in Residential Support) aimed to build community and achieve inclusion for people with disabilities by designing apartments for them in social housing projects that were intended for other tenants as well. In both these examples, the entities responsible for personal supports were different from those that owned and maintained the homes. This is considered a safeguard that the interests of a vulnerable person come first and are not subordinated to the interests of the agency.

Catherine Schaefer was supported practically and emotionally in her large home by several lifesharing companions. We liked the lifesharing (aka homesharing) idea very much, as a natural way of encouraging social relationships and building intentional community around the person. In our mind, the focus person would choose the people to share her home and support her. If difficulties could not be resolved, the support people were the ones who had to move on. The focus person stayed in her home. To make this work sustainably into the future, it was necessary to have the legal powers of a Housing Trust that was unencumbered by other responsibilities such as being an employer. To keep the focus on the person and her rights of decision-making, it helped when families were substantial partners in the enterprise—as funders of capital and other costs for the home, and also involved in whatever ways were needed to establish the new whole life.

So, for these reasons, GSA in late 1997 took up the new role of Housing Trust, to enable individual persons with handicapping conditions to own their own homes with the best possible support for everyday living and as a basis for a lifelong continuum of support. Anthony became GSA's willing pioneer, his abilities and needs prompting the fullest development of the GSA model. Responding to his situation, GSA and its lawyers immediately developed GSA's own revised bylaws to work as a Housing Trust. Anthony's parents bought a spacious and well-situated property to be his home and made a family funding agreement with GSA. GSA and Anthony signed the occupancy agreement, spelling out everyone's responsibilities in legal and plain language. The lifesharing agreement and procedures were drafted.

All so far had been achieved without official encouragement or help. During 1998, we had to work out ways for Anthony to receive the individualized disability support funding for which he was eligible, if he was not being sheltered by a traditional agency. For about 18 months, Anthony and his family were in limbo, his family paying for his home and a large part of his support costs. The ideas of a home of one's own and lifesharing

were regarded as too innovative and individualized for the traditional agencies or service system. Any funds for residential support could be flowed only through agencies recognized by the Ministry.

Thanks to networks among progressive advocates in Ontario during 1998, we reached Malcolm Jeffreys of Windsor Community Living Support Services who was then encouraging person-directed approaches for people and families in his jurisdiction as well as helping to found what would become the (unencumbered) Windsor-Essex Brokerage for Personal Supports (WEBPS). Malcolm was so glad to see a person, family, circle of friends and Housing Trust taking on innovative roles, that he offered his agency's help as transfer payment agency. A Personal Support Agreement and statement of Continuous Quality Improvement were drafted and signed by Anthony himself, his parents, and by representatives of GSA and the Transfer Payment Agency.

Thus, within one year of GSA's first re-orientation as a Housing Trust, four of the six agreements in this manual had been drafted and put into effect. As we now see, the other two agreements should come first in an ideal process of developing a good whole life in one's own home. GSA was constrained by Anthony's urgent need for his own home, and he was already able to express his thoughts and needs and had a strong circle of friends.

During the following two to three years, for others besides Anthony, we realized that full development of a good whole life depended on two other elements that should come earlier in the process:

- Reliable communication by the person in expressing thoughts, feelings and dreams, as the basis for a formal supported decision-making agreement;
- Incorporation of an Aroha entity as the core of a person's circle of friends and support network and a key agent in sustaining a good life and a partner in all the other agreements.

These two agreements were drafted and put in place to support Anthony's good whole life by early 2002.

## ***What are the essential principles of supporting a vulnerable person in a good whole life?***

### ***1. The person is centrally involved in planning and realizing her or his whole life.***

We must listen deeply to each person in whatever mode of communication works for them. This communication must be two-way. We don't just expect them to communicate our way and assume they have no intelligence or feelings if they cannot speak with their voices. We don't assume our vulnerable friends cannot understand our language. As friends and supporters, we also try to learn the ways they do express themselves. We have learned that "presumption of competence is the least dangerous assumption". We try to open our minds to the possibility that they are smarter than we may have assumed. When we shift our assumptions, we are continually amazed by their insights and wisdom.

We knew intuitively as loving family members that this is a first principle of support. But our understanding has been deepened since one of GSA's active members took the lead in forming a communication support group in 2004. All vulnerable adults should be encouraged and supported to express themselves. This is a basic human right and also a wise and sensible strategy to encourage coping skills and reduce frustration. We

would urge all families of children and teenagers with communication challenges to help them find the most reliable ways of expressing their thoughts and feelings. These can be the basis for supported decision-making and self-directed planning, using whatever two-way modes of communication work for the person. We support the mantra of various self-advocates' groups: "Nothing about me without me!"

These ideas are explored further in "Listening to the Person" with a model Supported Decision-making Agreement. But the person's voice and choices are involved in all the agreements.

## ***2. One's own home is an essential anchor of a good whole life***

For any homeowner, home is a haven, a place to relax and be oneself, a base for activities and interests, a symbol of control over one's life, and a place in which to host friends and express one's individuality. It is also often our biggest investment and the basis of financial security as we get older.

If a home is important to those of us without special needs or complex handicapping conditions, how much more is it vital for people who may have much narrower lives because of a developmental or other disability? A home can be customized for a person with the hypersensitivities that make group living so hard for some—using adaptive and assistive technologies of various kinds. If a home is equity for non-disabled people as they age, how much more should a person who is vulnerable be able to have a secure home?

People who live with complex challenges can grow into pride of ownership, a sense of responsibility, and the joys of being host. Support people are chosen by the homeowner and enter the home respectfully as they would the home of a neurotypical person. The activities of the home can revolve around the homeowner who may not want to go out to a day program every weekday. Having one's own home also allows the person to invite lifesharers to share the home and provide live-in support as an intentional household community. Home ownership is basic to all parts of the GSA model.

## ***3. Families (widely defined) are respected and involved for the friends and community connections they make for the person.***

Families are a key part of the GSA model, from their confidence in and love for their son or daughter to their willingness to provide funds for the person's home and to share their unique knowledge of the person with all the friends and entities that will make a good whole life sustainable. Instead of being sidelined as can happen when an agency takes over, parents and siblings should remain centrally involved as advocates and interpreters of the person to others. They can also take the initiative, with their son or daughter, to plan and realize a good whole life that is sustainable.

Parents or other family members can choose to invest in their son or daughter's home and good life, now and into the future. A family could contribute all or part of the capital and maintenance costs of the home, with GSA registering the family contribution as a mortgage on the property. This investment is not interest-bearing but could be repayable to the lenders or their estate under certain conditions--if the person dies or wants to move away, or if GSA cannot continue to protect the person's occupancy for any reason. Family members and friends may also make tax-creditable donations to help GSA and serve as directors of the incorporated Aroha entity or the GSA Board.

We encourage families to share the challenges and satisfactions of supporting a son or daughter who is vulnerable because of severe disabilities. But we know it can be hard to let go. Parents have deep knowledge and long experience in helping their family member to cope: their understanding of the ten thousand individual details is vital for those who may eventually succeed them. Sadly, some families living with Autism have sensed or imagined negative attitudes from extended family or neighbours and find it hard to believe that anyone else could want to help. Some agencies may seem to drive a wedge between adult clients in group homes and their families.

For aging parents of people with complex disabilities, it can seem easier, even more fulfilling, to continue coping and sharing life with their disabled son or daughter. They may have had to rescue their son or daughter from a failed group home or other kind of living arrangement, and are very reluctant to take another risk, fearing that they might not have the energy to rescue their family member again. Parents may just carry on and make very little provision for a future when they will become ill or die.

We understand and sympathize with these fears by families. We honour families who have continued their loving care of their disabled sons and daughters to the end of their lives. Their memories and records are invaluable. Many adults with Autism also seem most comfortable continuing in their family homes with their much loved parents and the familiar routines and culture. But we encourage families to plan for a combination of their continued involvement with encouragement of the person's own voice, interactions with more people, and sustainability for the longer term.

Rearing and advocating a child with disabilities, especially if these are severe and complex, gives good parents a great deal of knowledge about what does and does not work and the authority to speak and advocate for their family member. But an assertive parent might prevent their son or daughter's real voice from being heard. A wise parent will encourage all possible and positive ways for their son or daughter to express their own voice—starting at a young age.

Every adult with a severe disability needs and deserves relationships with others besides their parents, just as non-disabled people do. They need scope to grow and develop their own choices as well as the experience of relating to different kinds of people. This can begin from quite an early age with a circle of friends. The more formal Aroha entity, in concept and practice, brings together the family and trusted friends who can learn to supplement and eventually succeed the parents and thus sustain the person's good whole life. Members of the extended family can also be invited to be part of the circle of friends.

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#### ***4. Each person has a circle of support, that may be also incorporated as an Aroha entity or Microboard***

Friends are the greatest resource for a vulnerable person, building community and inclusion by sharing parts of their lives and interests, and connecting with others who can offer friendship as well as opportunities for the person to contribute their gifts. Friends can help to find potential support workers and lifesharers.

Everyone who is vulnerable should have a circle of friends of which the core can be formally incorporated as an Aroha.

Adults with Autism, contrary to stereotypes about ASD, know that friends are their most important allies. Friends accept and like you as you are. Friends understand and help with the ups and downs of your life. Autistic adults may particularly want friends who are neurotypical (i.e., not autistic) because they may have been limited to the company of only disabled people in segregated settings. Above all, they want to have choice in who will be their friends, support workers and lifesharers.

GSA strongly recommends that core members of the circle of friends incorporate as an Aroha entity of personal support in order to complement and eventually succeed the roles of parents. Anyone applying for a full relationship with GSA as an active member has to have an Aroha (or equivalent Microboard or self-directed support corporation) as key partner in all the agreements and vital to making them work.

### ***5. Individualized funding, self-directed planning and independent facilitation are essential.***

The more complex a person's needs, the more individualized the supports should be. Everyone is different—in their dreams, gifts and needs—and people with Autism may have little in common apart from their diagnosis. Vulnerable people should not be squeezed into moulds, for administrative or financial convenience. Plans should be individualized and evolving, indicative and flexible rather than binding blueprints. We know that a good whole life must have certain qualities, but we cannot foretell exactly how we will get there. There should be room for the serendipity factor when some wonderful opportunity may open up unexpectedly. A person's abilities and needs may change, sometimes towards needing less support. But sometimes, unexpected health issues may need a review and expansion of the essential supports.

For GSA, it is wise to have a balanced division of responsibilities among several kinds of entities that are linked by their commitment to the individual person. As a Housing Trust, GSA's function is to hold and administer property in trust for a person's lifetime, subject to any necessary personal and financial safeguards. An Aroha has powers to support the person with all necessary funds and in contracts and agreements with any people or organizations that provide service. The Aroha directors also help the person with supported decision-making in the three areas of financial/business matters, health, daily living and personal care. Planning, facilitation and brokerage of supports should be independent of any service-providing organizations. Every entity and person concerned signs their assent to the Personal Support Agreement and protocol for continuous quality improvement to ensure that a person's plan is well co-ordinated to achieve what he wants.

### ***6. Keeping connected with others who are thinking creatively and pioneering better ways of supporting people who are vulnerable because of disability***

GSA itself has taken a lead in some of this, offering information and connections among people interested in alternative options in housing, communication and social support. Since 2000 GSA's role has also been supported by OAARSN--the Ontario Adult Autism Research & Support Network website and the Listserv networks on Adult Autism Issues and Creative Supports for Vulnerable Citizens.

In November 2001, we organized the Guelph Focus on Microboards workshop, which was led by David and Faye Wetherow of British Columbia and attended by 60 from across Ontario. GSA's Autism Support Project: Information, Resources, Empowerment (ASPIRE) from 2002 to 2005, among other things encouraged vulnerable persons with their families in our larger region to plan, often using the PATH approach (Planning Alternative Tomorrows with Hope).

In April 2005, GSA offered a conference and workshops in Guelph to feature new forms of Creative Supports for Vulnerable Citizens, and published proceedings of this event and a summary videotape. As one result GSA has been one partner with other community organizations in efforts to make independent facilitation and planning available for adults with developmental disabilities in our Wellington-Dufferin region. Since 2005, GSA has also sheltered the Bridges communication and self-advocacy support group.

### ***Who could find the GSA model useful?***

This summary of GSA's experience is not a blueprint for all. We hope that it will spark hope and ideas of possibilities, with the knowledge that these strategies have all worked in Ontario. Persons with a disability, parents, siblings and extended family, friends, neighbours, community, agencies and society as a whole can all benefit from this approach.

The full GSA model is appropriate when a person (with family and friends) wants to plan a self-directed life for the long term, and there are family funds for the capital costs of the home and individualized funding for disability supports, as well as dedicated friends willing to be Aroha directors.

In the idealized sequence:

- The person is encouraged to express himself about all his wants and dreams, including the importance of a home of his own in his life; and everyone in his circle makes a commitment to listen and to support in whatever ways are needed. This process may be helped by an independent facilitator.
- Family and friends organize themselves into a larger circle of friends, with a core group able to incorporate as an Aroha entity.
- Parents (or other family members) plan whatever financial resources they can contribute to the capital costs of the home.
- The person, with help from the Aroha and perhaps an independent broker or facilitator, seeks direct individualized funding and negotiates agreements with any community organization or agencies needed for personal supports or infrastructure services.
- Relevant legal agreements are made and signed among GSA and all parties.
- Friends seek good people to be interested in lifesharing or as support workers or tutors; the person and Aroha conduct searching interviews, and agreements are made with whomever proves suitable.

At first glance, the GSA model might seem very complicated and rather formal. All those agreements! Parents preoccupied with coping from day to day might say "Let's wait till we die. Something might turn up before then. Couldn't we leave all the responsibility to the siblings? Or what about the local agency whose ED seems sympathetic?" But if you care for your son or daughter as a person and want them to have a good whole life, you should consider something like GSA's model that combines listening to the person with sustainability of

one's home, close personal relationships, and a mechanism for support funding. The Housing Trust's responsibility for the person's longterm occupancy of the home is balanced by the Aroha focus on the person's whole good life.

The GSA model is not for the faint-hearted or for tentative dabbling. But a deferred version of the full GSA model could suit some persons and families. Parents could continue to live with their son/daughter but intend to deed the family home to GSA or other Housing Trust when they become too old or ill to provide active support. Such a variant would suit a situation where the person and parents are very close and interdependent and the person has always lived in the family home. It might be an example of "aging in place" that is now recognized as an option for seniors wishing to live out their lives in their familiar homes. GSA could make a conditional agreement to administer the home and to respect the person's decision-making, on condition that an Aroha entity is already involved in relationships and responsibilities. The family might gradually make plans that are consistent with GSA's role. Once the occupancy agreement becomes effective, its features would be as in GSA's full model.

With suitable amendments to GSA's key agreements, two or three adults with their family groups might combine to finance a home. Sharing a property might make the capital and support costs more manageable. GSA would need to be sure that each person has chosen this path and can reliably communicate their dreams, needs and choices. Each person would need his or her own Aroha entity to ensure that his or her good life is self-directed and supported by caring friends. The two or three family and Aroha groups would have to know one another well and share the same values and respect for each adult sharing the home. There would have to be contingency plans to cover future possible changes—so that if one person and family withdrew for any reason the home would still be sustainable for the other one or two occupants. A shared project might best provide for the needs of two or three individuals in the same building if it were subdivided or remodeled into two or three private living units with some shared community spaces. There might, for example, be separate suites with bed-sitting room and ensuite bathroom for each person as well as a large shared kitchen, living room and recreational space.

With a combination of social housing and family funds, GSA might sponsor and co-ordinate a co-op or cohousing community of 4, 6, 8 or more individual apartment units sharing a community centre—which might be designed for the purpose. The GSA set of agreements would be used to support each person taking part in such a project. This version would also require more co-ordination and mediation among the various partners, as well as core funding for the whole project to supplement any contributions from family partners.

## ***GSA as a Pioneer***

When GSA began its role as a Housing Trust, there was no official recognition of a family initiating and being a partner in an individualized life and home for an adult with complex needs who could have real choices. By mid-2007, however, the Ontario Ministry of Community and Social Services was inviting proposals for the Individualized Residential Model Initiative (IRMI). For a limited period, adults who met certain criteria with their families and agencies could submit proposals for "individually tailored ...housing options" that also recognized the "ability of families to provide supports". More than 60 projects were approved to receive Government funds for support staff and 89 people were said by early 2009 to be living in an IRM thanks to this funding. GSA was consulted by families, facilitators and agencies in several of the projects. The Ministry

hosted forums in April 2009 to pool the reactions and recommendations of agencies and family members who had experience in working together in individualized residential projects. The summary report and appendices are available for reading online:

**“A Home That’s Right For Me” Valuing Choice, Evolving Individualized Residential Options.**

-Summary Report of Policy Forums. Sponsored by the Ministry of Community and Social Services. (July 2009: Prepared by Jenny Carver & Associates). <http://www.aaarsn.ca/wp-content/uploads/2021/08/IRM-2009-summaryreport.pdf>

-Appendices: <http://www.aaarsn.ca/wp-content/uploads/2021/08/IRM-2009-Append.pdf>

The Ontario Government offered no further funds for innovative housing or related supports for people with developmental disabilities, especially those with severe and complex needs. Pent up demand for housing and personal support grew until the Ontario wait list for adult residential places reached 12,000 in 2013 and over 15,500 in 2017. The Ontario Ombudsman took up the issue, eventually publishing a report **Nowhere to Turn** in 2016 that pointed to the most egregious cases.

**“Nowhere to Turn”: Investigation into the Ministry of Community and Social Services’ response to situations of crisis involving adults with developmental disabilities**

[Nowhere to Turn - Ontario Ombudsman NTT-Final-EN-w-cover.pdf \(ombudsman.on.ca\)](http://www.aaarsn.ca/wp-content/uploads/2021/08/NTT-Final-EN-w-cover.pdf)

<http://www.aaarsn.ca/wp-content/uploads/2021/08/NTT-Final-EN-w-cover.pdf>

In early 2014 the Ontario Government’s Developmental Services felt impelled to appoint a Housing Task Force mainly of volunteers and to commit to fund innovative projects with demonstration value. Applications for at least 280 projects were submitted by community groups and agencies, but limited funding allowed only 18 of them to be supported for two-year periods. The Housing Task Force’s final report, **Generating Ideas and Enabling Action: Addressing the Housing Crisis Confronting Ontario Adults with Developmental Disabilities** was submitted in September 2018 though not published by the Government until August 2019.

[HTF Final Report 2018 Generating Ideas Enabling Action FINAL.pdf \(agilitycms.com\)](http://www.aaarsn.ca/wp-content/uploads/2021/08/HTF-Final-Report-2018_Generating-Ideas_Enabling-Action_FINAL.pdf)

[http://www.aaarsn.ca/wp-content/uploads/2021/08/HTF-Final-Report-2018\\_Generating-Ideas\\_Enabling-Action\\_FINAL.pdf](http://www.aaarsn.ca/wp-content/uploads/2021/08/HTF-Final-Report-2018_Generating-Ideas_Enabling-Action_FINAL.pdf)

P4P digital guide to the 18 demonstration projects of the HTF:

[HTF FinalV2\\_Mar2020 \(plantoronto.azurewebsites.net\)](http://www.aaarsn.ca/wp-content/uploads/2021/08/HTF-FinalV2_Mar2020.pdf)

[http://www.aaarsn.ca/wp-content/uploads/2021/08/Housing-Task-Force\\_Booklet\\_Ph2\\_v6.pdf](http://www.aaarsn.ca/wp-content/uploads/2021/08/Housing-Task-Force_Booklet_Ph2_v6.pdf)

The Housing Task Force came out strongly in favour of fresh ways of supporting people with developmental disabilities and of balancing ideas with action, declaring:

*There is a housing crisis confronting Ontarians with developmental disabilities – and it is a crisis that has been growing steadily more serious for at least twenty years. For many citizens whose families are unaffected by the challenges connected with developmental disabilities, the housing crisis is often invisible. Too often, however, housing challenges can bring pain and consequences that profoundly limit the joys and opportunities that should be available to all in a province as blessed as ours. This report urges dramatic action. It is time to move with energy and determination to challenge and overcome the severe difficulties that have been so long endured. Given awareness, innovation, and commitment, the Housing Task Force also believes that a record of crisis can be turned into a legacy of success – one that can be a source of pride for future generations of Ontarians. The word “crisis” is exactly appropriate to describe the housing*

*challenges outlined in this report. Statistics alone are deeply disturbing and grow exponentially with each passing year.*

The Housing Task Force report is worth reading. Housing as basic shelter is not isolated from the other supports that disabled people need to live in their own place. Innovations that GSA has advocated, like Housing Trust, Aroha/Microboards, homesharing/lifesharing, and of course individualized funding and independent facilitation/brokerage are represented among the 18 demonstration projects and we were consulted by several of the groups. But only a few of the people gaining new support through the demonstration projects are described as being vulnerable with complex high needs. Autism, severe or otherwise, is not mentioned.

Nearly two years have passed since the Housing Task Force report was submitted to the Ontario Government. Will there be action to match the bright ideas and will there be resources to extend services to reduce wait lists? The pandemic restrictions have shown how vulnerable people's quality of life can be diminished in such an emergency. Will there be funds and political will to enable creative supports in homes and good lives? There's plenty of scope for GSA to continue speak up for adults with severe Autism and complex care needs.

While government funding for innovative projects has not yet been repeated, family groups are encouraged to plan individualized housing for their sons and daughters, using whatever resources they can find to be ready for future possible funding. The GSA model would be valuable in this process and help with what were considered weaknesses in IRM pilot projects—especially for a person's self-expression, the roles of Aroha and Housing Trust in sustaining a self-directed life and maintaining a person's home into the future beyond the lives of parents, and the need for more independence from direct service agencies

Various of GSA's model agreements could be used alone or could inspire analogous agreements. A Supported Decision-making Agreement and an Aroha entity and agreement are recommended for everyone who is vulnerable. The person-centred and self-directed qualities of the Occupancy Agreement and Personal Support Agreement are good models for other agreements tailored for individual needs.

GSA's model agreements as a Housing Trust are explained in two editions of its printed manual ***Creating a Home and Good Life of My Own*** (2008, 2012). Digital versions of the six main agreements may be found in further chapters on this webpage.

**Listening to the Person with Model Decision-Making Agreement**  
**Aroha Entities for Personal Support with Model Agreement**  
**Affording a Home of My Own: Model Agreement with Family Lenders**  
**Rights Recognized in Model Occupancy Agreement**  
**Lifesharing in My Home and Model Agreement**  
**Holding Everything Together with Model Personal Support Agreement**