

step four

making
sound
decisions

Compassion is maturity
and maturity is acceptance.

Maturity is precisely
the acceptance of yourself
with your own flaws,
as well as others
with their flaws.

JEAN VANIER

george's story

More than we bargained for

“THERE WAS A PERIOD when Rick didn't live with us. At the time we thought we were doing the right thing. He was getting pretty big and pretty bored and we thought he'd be better off with people his own age. My wife and I were both working, and we thought it would be best for all of us.”

George's voice softens as he discusses what he calls Rick's little adventure. Rick moved to a farm community where he lived in a group home with eight other young people his own age.

“At first it went okay for Rick, that is, but not for us. We were in shock for weeks. Next to burying my wife, driving away from that home was the hardest thing I ever had to do. Anyway, new people, and new things to do everyday kept Rick happy for a while.”

Rick is quite transparent. It is easy to tell if he's happy or not. He wouldn't tell George and his wife what was bothering him but after a while he looked so glum they knew something was wrong. It took them some time to get to the bottom of it.

One night George had popped over to the house to drop off some strawberries he had just picked at the U-Pick down the road. Staff was watching television and the residents were all in their rooms. It turned out that this was common practice. In fact, it was the nightly routine. The evening shift was sending everyone to their own room at 8:30 every evening. No one was allowed to watch TV, use a radio or CD player, or make any noise.

“It was just like the bloody Air Force, back in World War Two,” George explains. “No, it was worse. Lights out over there was at 10:00 p.m. for the crews who had to be up early for a flying mission. As long as we observed the blackout we could do what we pretty well wanted to.”

Rick's life was completely regulated at the home, George explained.

“Their lives were controlled from top to bottom. Heck, in the six months he was there, he had four supervisors. It was a regular revolving door. Even the little things were controlled. One supervisor lasted five days. His big thing was to serve all the food from pots on the stove. After he was gone the next supervisor changed the routine. All food was to be placed in serving dishes on the table! That's the way it worked for everything. No privacy, no respect, and no choice.”

It was too much for Rick and his parents. George and his wife invited Rick to move back home.

“We thought we were giving Rick more choices when he moved into the group home. Instead, we got more than we bargained for.”

One of the things that bothered Rick about his group home experience was the withdrawal of his spending privileges. Any of his own money, including the comforts allowance he received from government, had to be placed in a bank account that could be accessed by staff. And they often did, buying things he didn't ask for or want.

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step four

Making sound decisions

Do not see me
as your client.
I am your
fellow citizen.
See me as your
neighbour.
Help me learn
what I want
to know.

NORMAN KUNC

When you get right down to it, worrying about the safety and security of our relatives is a paradox. On the one hand, we want to protect them from discrimination, exploitation, abuse, neglect, and injury.

On the other hand, we want them to have a good life: a life where they enjoy themselves; where they get to try new things; a life where their choices are respected. We want to teach our relatives how to survive and work through adversity. We want them to learn from their mistakes, as all of us must. We want people to recognize their ability to make decisions and to support them to make sound decisions. This type of self-determination makes a life worth living.

It's a delicate balancing act faced by families the world over: keeping our relatives safe while at the same time respecting their choices. Make no mistake about it. This balancing act is a tough challenge. Families find it difficult. So do service providers. So does government and its institutions.

In this step, we guide you through the ways in which you and your relative can create your own balance between safety and choice. We introduce the concept of supported decision-making. We also describe the types of powers of attorney available to you.

It starts with choice

A good life includes honouring the choices of our relative. This means recognizing their tastes, preferences, and values; it also means

Choosing a guardian

For information on choosing a guardian for your minor children, see [Choosing a guardian for children under the age of 18](#) on page 102.

george's story

continued from page 86

“After my wife died I decided I would use my money to keep Rick out of group living arrangements like that. Since he was in good health he was able to purchase a life insurance policy outright. This would nearly double the size of Rick’s trust. George was quite worried that Rick would be taken advantage of by some unscrupulous person. “Rick isn’t a whiz with money but he is careful with small amounts,” George explained. He wanted Rick to have easy access to his money, but he wanted some checks on his spending. So he set up a trust. Not a discretionary trust but an income trust.

“I’ve got the local credit union acting as my trustee now. They’re good at managing and investing the money. But just to make sure they keep Rick’s interests in mind, I’ve appointed a co-trustee from Rick’s Personal Network. And to top it all off, my Will instructs the trustees to seek advice from PLAN. All this may sound complicated, but it acts like a system of checks and balances.

“When all is said and done, I’m finally getting what I bargained for. Rick’s choices are respected and so are mine. You can’t beat that. ■

Choice is like
a muscle: if not
exercised, it
will atrophy.

acknowledging our relative's ability to discriminate, to select, and to choose. We know how determined our relatives can be to express their approval or disapproval. We know they often are aware of their limitations and exercise prudent judgment in the face of it. We know they have views and opinions on a variety of topics. Unfortunately, not everyone is aware, understands or accepts the capability of our family member.

The assumption of others that our family members don't have opinions or cannot make decisions is an additional hindrance. This can lead to ignoring their wishes and eventually making all decisions, big and small, on their behalf.

We want the people involved with our relative to see what we see: a person capable of making their intentions known. We want the people in their lives to be patient, to be willing to listen, and to watch, and if necessary to be willing to learn our relative's unique and perhaps non-verbal communication style. We know all behaviour is a form of communication and we want our relatives surrounded by people who will take the time to search for that meaning.

We are wary of people who won't make an effort to learn how our relatives express themselves, who are too busy, or who ignore—and perhaps worse—think they know what is best for our relative.

Once there is recognition of their choice making ability, we can turn our attention to supporting our relative to make decisions. This may mean, in certain circumstances, speaking or making decisions on their behalf. We do this informally when we set up a joint bank account or when we accompany them to a medical appointment.

We believe in nurturing the decision-making ability of our relative rather than giving someone else the power to make decisions on their behalf. The decision-making ability of our relative can be nurtured by:

- respecting their inherent decision-making ability
- enabling their own, authentic decision-making voice
- presenting them with genuine choices
- helping them to sort out and understand the options, and
- supporting them in making the actual decision.

Is offering
choice too
risky?

How big a
risk are you
prepared to
take?

Can you
balance safety
with choice?

Whom do you
trust?

In reality, many people with disabilities are offered few choices in their lives. Instead, they are treated as an object to whom things are done. They become passive and submissive. When we surround them with people who respect their capacity to make decisions, we also create the conditions for our relative to become a self-advocate. This reduces the risk of exploitation, neglect, and abuse. Ultimately our relatives are safer when they are able to speak for themselves.

Take Tim's situation, for example. When we first met Tim his caregivers made all his decisions. They decided what he should wear, what he should do during the day, what time he should have dinner, and so on. These decisions were based on what suited his caregiver's schedule. Tim was never consulted. For example, Tim loved country music but his caregivers didn't, so he never had the opportunity to listen to the country music station.

Over time, Tim retreated so far into the background of his own life that he might as well have been invisible.

Fortunately Tim and his family joined PLAN. As his Personal Network developed, so did the relationship between Tim and his staff. Eventually new caregivers were hired based on their willingness to learn Tim's communication style.

Change is a constant. It is hard to predict what we or our relatives will have to adjust to, and what critical decisions will have to be made in the future. We can make educated guesses about some of the areas we want protected for our relative but there are no guarantees. Rather than wasting our energy on trying to control the uncontrollable, we suggest you prepare for any eventuality by providing your relative with the best possible people to assist them in making their own decisions.

Supported decision-making

Supported decision-making is how the majority of people make decisions. We face a dilemma, look at the options, gather information, talk to people, and ask for support.

Supported decision-making for our relative means:

- they actively participate
- their views are sought and taken into consideration
- they are surrounded by caring, knowledgeable, trustworthy people who can assist with their decision-making and communicate their decisions
- their needs are the primary consideration, not the needs of staff or the service system
- the focus is on their abilities and wishes
- all their choices and options are considered
- their tastes, preferences, motives, and ability to discriminate are taken seriously
- their risks, failures, and mistakes are recognized as learning opportunities.

In the absence of a legally recognized supported decision-making agreement, families can create their own supported decision-making agreement that has practical benefit and a moral authority.

To ensure good decision-making for your relative with a disability, we suggest you make the concept of supported decision-making the basis of your approach.

1. Do everything you can to enhance and validate the role of family, friends, and supporters as advocates and advisors to the decisions your son or daughter makes.
2. Identify and use the existing advocacy system for people with disabilities.
3. Identify people who would be willing to serve as temporary substitute decision-makers.
4. If you must use the legal system, consider a guardian for specific reasons and on a time-limited basis.

There is no magic to the task of keeping people safe and respecting their choices.

It is a matter of mastering the high wire. A tilt in the direction of over-protection creates a barren lifestyle. A tilt in the direction of complete autonomy without supports or safeguards is a license for exploitation. The risk in either direction can be minimized only when friends and family are there to provide support.

Progress
always starts
with bold ideas.

JANE JACOBS

The secret of good decision-making

Have you ever made a bad decision or a decision you regretted? Have you ever changed your mind?

You are not alone. Some of the poor decisions we have made are minor, some alas, are major and we would like to take them back. The same is true and will be true for our sons and daughters, all of them, including those with disabilities.

Decision-making means taking risks, understanding consequences, learning from mistakes, and trying again. An old Chinese proverb says the risk is not in falling off the horse, but in lying there.

Relationships are the foundation of sound decision-making

By now it should come as no surprise that relationships and Personal Networks have additional benefits—they enable good decision-making and assist to protect and keep your relative safe.

The first order of business, therefore, is to consolidate your relative's friends and supporters into a network. Members of a network can monitor the services and programs your relative receives; they can also advocate to maintain the quality of those services and programs.

Network members are often more than willing to support good financial, health, and personal care decision-making for your relative.

Should I consider legal guardianship?

Traditional legal guardianship permits another person to take over the affairs and decision-making for an adult who has been declared incapable by the courts. A legally appointed guardian has complete power to make financial, medical, and legal decisions for the person. There are two types of guardians:

- **Guardian of Property:** authority to make financial and legal decisions, and
- **Guardian of the Person:** authority to make health and personal care decisions.

A good life
includes
honouring the
choices of
our relative.

We have reservations about guardianship:

1. Most guardianship orders are blunt instruments. Even though adults may only need help in certain areas of decision-making, guardianship orders are not easily tailored. All of a person's financial and personal decision-making power may be removed. The adult can no longer assist with the decision-making process. In the eyes of the law, they are no longer a capable person.
2. Obtaining a guardianship order, especially with regards to the person, is costly, intrusive, and time-consuming.
3. Guardianship doesn't allow for joint or supported decision-making. It's an all or nothing proposition.
4. People with intellectual impairments and other noticeable differences are usually presumed to be incapable which makes it even tougher to assert their capability.
5. The appointment of a guardian involves the Office of the Public Guardian and Trustee (OPGT).

Few people with disabilities will ever need this form of guardianship. In the past, some parents applied to the courts to become guardian of their adult son or daughter assuming this would give them enhanced status when dealing with government or service providers. Unfortunately, this proved frustrating and costly without providing any more influence or authority.

Types of decision-making

As you've no doubt learned by now, we strongly advocate that—whenever and wherever possible—your relative participate meaningfully in the decisions that affect their own lives. How your relative participates will vary from family to family. One thing is clear: your relative can't participate if they are not involved in the process.

There are situations, however, where it is in the best interest of your relative, your family, and your friends to create a more formal—and legally recognized—decision-making tool.

We have got to put our human spirit on the line if we hope to communicate with others at all. Maybe that is when people feel cared for, when they feel that sense of human spirit.

MARGARET SOMMERVILLE

There are three broad areas of decision-making that affect your relative's life:

1. Financial Decisions
2. Health/Medical Decisions
3. Personal Care Decisions

Personal Networks are critical to each. Combined with a number of non-legal options, they offer further assurance that decisions will be made that protect and enhance the quality of life of your relative.

1. FINANCIAL DECISIONS There are a number of legal and non-legal options to protect the financial assets of your relative, prevent exploitation, negligence or impulsive purchases, and to ensure good financial decision-making.

First, a Continuing Power of Attorney for Property may be useful. A Continuing Power of Attorney is a written document that allows a person to confer authority to someone else to make financial decisions on their behalf. When you confer this authority on someone else you don't lose your own authority. The Power of Attorney can be revoked at any time by the person who conferred it. A Continuing Power of Attorney has a more traditional legal test of capability which your adult relative may not pass.

Trusts are another option used by families to protect the financial assets of their relative and to ensure the funds are used in their best interest. Step Five explores this option in more detail (see page 107). Trustees can be appointed at any time to manage trust funds.

Other practical approaches used by families to safeguard their family member's assets include:

- establishing a joint bank account with their son or daughter
- purchasing property in joint title.

2. HEALTH/MEDICAL DECISION-MAKING You can divide this into emergency and non-emergency decision-making.

Families want assurance that their relative will receive medical treatment in the event of an emergency, especially if the doctors are unable to obtain legal consent. You need not worry. Doctors and hospitals in Ontario can—and do—provide emergency medical

treatment when it is needed regardless of whether consent can be obtained.

For non-emergency health care, the experience is more varied. Many adults with disabilities enjoy a long-standing relationship with their family doctor. They know each other's abilities and communication styles. In these situations, the capacity of the person with the disability to give consent may not be an issue. The physician is willing to take the time to give the individual the opportunity to express their wishes.

In other situations, it has become common practice for the doctor or health care provider to consult with parents or other close relatives around health care treatment for the adult with a disability. The medical profession has long recognized relationships of trust and caring.

A Power of Attorney for Personal Care might be applicable here. This legal document allows a person to confer authority to someone else to make decisions on their behalf concerning their own health care, nutrition, shelter, clothing, hygiene or personal safety. A Power of Attorney for Personal Care only comes into effect when a person is—or becomes—incapable of managing their own personal care.

If there is no guardianship order or a Power of Attorney for Personal Care in place and the individual is found to be incapable, then their doctor, health care provider or hospital must find someone to give consent for health care.

There is provision in the *Health Care Consent Act* that appoints a person to give or refuse treatment on the person's behalf. Such person is chosen by the health care provider in the following order:

- Guardian of the Person
- Attorney for Personal Care
- Representative appointed by the Consent and Capacity Board
- spouse, including common law and same-sex partner
- child or parent
- parent who only has right of access
- brother or sister
- another relative by birth or adoption.

Because the heart is bigger than trouble. And the heart is bigger than doubt. But the heart sometimes needs a little help to figure things out.

CONNIE KALDOR

The substitute decision-maker must be at least 16 years old, capable, and available and willing to assume the responsibility of giving or refusing consent.

If no family member qualifies, then the Public Guardian and Trustee has the power to give or refuse consent.

To ensure that your relative has someone they trust to help with health care decisions, it is best for them to make a Power of Attorney for Personal Care.

3. PERSONAL CARE DECISIONS This is an area of decision-making that is by far the most elusive because the forces are largely out of our control. Our relatives will likely be dealing with paid caregivers or service providers and educators for the rest of their lives. These service providers will make daily decisions which will have a huge impact on our relative.

We can't predict the future of government funding for these critical supports and the repercussions on the quality of programs and services. We are pleased that regulations and policy set standards for service providers. And we acknowledge the value of accreditation and formal evaluation. But we know this doesn't go far enough. These tend to focus on broad system standards. They don't address the personal daily circumstances of each of our relatives. You might want to consider a Power of Attorney for Personal Care as a more formal way to support your relative.

Monitoring and advocacy are natural extensions of our parenting skills. While we are alive, we can engage with service providers. We know how important it is to maintain a relationship with them. We have a good idea of how much work this requires and how much time it takes. If there is a concern we can do something about it. We can join an agency's Boards of Directors. We can create our own society! As in other areas of decision-making, Personal Networks are essential. Here are additional options and resources for you to consider.

Individualized Funding

Most service providers receive their funding under contract from government. Often one agency or organization provides the full range of services needed by the individual. That is, they own or lease the homes,

provide the staff, and offer residential, employment, recreational, and other support services. People who use these services often have very little say over what happens to them. Many parents and individuals are now promoting a new approach called individualized funding. So are governments. For example, the Province of Ontario recently passed the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (the “*Social Inclusion Act*”) which facilitates both individualized and direct funding arrangements. At the time of writing, however, the *Social Inclusion Act* has yet to be proclaimed into force.

Individualized funding gives money directly to the individual with a disability to enable them to purchase the goods and services they require. Individualized funding covers the cost of food, clothing, shelter, transportation, and technical aids as well as program and personal care supports. The individual—with the help of their supporters—can then determine where to live, with whom to live, who to hire, and so on.

Microboards

Imagine a non-profit society that exists only to provide programs and services to your relative. That’s what a microboard is.

A microboard is a small (hence the name, micro) society with a board of directors. The board of directors—usually no more than five—is made up of committed family members and friends. This board of directors receives funding from government on behalf of the person with a disability and negotiates with service providers to provide the support services. The board of directors—along with the person with a disability—directs and customizes these support services. A microboard is a successful variation on individualized funding and personalized services.

Microboards serve a variety of other purposes as well because they create opportunities for relationships of support to flourish. Overall, they allow people to achieve greater control over their personal support needs. The Vela Microboard Society pioneered microboards in British Columbia and around the world. It is an excellent resource. For more information see Resources, page 185.

Powers of Attorney

Most lawyers will suggest that their clients use a Continuing Power of Attorney for financial matters and a Power of Attorney for Personal Care for health and personal care matters.

We become
what we behold.
We shape our
tools and then
tools shape us.

MARSHALL MCLUHAN

Advocacy

Yeats, the Irish poet observed: “things fall apart; the centre cannot hold.” Human services are human creations and are, therefore—by definition—imperfect. Things can fall apart.

Families know this instinctively. The work at PLAN bears this out. We are often called to support an individual, family or Personal Network as they advocate for change and improvement in a program or service. People who know our relative make the best advocates. They may not know all the details of service provision and funding but they are grounded in what is best for our relative and will fight on their behalf. There are many groups in Ontario who offer advocacy and support. See Resources on page 185.

An effective personal advocate is someone who:

- cares about our relative
- knows their requirements
- has good problem solving and negotiating skills
- is free of conflict of interest
- is self-confident and willing to be assertive if necessary
- is willing to seek out—and follow—good advice.

We have discovered that Personal Networks are a great training ground for advocates. Parents can impart their skill and wisdom and teach by doing.

Lastly, we should point out the value of teaching our relative self-advocacy skills. They will learn about their rights and responsibilities; how to speak up for themselves; how to support other self-advocates; and gain confidence. There are excellent written resources and many organizational supports in Ontario. For more information, see Resources, page 185.

Choices

We suggest that you support your relative to make good decisions by asking yourself the following questions:

- What choices do they have now?
- What experience do they have with decision-making?
- What decisions can they make independently?
- What decisions will they need help with?
- What informal arrangements can be made to assist with decision-making?

Conclusion: the secret to good decision-making

There is no magic to the task of keeping our relatives safe while at the same time respecting their choices. A tilt in the direction of over protection could lead, at the extreme, to a barren existence. A tilt in the direction of complete autonomy could lead to abuse and exploitation. The secret is balance. And checks.

And the best way to do that is by assembling the best people and resources. A Personal Network—combined with control over the funding, and ongoing advocacy—is the best safety net we know.

Summary of Legal Options

- A Continuing Power of Attorney for Property: covers financial matters but not health and personal care decisions
- A Power of Attorney for Personal Care: covers health and personal care decisions but not financial matters
- A Substitute Decision-Maker authorized by the *Health Care Consent Act*: used to seek permission for health care when a Power of Attorney for Personal Care or guardianship order does not exist.
- A Guardian of Property and of the Person: has the authority to make financial, health, and personal care decisions on behalf of another person.

Diving

WHEN I WROTE this fictional meditation, I had not yet read Jean-Dominique Bauby's extraordinary book *The Diving-Bell and the Butterfly* (see Resources, page 185). His story is better known now as a result of the movie of the same name. At the age of 45, French journalist Bauby suffered a massive stroke that left him without speech and movement. He was, as he says, "like a mind in a jar." Patiently, letter by letter, Bauby tells his story, using one eyelid to signal at what point in the chorus line of letters his friend is to stop transcribing. Bauby's reality is bright, vivid, and compelling.

What would you do in a similar situation?

You are heading to the grocery store on a sunny Saturday morning. You are a careful driver but your mind is elsewhere—on automatic pilot. Suddenly an approaching car jumps lanes and heads towards you. In a terrifying instant your life changes. After the impact you lose consciousness.

You wake up in the hospital. The pain is excruciating. You are unable to move your arms and legs. Then you discover you can't speak. A doctor and a nurse are hovering over you. They are asking a lot of questions. They want to know your blood type. You aren't able to respond. For one thing, you are in shock. For another, they aren't watching your facial gestures and you have no other way of communicating.

They are now explaining what needs to happen to you. No one seems to notice the fear in your eyes. You hear medical terms you don't understand. You're scared and all alone. Where is your wife? Have they tried to reach her?

Suddenly you are placed on a stretcher and rushed down the hallway into an elevator, then

down another hallway and into an operating room. Your last thoughts before the anesthetic takes hold are of ...

Who would you think of? Your spouse, your children, your parents, your brothers and sisters, your friends? Or your lawyer, your mechanic, your dentist?

You do survive. The hospital is crowded but they manage to find a semi-private room for you. And they locate your spouse. She comes in several hours after you return from surgery. She immediately understands your terror. You are covered with blood. The needle from the IV tube is already causing noticeable swelling and bruising. Your wife calls a nurse. They respond immediately. They are cooperative and friendly. They didn't expect you to wake up so soon. They were busy elsewhere. The IV tube is adjusted and they give you a warm sponge bath. Eventually you drift off to sleep, comforted by the presence of your wife. At least you are not alone.

When your wife and friends are around, you feel safer and your needs are met. They notice when you are uncomfortable. They do all the little things that make your stay tolerable.

On one occasion you had to contend with an inexperienced intern who insisted on giving you a needle in your arm even though he couldn't find a sizable vein. You were helpless to protest. Your arm became a personal challenge to him. When a colleague from work arrived, it was bruised and bloodied. Within minutes he had your wife on the phone. She spoke to the charge nurse and a notation was made on your chart. It won't happen again, they promised. It doesn't.

What keeps you safe during your hospital stay? Is it hospital rules and regulations? Is it the

professional training of medical staff? Is it the nurses and doctors? Or is it friends and family?

Friends and family remove the cloak of anonymity. With them you become a person again. It's not that professional paid care isn't important; it's just that you are more than the sum of your health needs. Make no mistake about it, this move from being an object of service to a real person depends on your relationships.

Why would it be any different for people with disabilities?

It isn't. However, we often make the error of assuming professional paid care is all that is necessary to keep people with disabilities safe and guarantee choice. Programs, professional supports, rules, and regulations have their limitations. Paid service should supplement—not supplant—good, old-fashioned human contact, warmth and love. ■

Al Etmanski

Choosing a guardian for children under the age of 18

It is difficult to discuss who should take care of our children under the age of 18 should we die unexpectedly.

Unfortunately it does happen, leaving the surviving children, remaining relatives, and friends in legal limbo. The courts become involved and a judge makes a custody order. You cannot assume grandparents, godparents or other choices you think are obvious will automatically be given responsibility. More than 40 per cent of Canadian parents have not legally appointed a guardian for their children. **NOTE** Contrary to popular belief, you cannot appoint a guardian for your adult children in your Will. See Step 5 for more details.

You must add a guardianship clause to your Will. One of the toughest decisions faced by parents is determining who to appoint as legal guardian of our minor children. To ease this emotionally difficult process and to prevent further upset, here are some suggestions to assist you in choosing a guardian:

- list your parental values, your aspirations for your children, as well as any religious, financial or cultural concerns;
- choose the person who comes closest to your parenting style and who would guide your children the way you intend to guide them. A child's aunt or uncle is a common trusted choice, followed by close family friends. Trust in that person's judgment is paramount;
- try to select someone close to your age rather than someone of your parent's generation. Your parents may be excellent grandparents but they may not be able to manage another set of children, especially through the teenage years;
- becoming a guardian adds additional financial as well as emotional responsibilities. In recognition of this, some parents take out a life insurance policy naming the guardian as beneficiary;
- parents of other children with disabilities are a good source of advice. Because of their common bond, parents often choose each other as guardians.

Worksheet 8

Supported decision-making

Use this worksheet to organize key decision-making information, issues, and resources that affect the choices and safety of your relative.

A. Checklist

MEDICAL DECISION-MAKING

- | | | |
|-----|----|---|
| YES | NO | I have discussed issues of medical consent with my relative's doctor. |
| YES | NO | The doctor accepts consent from my relative for medical treatment. |
| YES | NO | The doctor accepts my consent for medical care on my relative's behalf. |

FINANCIAL DECISION-MAKING

- | | | |
|-----|----|--------------------------------------|
| YES | NO | I have set up an income trust. |
| YES | NO | I have set up a discretionary trust. |
| YES | NO | My relative has a RDSP. |
| YES | NO | My relative has a bank account. |

YES NO Withdrawals from that bank account are protected by:

- joint signature for withdrawals
- my family member is well-known to bank employees
- funds in the account are kept to a minimum
- don't need to be protected.

PERSONAL CARE DECISION-MAKING

YES NO My family member has an advocate(s).

YES NO The services my relative receives are monitored by a separate and independent agency.

YES NO Housing supports are kept separate from other services.

YES NO Staff understand and support the importance of family involvement.

YES NO Staff understand and welcome the involvement of spouses, friends, and members of the Personal Network.

YES NO Service and program staff recognize the importance of offering and respecting my family member's choices.

YES NO Family and friends provide support by reviewing services and programs on a regular basis. **NOTE** This is different from the service plans developed by service providers.

YES NO Members of the Personal Network are familiar with the personal care issues.

B. Information

GENERAL

Who does my relative trust? _____

Who would I trust to assist my relative with decision-making? _____

Who understands my relative's communication style? _____

MEDICAL DECISIONS

Who is my relative's doctor? _____

What assistance would they need to make medical decisions? _____

Who would my relative accept to assist with medical decision-making? _____

What aspect of their medical care do I think my relative might understand? _____

What formal arrangements do I need to make to ensure medical care is easily available to my relative? _____

FINANCIAL DECISIONS

My relative's trustees are: _____

My financial advisors are: _____

My relative has the following bank accounts: _____

Signing authority includes: _____

Who would be willing to assist my relative in making financial decisions? _____

I have asked the following individual to monitor the trust I have set up for my relative: _____

PERSONAL CARE DECISIONS

My relative's advocate is: _____

The independent agency that monitors services is: _____

Who would be willing to assist my relative in making lifestyle and personal care decisions?
