

## ***Holding Everything Together with a Model Personal Support Agreement***

*GSA's mission is to support adults with moderately severe and complex Autism who are very different from one another. Most feel uncomfortable and even extremely upset when grouped (without consulting them) with others who are considered to have similar problems. When we shift our focus to presume competence, listen deeply and see each individual life from their point of view, it makes sense to think of support that is person-centred and self-directed. We know that the more complex the needs, the more individualized the supports must be. We must continue speaking up for and acting upon the principles of self-determination, citizenship, flexibility and ease of access to direct individualized funding, and ensuring safeguards through independent facilitation.*

When GSA developed its role as Housing Trust from 1997, we knew that our adults needed disability support funds to complement the basic income support for living expenses and any capital contributions by families to the cost of the home. GSA's first active member, Anthony, was eligible for some funds, but without a clear way of using them for his needs. With the co-operation of an enlightened administrator in another region, it was possible for these funds to be flowed through his Transfer Payment Agency (TPA) to Anthony. As this was an innovative form of (indirect) individualized funding, the people around Anthony and his Aroha and Housing Trust were required to agree to all sorts of safeguards absolving everyone else of any responsibility.

The Personal Support Agreement reproduced below was the result. As with other GSA documents, it is expressed in the first person. It is reviewed regularly and has been revised as needed, for example when a TPA in our region was found to flow the funds. The statement of Continuous Quality Improvement has two main functions. One is to assure the TPA and Government that the funds are being used responsibly. More important from our point of view, this document is a systematic summary to guide all who support Anthony in his good whole life. Below we present a plain-language version from Anthony's point of view.

We hope that the eligibility and procedures for direct individualized funding in Ontario will become more straightforward and fair. There will probably be changes in detail and format of agreements, but GSA will continue to advocate for the qualities and values that help adults with high support needs.

### ***How My Good Life Is Supported With Funding Anthony Butler's Summary in Plain Language***

*I want to encourage people to not give up trying for individual funding and services. I think Individualized Funding has made all the difference for me. I might tell people that it is essential to get IF, because it is the only way to give people choices and options. We must have the freedom to have our own life, choose our own path, choose our own supports. I think we need to know we can provide for our own supporters, so we can choose good ones.*

*I am a man with complex disabilities and high support needs, I have developed the foundations of a very good life in my community during the past 20 years. My family and friends are committed to me and believe in me. I am determined to understand my options and challenges and do my best. It is important that everyone in my*

*life knows that I understand language and what people say, but I need Supported Typing to express myself. People need to listen and pay attention to what I say with my way of communicating.*

*Two organizations are very important in my good life. My housing trust (HT) owns and maintains my home and recognizes me as sole tenant for my lifetime or as long as I wish to live here. My Aroha is a not-for-profit corporation of family members and friends that, with me, has powers to advise on the supports I need to live a good life. Both the HT and my Aroha support my rights to express myself and to make informed choices.*

*I receive special funds to pay for the time and training of my tutors, coaches and caregivers, for consultations with people who are expert in my special needs, and for equipment and supplies to support my learning, communication, health and training. Special funds have been approved by what was then the Ontario MCSS (now MCCSS).*

*An agency located in our region is my transfer payment agency (TPA) as a simple banker, recognized by the MCSS. The TPA flows funds to me each month, and we report on how the funds are spent. The TPA does not charge fees for simple administration. If we ask this agency to do certain extra tasks, we might have to pay for their services.*

This is how the funding relationship among all of us will work:

1. Each month, in advance, the TPA transfers one-twelfth of the approved funds to my special bank account.
2. My agent keeps records of all expenses and reports monthly to TPA, both about how the money has been spent and how my life is going.
3. My Aroha is responsible for the quality of support I receive from tutors, coaches, caregivers etc.
4. My Aroha is responsible for advocating for my needs, including any negotiation with the Ministry.
5. My bank account transfers to the HT some funds each month to maintain my home and pay for the costs of utilities and insurance. HT takes responsibility for the health and safety of my home.

My Aroha, HT and the TPA understand and share the following values and agree to the following arrangements:

1. All the service providers, agencies and people in my life support me in self-determination, my rights to make decisions that affect how life unfolds daily. My decision-making rights include employment, education, personal goals, friends, the use of community amenities, leisure pursuits, types of services and supports. I have choice in the people (paid and unpaid, formal and informal) who provide personal support and a role in describing job expectations, scheduling, supervising and evaluating them. I will make my own choices and everyone else will respect them. I will tell honestly how I feel about the support I am given.
2. Anything written down about me is mine and I can read it when I want. All documents will be respectful of me and focus on my abilities. Personal records will be kept at my home unless I ask otherwise.

3. My special funding is to be used to support me to fulfill the objectives of my individualized plan. The funds are portable: if the agreement with a TPA ends because of dissatisfaction, the allocated funds can be used in a new agreement with a TPA that I choose. The funding is also flexible and may be adjusted to meet my changing needs.

4. XX is my Key Contact in my supportive decision-making process and my daily quality of life: she is the person to call to talk about me. XXX, president of my Aroha, is my advocate/broker to act on my behalf and with other directors of my Aroha in planning, negotiating necessary funding, reviewing and monitoring my plan, and making adjustments.

5. We will review this agreement every twelve months. Changes to this agreement must be in writing and signed by all parties. If we disagree about something, we will talk to each other about it in a timely and effective manner. We will make every effort to resolve issues and disagreements informally. If an issue cannot be resolved in this manner, we will seek mediating support in a form on which we agree. If the TPA or I (with my Aroha) want to end this agreement, we can give two months' notice, or some other term of notice if we agree in writing.

## **Model Personal Support Agreement of Anthony Butler with His Aroha, Transfer Payment Agency (TPA), and Housing Trust (HT)**

This agreement concerns the use of funding provided by the Ontario Ministry of Community and Social Services [MCSS] to support the implementation of a personal living plan. The allocated funds for implementing this agreement are based on an annualized amount of \$xxxxx. This amount may be adjusted and increased by further negotiation and planning and as approved by the MCSS.

### **Parties to the Agreement:**

1. I, Anthony Butler [AB], a man who lives with complex challenges, have developed the foundations of a good life in my community. This agreement is expressed mainly from my point of view.

2. My Aroha [FAB, Friends of Anthony Butler], an incorporated entity of personal support formed of family members and friends, and the core of my circle of friends, with powers to advise on the supports I need to maintain a good life in the community.

3. [Transfer Payment Agency named, TPA] is recognized by the Ontario Ministry of Community and Social Services as a transfer payment agency for transferring funds to support persons with disabilities.

4. [Housing Trust named, HT], a not-for-profit charitable organization which functions as a housing trust to help adults and their families to implement personal support plans. HT owns and maintains my home and has made a legal agreement with me to recognize me as sole tenant for my lifetime or as long as I wish to live there.

5. Ontario Ministry of Community and Social Services [MCSS] through its XXX XXX Region administration.

## 1. Responsibilities

### a. Transfer Payment Agency named [TPA]

- I, **Anthony Butler**, understand that [TPA] through your accountable mechanisms as a transfer payment agency, will:
  - Allow/enable/empower me (and all my caregivers, friends, Aroha entity, and any other direct service providers) to provide and co-ordinate the supports that I need to live in my home, enjoy the community and do my best;
  - Act as a funding broker to facilitate the flow of MCSS funds as needed to support my direct services in my community, e.g., for housing, work and learning, health and nutrition, communication and social relationships, exercise and recreation, management of mood and movement disorders, personal support and encouragement;
  - Receive support dollars provided on my behalf from the MCSS and account to the Regional Office on all expenditures up to the maximum amount approved;
  - Maintain financial records of all expenditures authorized under the support agreement;
  - Pay monthly e-transfers in advance for 1/12 of the designated support dollars, the expenditure of which will be accounted for by me or my agent;
  - Monitor and evaluate the quality of the support and assistance that is provided to me, using the standards and guidelines in my "Support Plan: Continuous Quality Improvement" and report back to me and my Aroha as well as the MCSS as required;
  - Cooperate with the Regional Office of MCSS in assisting my Aroha successfully to implement my desire to live in the ways which have been expressed in my personal support plan.
  
- I, Anthony Butler, agree that:
  - Transfer Payment Agency named [TPA] will not be responsible for any costs in excess of the approved level of funding provided to TPA by MCSS.
  - TPA is not expected to take responsibility for negotiating or justifying the appropriate level of funding to meet my needs or the requirements described in my personal plan.
  - TPA will not assume any responsibility or liability whatsoever associated with the implementation of my home life or place of support. It is understood that full responsibility for the health, safety and security of my life will be assumed by me, by my Aroha and by the HT.
  - If TPA takes on some obligations to me, to FAB, or to the HT beyond those outlined in this document and the time and cost of meeting its obligation therefore increases, negotiation of such administration costs will take place between TPA, my Aroha and MCSS.

### b. Housing Trust (HT; a not-for-profit charitable corporation--Ontario Letters Patent XXXXXX)

I, Anthony Butler, want you to:

- Assist me in your capacity as a housing trust, to enable me to maintain my home and home life in the manner that I choose;
- Maintain ownership of my house and the responsibility of care and upkeep;
- Co-operate with my Aroha in meeting and reviewing the best ways to find people to share my house;
- Continue my lifelong occupancy agreement that was originally executed in XXXX
- Make legal agreements with individuals who are selected to share my home. I understand that these individuals may live in my home rent-free (or at reduced rent) and that you will undertake to protect my

interests as best you are able to ensure that people I live with are neither tenants nor employed to support me;

- Indemnify TPA and the MCSS against any liability or risk arising from any occurrence or incident in the implementation of this agreement, including any liability relating to AB's employees or lifesharers, and satisfy TPA that the requirements of MCSS have been met and will continue to be met at all times with respect to conflicts of interest.

- **c. Anthony Butler in my Aroha (an incorporated not-for-profit entity for personal support)**

- My Aroha will assist me directly by ensuring my well-being. Members of my Aroha will also ensure that I have opportunities for a positive and proactive role in planning, decision-making and efforts towards continuous quality improvements;
- We will recruit, select, support, direct and supervise my tutors, personal support workers as well as all relief, part-time and occasional staff. The staff who will be hired will understand my job expectations and will support me in achieving the outcomes listed below:
  - Each day needs to have a purpose and a routine that I am comfortable with
  - I will have meaningful and useful work, continued learning and exercise
  - I learn, and can be sure that the people working with me are helping me to learn, about the choices I have. In particular, I can choose the activities which interest me and can change them if I later decide that I don't like them
  - I will gain more independence in being able to communicate with people
  - I will achieve a sense of satisfaction with my life so I can manage the hard time better
- We will recruit, select, support, direct and supervise the people who agree to live with me;
- We will provide advice and other legal and financial information as required by the HT Board
- We will provide advice and any information needed to assist and enable TPA to fulfill its requirements under this agreement
- We will cooperate fully with TPA in meeting its responsibility under the terms of this agreement with the MCSS. We will provide all information needed by TPA to meet its statutory responsibilities and to maintain our mutual compliance with all relevant federal/provincial acts and regulations as well as the policies of the MCSS
- We will review information provided by TPA concerning financial transactions made on my behalf and the amount of available funding remaining to me to implement the support plan within the funding/budget period. We will take appropriate action as necessary or recommended to ensure that we do not commit funding beyond our fiscal allocation.
- My Aroha will provide me with ongoing support with respect to personal and financial choices and actions in operating the household (and/or other) accounts for which the support cluster will be fully responsible. My Aroha will ensure that I am assisted to understand the choices that are available and to be able to express those choices in ways that are valid and reliable
- We will cooperate with TPA in the monitoring of continuous quality improvement (see attached statement). My Aroha will assist TPA in the administration of the checklist as needed

- We will establish and maintain all necessary connections with professional resources and consultants
- We will have primary responsibility for advocating for my needs
- We know that my Aroha and HT agree to indemnify the TPA and the MCSS against any liability arising from any occurrence or incident in the implementation of this agreement.

## 2. Self-Determination

All my service providers and informal support people will help me to make my own decisions. I have fundamental rights to make those decisions which affect how life unfolds daily. All service providers will offer encouragement, support and adequate opportunities in the process. My decision-making rights include but are not limited to: employment, education, personal goals, friends, the use of community amenities, leisure pursuits, the type of service being provided by the service provider and the manner in which the service is being provided. This includes choice in the people (paid and unpaid, formal and informal) who provide personal support, a role in describing job expectations, scheduling, supervising and evaluating staff.

## 3. Supports to Self-Determination

- 3.1 **My Aroha is my support circle of my family and friends.** They are people in my life who provide friendship, counsel and support in the decision-making process and assistance in monitoring service quality. They are involved in various aspects of my life and help me to meet new people in the community.
- 3.2 **My Key Contact is the person who can be called to talk about me.** XXXX XXXX will sign along with me so I have support to understand the nature and purpose of this document. In this supportive decision-making process, she will consider what she knows about me and how she observes and records my communications through supported typing and in other ways. She will also work with other family members and friends in my Aroha entity for personal support to ensure continuity.
- 3.3 **XXXXXX XXXXXX is president of my Aroha and my planner/broker** who will act on my behalf and with other directors of the Aroha in planning, negotiating funding necessary to achieve the objectives of the plan, supporting me and the Aroha to review and monitor the success of the plan, adjusting the plan if necessary. XXXXX is the designated person to be recognized by all parties with respect to budget negotiation with the MCSS.

## 4. Individualized Funding

An individualized approach to funding is a tool to ensure an individualized range of supports and services. It is understood by all parties that the allocated dollars are to be used in supporting me to fulfill the objectives of my plan. Portability and flexibility are important features. Portability means that, if this agreement is terminated because of dissatisfaction, the allocated funds may be applied toward a new agreement with another service provider of my choice.

## 5. Flexibility

Recognizing that the need for support may fluctuate during this agreement, it is understood that the allocated funding will be flexible to enable necessary adjustments.

In the event that the allocated funds are not fully used during the terms of the contract, the following may be negotiated:

- a) with the agreement of all parties, the present agreement may be extended;

- b) a new agreement may be drawn up with this service provider or with another service provider subject to negotiation with the funder;
- c) if neither of the above is done, the unused funds will be used to support another person.

## **6. Monitoring**

You TPA, I and my Aroha will be watching to make sure I'm getting what I asked for, as described in my personal plan and enabling maximum self-determination. We will also monitor service quality through the use of a quality assurance checklist and other procedures for continuous quality improvement and by taking part in periodic reviews of the supports and services being provided.

6.1 Changes to this agreement must be in writing and signed by all parties.

6.2 Anything written down about me is mine and I can read it when I want. Service providers will keep and make available to me upon request, information and particulars about their responsibilities, e.g. housing, financial and employee information. All documentation will be respectful of me and focus on capacities. Personal records will be kept at my home unless I ask otherwise.

6.3 TPA, with its legal and financial responsibilities for this agreement, keeps a copy of this agreement on file and proper accounts, records and receipts of all income and expenses related to this agreement for audit purposes, and these records are the property of TPA.

6.4 TPA will receive invoices from my Aroha through my key contact and provide written statements monthly.

6.5 If we disagree about something, we will talk to each other about it in a timely and effective manner. We will make every effort to resolve issues and disagreements on an informal basis as they arise. If an issue cannot be resolved in this manner, we will seek mediating support in a form on which we agree.

## **7. My Rights and Responsibilities**

I will make my own choices and you will respect them. I have the same human rights as everyone else under the Canadian Charter of Rights and Freedoms and the Ontario Human Rights Code. I will tell you honestly how I feel about the support you are giving me.

## **8. Review of Agreement**

We agree to review this document and the budget within 12 months, and to look at outcomes and successes and financial information in relation to meeting my needs according to the terms of my personal plan and lifestyle choice. Any mutually agreed upon revisions will be made at this time.

## **7. Termination of Agreement**

If you or I want to end this agreement, we can give two months' notice, or some other term of notice if we agree in writing.

**These papers have been explained to me in a way I understand and I agree with everything said in these papers.** Signed and dated by: AB and Representatives of Aroha, Housing Trust and Transfer Payment Agency.

## Schedule

### Anthony's Support Plan: Continuous Quality Improvement

original [date], updated at intervals to [date]

#### SUMMARY

*My plan, first presented in [year], has several crucial and interrelated parts:*

- *Opportunities to make informed choices about my own life and to feel control and responsibility*
- *Friends who understand and believe in me, organized as a circle/cluster the core of which is my Aroha entity for personal support*
- *A regular, structured and well-co-ordinated pattern of activities including learning, work, recreation and community experience with both formal and informal people*
- *Recognition of my severe and complex challenges in health, communication and adaptive functioning and the need for access to expert consultants for me and my support team*
- *Living in my own home with people I choose--in health and safety, and with a high quality of life and personal fulfilment*
- *Responsible use of resources, including accountability for public funds and for my well-being and quality of life.*

*To implement this plan, I with my support circle, now incorporated as an Aroha, first made an agreement in [date] with the transfer payment agency [TPA] recognized by the Ministry of Community and Social Services (MCSS), for the purpose of flowing funds to my support plan. HT, the non-profit charitable corporation that owns my home in trust for my lifelong occupancy, is also a partner in this agreement.*

*We have learned so much together as pioneers. At my request, my support circle of family and friends incorporated as an Aroha entity for personal support and became a corporate partner in any personal support agreement.*

*To be fully sustainable, my personalized plan may require a more adequate budget--as proposed with the original plan. My Aroha will continue to advocate for such a budget while being creative with the available resources.*

*My plan is distinctive for being person-centred and self-directed. I know that I inspire others by showing how a person with quite severe disabilities can be supported to live a good life in the community, relating to people who are not defined by their disabilities, and having a wider range of friends than those who are paid to be with me. But all this is not easy: there are no detailed charts or blueprints. For my sake, and as a guide to others who would like to implement similar individualized plans, my support team has pledged various methods of quality assurance and continuous quality improvement. Outlined here in plain language, they are all attainable if we have imagination, faith and patience.*

#### Goals and Strategies of Quality Assurance and Improvement

Quality assurance goals and methods must be proactive, positive and continuously reviewed for four main reasons:



a) The TPA is accountable for the proper use of public subsidy funds flowing to my personal support. Others involved in implementing my plan must keep proper records and report regularly to the TPA through the key contact who is secretary of the Aroha.

b) The HT, the charitable non-profit corporation that functions as my housing trust, must report annually to Canada Revenue Agency on the proper use of its funds.

c) [Aroha], incorporated in [date] by me, my parents and core members of my circle of friends, is accountable for its management of the resources that are meant to support me. Above all, those who know me need procedures and checks to ensure that all the plans, funds and efforts are really being co-ordinated to benefit me. While this may seem self-evident, we need policies and procedures to ensure real accountability for me as I do not speak with my voice, and to protect me from abuse or neglect.

d) In concepts and implementation, my plan has innovative features that may be useful to other vulnerable adults and their families. So we document goals, objectives, strategies, responsibilities and outcomes, as well as the ways we address and solve new challenges.

Significant people and organizations, involved in implementing my plan, share its values, goals, objectives, strategies and safeguards:

(i) I, **Anthony**, take seriously my central role in understanding my options and making choices and decisions about any aspect of my life and the people who support me.

(ii) My incorporated Aroha [name], formerly called my **circle or cluster**, has a crucial role in ensuring that my plan works to benefit me in real support and quality of life. Directors of my Aroha have joint corporate responsibility but also specific roles. XXX XXX, formerly advocate/broker for my plan and liaison with the Ministry in advocacy and negotiation for budgets, improved services and general co-ordination, continues these roles as president of the Aroha. The vice-president has special responsibility for overseeing the physical safety and integrity of the house and property. The secretary-treasurer (and general manager) has key roles. Individual directors have special roles with my supported decision-making and personal quality of life, finding and mentoring people to be lifesharers and support workers, and ensuring that the members of my household form a harmonious community that shares the values of my support plan.

(iii) HT owns and maintains my home in trust for my lifelong occupancy and carries liability insurance covering the implementation of my personal support plan.

(iv) My **lifesharers**, whom I have a key role in choosing, provide me with care, companionship and support in return for rent-free accommodation. Several compatible and responsible adults are needed to share the various roles of supporting me and maintaining a safe, healthy and satisfying lifestyle for the whole household. One major role for one or two lifesharers is to look out for my rights, well-being and quality of life in the household. Another role is that of health, safety and security officer for the household. A third role, probably shared between two lifesharers, is that of bursar, looking after supplies and accounts. Lifesharers with these roles report and relate to directors of the Aroha and the HT.

(vi) The Aroha, taking its lead from me, screens and advises on contracts with **several tutors and support workers, and with professional experts** who consult in the areas of augmentative and supported communication, diet and nutrition, sensory integration, anxiety and behaviour management, community inclusion, and independence technologies.

(vii) TPA has assumed the role of transfer payment agency to flow individualized subsidy funds to support my plan. XXX XXX, my agent and secretary-treasurer of my Aroha, is designated key contact in relating to the TPA and reporting on behalf of my support team.

The most important evidence of quality in implementing my plan is that I am content and healthy and feel satisfaction with my quality of life and range of activities and relationships. Four of the six goals of quality assurance and improvement are concerned directly with my well-being and are considered first. For each goal, we outline strategies, persons responsible and specific quality assurance checks. We add a summary of the records that will be kept and checks that will be made by my lifesharers, my Aroha and the HT.

**GOAL I: I am encouraged and stimulated by all effective strategies towards greater exercise of initiative and choice and to feel a sense of control over my life.**

I have rights to choose and comment about the people in my immediate support team, and the activities and emphases of my daily and weekly timetables. This major goal cannot be achieved by vague goodwill and wishful thinking, but requires untiring patience and imagination by the people close to me. The following strategies are designed as vital safeguards against the kinds of abuse or neglect that can occur with a trusting person who does not speak.

Persons Responsible

Co-ordinated by the key contact person for my plan, in conjunction with the lifesharer(s) and Aroha members who take particular responsibility for my well-being. Other members of my support cluster meet individually with me to facilitate my understanding of important options and my expression of my preferences and other comments. We regularly consult with communication specialists.

Strategies:

1. My various communication methods are used consistently and integrally in the various areas of my life by people I know and trust and who will keep informed of best practices.
2. I am fully informed in advance about choices of all kinds and will be involved in planning my timetables of activities.
3. For critical decisions, three people close to me have special roles in ensuring that I am informed about my options, can make choices, and am satisfied with my life in its various aspects. This strategy has the following stages and be used on the eve of important decisions and routinely.
  - a) With my agreement, questions are carefully defined for me to consider and answer, several days before the events described in (b) below, so I have time to consider important choices after I have been helped to understand them. It helps me if the choices and questions are expressed in various ways, e.g., written out and illustrated as well as spoken about, and spread through several conversations.

b) At least three of my friends arrange times and shared activities with me in settings or environments where we have optimal rapport. We also agree on the most reliable modes of communication.

c) When I meet with each communication partner, the critical questions are put to me in the context of some shared and enjoyable activity in which we are relaxed and at ease with each other. My communication partners record my answers and comments and later compare notes and share their findings with significant others in my life. Others who have used this strategy report remarkable consistency of choices and responses.

d) Any necessary changes are made in my timetable, activities or support people.

4. I have regular opportunities weekly to express my feelings and degree of satisfaction with the way my life is organized. My communication partners for these occasions include people not personally involved in my everyday activities and relationships.

### Quality Assurance Checks

a) Records of my communications--daily, weekly and monthly--including topics and questions, partners and modes, and my messages, and how these were shared among lifesharers, teaching and other support people, and my Aroha group.

b) Minutes of discussions of significant findings that indicate need for changes in how to support me, and of the actions taken.

c) These records, with my permission and appropriately generalized, may be shared with the partners in my plan--including Aroha, other support circle members, HT and TPA.

### **GOAL II: I gain a widening range of friends with whom to share interests and relationships that give more meaning to my life (and probably to their lives too).**

I know friends are the most important positive factor in my life—my lifeline, safety net and the “bridge from my island to the mainland.”

### Persons Responsible

Creative ideas from my whole circle of friends are pooled by the lifesharer(s) and Aroha/support cluster member(s) who take responsibility for my well-being. Advice, resources and timetable co-ordinated through key contact.

### Strategies

1. Continuous and imaginative efforts to foster friendships with new community people--especially through my friends and lifesharers, contacts in my neighbourhood, people for whom I work as a volunteer. While it is recognized that some of my circle of friends find it easier to help me through meetings, phone calls and paperwork of advocacy--all valuable and vital—I really need more personal contacts with individual friends or small groups.

2. Finding new friends with similar interests (exercise such as swimming and workouts, walking my dogs, music, books, puzzles and games, farms and outdoor work, my computer, trips and outings including special events and meals in restaurants).

3. Some features of my house attract friends--including the model railway, the piano, the naturalized garden and greenhouse, and the nearby parklands.

4. New friends may find it easier to include and relate to me in small groups.
5. New friendships should, as much as possible, not need to include my parents--so that I have scope to grow, and to decrease my dependence on them.

#### Quality Assurance Checks

Records kept daily and reviewed monthly, noting frequencies of meeting and size of group, and distinguishing formal and informal people and relationships which do not depend on parents.

**GOAL III: My daily, weekly and monthly timetables include a balanced structure of continued learning, work (household, paid and volunteer), exercise and community experience. There is a balance between skills which are already well known (and might become more independent) and new skills that have to be patiently learned.**

I clearly state the importance of the various activities of my daily life. I have sensible ideas about the varied kinds of work I want to do, which work should be paid for, and why we work. I want to continue learning, and I know how important exercise is for me. I like to work and exercise with men. I do much better when I know in advance the structure or timetable of a day or a week—but I can manage occasional pleasant surprises. Regular timetables may be modified in detail depending on weather conditions (such as high temperatures) or my mood and movement problems when I can manage to practise familiar skills but find it impossible to focus on learning new skills. In choosing skills in which I might try to be more independent, we give priority to those that have to be done every day and those for which I do not need others for non-work reasons such as transportation.

#### Persons Responsible

Key contact co-ordinates timetables and priorities with me, and advises the lifesharer and the Aroha member who take particular responsibility for my well-being. Professional advice, e.g., occupational therapy consultants.

#### Strategies

1. In drawing up timetables with my participation, there is a daily and weekly balance in activities--between those based at my home and out in the community, indoor and outdoor, sedentary and more active, and also between learning new skills and practising those that are already well known.
2. I continue to be able to learn about the range of possible activities, and to be introduced with support to new activities in which I express interest.
3. I am informed and questioned about my preferences and priorities in activities by the methods outlined in I above, and changes I consistently request are respected.
4. I am encouraged and supported to develop increasing independence and initiative in various skills and daily living activities. My degree of independence in various current skills and activities is assessed, to provide a benchmark for discussing those in which I might learn to do more for myself. Part of learning to become more independent may be getting used to support from a different person (from a primary support person to another paid support person or to a volunteer), from which the step to even more initiative might be taken. In any case, learning to adapt to other companions is prudent in case of staff change.

#### Quality Assurance Checks

- a) Timetables compiled and revised as necessary to show the balance of activities

- b) Assessments of skill levels, compared over time. Records of efforts to attain more independence and results in maintaining skills levels or making gains great and small.
- c) My communications about this major part of my life.

**GOAL IV: My individualized support plan matches my very significant health and communication needs which must be recognized. I and my support team require access to the advice of expert professional consultants.**

- i. Moderately severely disabled by Autism all my life, I do not speak with my voice though my receptive language is fairly good and I try hard to become proficient in alternative and augmentative systems. I am very expressive with supported typing, and also love to copy-type independently for several hours at a time.
- ii. At some times especially, my brain and central nervous system are noticeably slow in processing information coming in from my senses.
- iii. I seem hypersensitive to all sensory stimuli, reacting particularly to changes in weather, temperature and pressure. In my thirties, I have experienced intermittently various neurological problems with mobility and sensitivity to touch of all kinds, being disabled in ways not previously detected. My friends observe a roughly cyclical pattern--though this is now less clear than earlier in the 1990s--in which I may be perpetually hyperactive for a stretch and then locked in frozen immobility at other times. Such cyclical patterns may be expressed in and are certainly exacerbated by sleep disturbances. I can be very tense indeed and have bad headaches. My blood pressure and heart rate can go up and down. Since the age of 30, I have had grand mal seizures, now averaging one every 4 weeks.
- iv. I have food sensitivities or intolerances--notably to all gluten, casein and sugar in any form or trace--and show paradoxical reactions to all drugs. I respond well to my special diet which uses basic organic food ingredients, and from several micronutrient supplements prescribed by my health professionals.
- v. Perhaps because of my hypersensitivity to touch and texture, and fear of new situations, I strongly resist wearing new clothes and tolerate only a very narrow range of garments.
- vi. For the same reasons and through my past experiences, I dislike visiting and being examined by doctors, dentists etc, even barbers, or giving blood. Because of this resistance and my paradoxical reactions to drugs, I do not use funded medicare services. What I reveal through my supported typing and what my closest supporters observe and record becomes highly relevant--either for explaining to health professionals or in indicating helpful remedies and strategies.

Persons Responsible

Lifesharers and Aroha members are especially responsible for my well-being and the health, safety and well-being of my household:

- co-ordinating records kept by all people around me
- seeking and sharing advice from my physician, consultant dietician and other professionals
- relating to my communication partners for discussions with me about my health

Strategies

1. With respect for my privacy, I and the people close to me continue to keep daily records of how I feel, noting any factors (weather changes, sleep disturbances, changes in my companions or program of activities) that may trigger disturbances in my state of mind or body. These records are reviewed weekly and monthly, to detect

patterns of possibly troublesome factors as well as those factors that seem to reduce or offset the worst stress for me.

2. My communication partners continue to plan weekly and daily timetables with me, and through social stories help to prepare me for any predictable changes in weather, companions and routines.

3. My special diet is maintained with nutritious and interesting meals that I help to prepare.

4. Daily relaxation exercises are continued, with the intent that I can continue these and call upon them at times of stress. I do yoga at least twice a week, a personal fitness trainer visits twice a week, and I have Reflexology treatments every other week.

5. Contact is maintained with professionals and specialists in fields that may help me. Advice from these people may need to be blended and tailored to my unique needs. One example is in helping me to accept and wear a wider range of clothing--a challenge that may need a combination of sensory integration, communication and relaxation techniques.

6. Strategies for crisis intervention and backup are needed for the times (less frequently than once a month) when I cannot contain and control the stress in mind and body. Strategies must be gentle, respectful, safe for everyone, and effective in calming and reassuring me so I can relax.

These may include offering me:

- the means of expressing myself (especially with supported typing)
- drinks of cold water and applications of cold facecloths at pressure points
- special classical music and soothing words about how my friends understand that it's all too much for me just now, but it will pass and I'll feel better, and be able to sleep etc
- encouragement to rest under my weighted blanket

During the years in my own home, I have learned to feel any signs of restlessness and can often suggest to others that I need one of these gentle strategies. My supporters can also read the signs and help me to control myself by one of these strategies. They may see warning signs of an approaching crisis and take avoiding action. Drugs do not help at all, as they prolong and intensify the crisis for days or weeks. Nor does meeting any sign of acting out with harsh words or physical restraint.

#### Quality Assurance Checks

- a) Records kept and graphed of my mood balance, contentment and ability to function, with indications of likely factors, both positive and negative.
- b) Evidence of support with my involvement in planning and carrying through a balanced timetable of activities.
- c) Evidence of balanced and nutritious diet and relaxed and pleasant household dinner meal-times;
- d) Daily records of my weight, and blood pressure and pulse readings three times daily.
- e) Notes of contacts with relevant professionals.
- f) Evidence of crisis intervention strategies.
- g) Monthly review of my total health and well-being, considering stressful and helpful factors

h) Annual physical exam, screening and immunization by medical practitioner; annual dental exam encouraged, but I have the right to refuse.

**GOAL V: My home, shared with the people I choose, is a safe and satisfying living environment for all**

Persons Responsible

Lifesharer who is household's health and safety officer (or deputy, if that person is absent) is responsible for making and recording daily and weekly checks and tests. Consults with Housing Trust director responsible for house safety and maintenance, who reports to each HT Board meeting.

Strategies and Quality Assurance Checks

1. All safety devices and procedures to protect my household against dangers of fire, burns, smoke inhalation or intrusion will be checked and tested regularly. These include:

- smoke detectors, carbon monoxide detectors, fire extinguishers, and emergency first aid kits on every level (tested monthly and serviced annually)
- exits and evacuation procedures in case of fire or other emergency (monthly)
- Fire Department inspection of property
- indoor air temperature (several times daily)
- hot-water temperatures set at maximum of 120 degrees Fahrenheit
- storage of hazardous materials of any kind
- emergency lighting to come on in power outage
- door locks and keys (daily checks, with locking up routine last thing at night)
- no smoking policy inside the house

2. At all times, someone is particularly responsible for my physical safety and general well-being (lifesharers taking this in turns at nights), with alternative backup procedures as well.

3. I discuss safety concerns and procedures (I am already cautious about water temperatures, rangetop hotplates etc.)

**GOAL VI: Household, subsidy and personal accounts are kept responsibly**

I am rich in my friends, my spacious home, and my imaginative plan with its high quality of life. But these are intended to compensate and plan for a present and future in which I am cash-poor and have no family except for my parents. My pension income goes to pay my monthly rent and utilities. My special diet and supplements cost about five times the average dietary costs of other people. I also need special equipment and services for communication, special exercise, continued learning, transportation and my service dog(s).

Accounts

Financial accountability is maintained through three main accounts: the household account used for food, utilities and small contingencies; my personal living account (with a small balance for pocket money after rent and household contributions are paid); and the account for funds for my disability support funds flowed through the TPA.

Strategies

1. Household accounts are kept by my anchor lifesharer who acts as bursar and is responsible for receiving and paying utility bills and meeting costs of all shared food and other household consumables and small contingencies and repairs.
2. I operate my personal account for ODSP income, supported by my key contact and agent.
3. With other officers of my Aroha, I am a signatory for the disability support account for funds remitted from the TPA. Records of this account are summarized monthly for the TPA.
4. Accounts are balanced monthly, and any trends noted and shared with others responsible for my well-being and that of my household.

Signed and dated (with details of dates of review and any revision) by:  
AB and Representatives of Aroha, Housing Trust and Transfer Payment Agency.