

Listening to the Person with Model Decision-Making Agreement

How do we ensure that the real wishes and values of adults with complex disabilities are respected? Adults with Autism may not communicate in ways that are easily understood, so others may stop “listening” and doubt the person’s intelligence. While we may speak up for self-determination in theory and want to respect the tastes and preferences of each person with a disability, in practice or by default we tend to err on the side of safety and protection. Some parents may seem over-protective, offering very few choices. Some supporters may be so keen on choice that they would remove all safeguards, so that a vulnerable person may be open to exploitation.

GSA upholds the communication rights and abilities of its members, both as a matter of social justice and as a vital way of ensuring that their good whole lives are self-directed. The Bridges-Over-Barriers self-advocacy group, sheltered by GSA, is showing the way. Supported Decision-making Agreements are recommended to ensure that adults with complex challenges and high support needs such as Autism become “the authors of their own lives”. These agreements should be set up while parents are still alive to support the process.

It is now more than 70 years since the United Nations passed the Universal Declaration of Human Rights, asserting in its first clauses: “All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.” But with so much that needed rebuilding in the world then, the rights of people with disabilities were overlooked. In 1975, the UN General Assembly approved the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities are entitled to the rights stipulated in the Universal Declaration of Human Rights. At the time this made little or no difference in the lives of people with severe disabilities.

In December 2006 the Convention on the Rights of Persons with Disabilities was adopted by the UN General Assembly. According to ENABLE, the UN agency charged with administering disability issues, the Convention took “to a new height the movement from viewing persons with disabilities as ‘objects’ of charity, medical treatment and social protection towards viewing persons with disabilities as ‘subjects’ with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society....[The Convention] reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced. [In the Convention] ‘Communication’ includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology...”

Meanwhile a few organizations in developed countries had made declarations in favour of the communication rights of people with disabilities such as The Communication Bill of Rights of the American Speech-Language and Hearing Association in 1992, composed by the National Joint Committee for the Communicative Needs of

Persons with Severe Disabilities as part of “Guidelines for meeting the communication needs of persons with severe disabilities”.

COMMUNICATION RIGHTS (summarized)

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. All people have the following specific communication rights in their daily interactions, to:

- *request desired objects, actions, events and people*
- *refuse undesired objects, actions, or events*
- *express personal preferences and feelings*
- *be offered choices and alternatives*
- *reject offered choices*
- *request and receive another person's attention and interaction*
- *ask for and receive information about changes in routine and environment*
- *receive intervention to improve communication skills*
- *receive a response to any communication, whether or not the responder can fulfill the request*
- *have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times*
- *have AAC and other AT devices that function properly at all times*
- *be in environments that promote one's communication as a full partner with other people, including peers*
- *be spoken to with respect and courtesy*
- *be spoken to directly and not be spoken for or talked about in the third person while present*
- *have clear, meaningful and culturally and linguistically appropriate communications*

Communication is a basic human right. Humanity and compassion should move us to do our best to “listen” to someone who often lives in pain and discomfort and cannot speak with his voice. At the very least, it is also rational and prudent to help someone to express himself and be understood when the alternative may be extremely frustrated behaviour that is inconvenient or even dangerous.

People who live with the complex disabilities of severe Autism are in a triple bind. Their severe neurological challenges mean that many cannot use their voices to speak reliably. Their muteness and behaviour may be misunderstood as lack of intelligence or feeling for others. Some adults with Autism (or with other reasons for being nonspeaking) were fortunate to be introduced from 1991 to a form of AAC that we now call Supported Typing (S-T or ST). For those who were able to persevere, “typing to talk” has been a liberating experience. Sadly, however, a reaction based on misunderstanding how S-T works has cut off people who might benefit from using this mode of communication for the past 25 years. Adults who asserted their rights and abilities to express themselves in alternative ways have had to struggle against negative assumptions by others, including those in authority. It often seems that the bar has been set higher for adults with severe Autism than for other people.

We knew intuitively and by close observation of our friends with Autism that support for self-expression and two-way communication is a basic principle. But our understanding has been deepened since one of GSA’s active members took the lead in forming a communication support group in 2004. Other adults whose

movement differences do not let them speak reliably with their voices meet regularly in Guelph for conversations about their lives, using the form of AAC known as Supported Typing. Now sheltered by GSA, the Bridges Communication Group members co-operated to produce and publish a DVD and book in 2010. They share their “struggles and strategies” and learn from one another about their rights and about choices they may make to improve their lives. For more about Bridges visit the profile on the Communications page of this website.

The Bridges experience also provides lessons for how adults with severe Autism can effectively be helped to share their thoughts with people who may be able to help them realize their goals. We need to make accommodations and adapt environments and meeting formats to help communicators express their real and full intentions. People with complex movement disorders and sensitivities to all stimuli, and who have to tap out their words slowly letter by letter, need everyone present to be quiet, patient and supportive. Large gatherings with lots of social chatter may be overwhelming. They do not like to be taken by surprise and certainly not to be put on the spot by requests for simple “Yes or No” answers.

Circle meetings, good as they may be for some people with disabilities, may not be the best way for adults with complex Autism to express their thoughts, needs and dreams. Yet circle meetings are valued and accepted ways for a person’s non-autistic friends to get together. For our Bridges and GSA friends, a several-stage process may be most effective. A communicator can compose thoughts in advance about his priorities and the areas in which he needs his friends’ help. These messages, with the person’s consent, can be shared around the circle of friends and may prompt questions and suggestions, with some email conversations. The person can be well prepared for a larger event by composing a social story with the agenda. At the meeting itself, the person may choose just to listen, and then to comment later. After the meeting it is good to have debriefing conversations using Supported Typing.

A Supported Decision-making Agreement is recommended to ensure that adults with complex challenges such as Autism become “the authors of their own lives.” Such an agreement should be set up while parents are still alive to support the process. Institutional and legal alternatives (such as in funding for programs and services; regulations and policy; and legal guardianship) all have weaknesses and are based on false assumptions.

Almost everyone—with or without a disability—has some kind of support in making decisions. Most of us make decisions in collaboration with others. We ask advice from experts in various fields and may trust their recommendations even when we do not fully understand the financial, legal or medical intricacies. We often discuss choices with partners, spouses or best friends. The only real protection for our sons and daughters with a disability is the quality of the committed relationships they have. In the GSA model, these relationships are strengthened by the legal powers of the Aroha entity. See next section.

Why can’t we rely on legal guardianship? Parents are often unaware that they cease to be the natural legal guardians of their sons and daughters at the age of majority. For them to continue as guardians, their son or daughter must be judged incapable by court order and a guardian appointed to make financial, medical and legal decisions for that person. The drawbacks of guardianship are that all decision-making power is removed from the person, with all citizenship rights so that, in the eyes of the law, he or she is no longer a person. Obtaining a guardianship order is also costly and time-consuming.

It is possible to keep a son or daughter safe without resorting to legal guardianship. As Al Etmanski points out in ***A Good Life*** (PLAN, 2000; Chapter 5: "Ensuring Choice", p.183), a Supported Decision-making Agreement can be recommended. Here are the advantages from the point of view of a vulnerable person:

- *I actively participate*
- *My views are sought and taken into consideration*
- *I am surrounded by caring, knowledgeable and trustworthy people who can assist with my decision-making, support my communication, and listen to and interpret my decisions*
- *My needs are the primary consideration, not those of the staff or service system*
- *The focus is on my abilities and wishes*
- *All my choices and options are considered*
- *My tastes, preferences, motives and ability to discriminate are taken seriously*
- *My risks, failures and mistakes are recognized as learning opportunities*
- *My intuition and feelings have as much weight as my intellectual ability*
- *All my methods of communication, both verbal and non-verbal, are recognized as valid."*

There are three broad areas of decision-making for a person with a disability:

- Health/medical (emergency and routine) decision-making
- Financial decision-making
- Personal care decision-making

A durable/enduring power of attorney is a good idea for the first two areas, but a more comprehensive Supported Decision-making Agreement (SDMA) is compatible with this too.

An incorporated entity of personal support or Aroha fits perfectly with an SDMA, with three or more directors sharing knowledge and responsibilities for health/medical, financial and personal care matters. Organizations that support family groups to form personal networks might also recommend an SDMA and might offer the services of their facilitators as monitors.

Reasons for discussing and making an SDMA:

- The process is powerful and useful in helping the person with a disability to become accustomed to making decisions.
- The SDMA is a tool to strengthen existing relationships, involve others, and thus help a personal support network to grow and increase its commitment to the person. An SDMA provides status to family and friends and involves a broad group of people who reflect the person's multi-faceted nature.
- The existence of a SDMA creates at least moral authority for assisted or supported decision-making. So far only some jurisdictions clearly recognize SDMAs. Yukon was the first Canadian province to do so, and British Columbia now recognizes the equivalent Representation Agreement. The pace of recognizing the case for a SDMA has quickened in other jurisdictions. If enough people make SDMAs, the moral authority will influence legal authority, as has happened with "living wills" and "health care consent forms".
- SDMAs can enhance existing enduring powers of attorney.

Key components of an SDMA:

- Initiated by the person with a disability.
- Addresses three areas: financial/business, health, daily living/personal care.
- Conveys an understanding that decision-making assistance will be based on person's values, beliefs, experiences, preferences—and not on what is perceived by others to be the person's best interest.
- Identifies the ways in which the person expresses preferences, makes choices and conveys understanding, and if necessary witnesses who are expert in that system of communication and/or know the person well.
- Contains a clause stating that the intention is to assist and support decision-making while recognizing that an SDMA does not yet have legal power in all jurisdictions.
- Identifies one or more supporters (individuals to assist with decision-making), with each person's area of responsibility, and name which person may speak on behalf of others, a process for resolving disagreements, and any alternate or replacement.
- Appoints a monitor who knows the person, is willing to stay in regular contact, and able to:
 - ensure the SDMA is working
 - prevent abuse and exploitation
 - give support and assurance
 - act as contact for person and supporters

People with severe Autism may endure periodic health challenges that can affect their ability to communicate with Supported Typing. For this special reason, it is possible and may seem wise to include a Ulysses Clause or Ulysses Agreement in future planning for all contingencies as part of an SDMA.

A Ulysses Agreement lets a person plan for episodes of intermittent incapacity that may leave them temporarily unable to make decisions of their own. A person can, when in good health, communicate instructions for times when they would be unable to type or otherwise express their wishes. The name comes from the epic story of Ulysses who told his men in advance to restrain him from temptations when he might not make wise decisions.

The Ulysses Clause or Agreement has been used by people who are intermittently unable to make responsible choices because of mental illness, such as bipolar disorder. It may also be used by people facing serious illness or dementia. It can also be helpful for people on the Autism spectrum who may have hard times alternating with lucid and competent periods. Someone who cannot rely on his voice and uses Support Typing to communicate can plan for times when he may be so distressed and incapacitated that he could not concentrate on typing.

A man we know suffers tonic clonic seizures as well as prolonged periods of stress when he cannot think straight. With Supported Typing, he has told his supporters what specific forms of medical treatment he is willing to have. He hates and fears hypodermic needles. But he may agree that, if he has suffered concussion during a seizure, he needs a needle to receive local anaesthetic for stitches to his head. He would agree that, even if fear drives him to resist medical attention, he wants his supporters to reassure and help him to submit. On the other hand, he could also veto any kind of psychotropic medication to calm him, as he is allergic and has had paradoxical

reactions to all drugs in the past. He has also stated that “I want to die when there is still life in me. I don’t want to be kept alive if I am on a machine—not at all!”

These provisions must be formally written into a SDMA (see next pages) and witnessed and accepted by a person’s supporters. Then supporters are empowered, at such times, to remain faithful to the original instructions and to act on the person’s behalf in the way previously decided.

Model Decision-Making Agreement

Date _____

Name of Grantor _____

Address _____

Phone _____

Date of Birth _____

Health Card Number _____

I am making the agreement because I need and want support and guidance from my friends in making some decisions in my life. The reasons I want supporters to help me in making decisions:

I have discussed all this with my supporters and friends and understand the meaning and purposes of this agreement.

Supporters

1 _____

2 _____

3 _____

4 _____

Responsibilities of Supporters

A. Financial Affairs and Legal Matters:

I would like _____ and _____ to support, guide and/or represent me in legal and financial matters.

If either is unavailable, I would like _____ to act as the second representative.

B. Personal Care and Health Care:

I would like two of the following three supporters _____, _____, _____, to support, guide and/or represent me in health and personal care issues.

If only one of these three is available, I would like _____ to act as the second representative.

In a medical emergency, if two supporters cannot be reached, then any one of the three supporters may act alone.

I would like my supporters to inform my parents (names and contact details) regarding significant health-related issues.

I want the supporters to agree on their decisions. If there is a disagreement between the two supporters, there will be a consultation among at least three supporters to make a decision that is acceptable to everyone present.

Responsibilities of Health Care Professionals

Any time there is a question regarding my health or well being, my supporters must be consulted.

Effective Date of This Agreement and Reviews of This Agreement

This agreement will be effective immediately upon being signed and witnessed or

This agreement will be reviewed two years after coming into effect and every two years thereafter, or upon the request of myself and/or my monitor and/or my supporters.

APPENDIX A DESCRIPTION OF SUPPORTERS' RELATIONSHIPS WITH ME

APPENDIX B OTHER SUPPORTERS AND THEIR ROLES

APPENDIX C EXPRESSION OF PREFERENCES

I am normally able to express myself using Supported Typing and want my supporters to pay attention to what I say in that mode of AAC. If I am unable to use S-T, I will try to give my supporters a clear indication of my preferences, either through eye contact or through body language, so my supporters will act based on my indicated preferences. If I have added Ulysses clauses to my SDMA, I want my supporters to act accordingly. If I have not planned for a specific situation with a Ulysses clause and if I am unable to give my supporters a clear indication of my preferences by any other mode, then the supporters will act based on their relationship with me, their knowledge, and their shared past experiences with me.

I express my preferences in the following ways:

My likes:

My dislikes:

Note: This should not be seen as the final word regarding my preferences and communication as my life can change and my abilities can evolve.

ULYSSES AGREEMENT

I hereby authorize my supporters to act in accordance with my previously expressed wishes, if for any reason I am unable to communicate at a critical time.

APPENDIX D: INFORMING RELEVANT PARTIES.

Copies of this agreement given to named persons

Signatures with Dates of Person, Witnesses, Supporters

Certificate of Witnesses

Full names and addresses of witnesses:

We certify that:

We witnessed the signing of the SDMA made by.... (full name of grantor)

We have both reached the age of legal majority.

Neither of us is a supporter or an alternate supporter.

Neither of us is the spouse, child or parent of a supporter or alternate.

Neither of us is an employee or agent of a supporter or alternate.

We were present during the signing of the SDMA.

We understand that the grantor has had the SDMA read or communicated to him/her and has signed it freely.

The truth of this statement is certified at [place] on ..[date]..

Signatures of two witnesses: