

REPORT OF THE

C.A.C.L. TASK FORCE

ON

ALTERNATIVES TO GUARDIANSHIP

AUGUST 1992

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CACL TASK FORCE ON ALTERNATIVES TO GUARDIANSHIP

MEMBERS OF THE TASK FORCE*

Murray Charleson, B.C.

Audrey Cole, Ontario (Chair)

Jo Dickey, B.C.

Ray McIssac, Newfoundland

Ken Pike, N.B. (participating on behalf of the Fundy Regional Council A.C.L. Older Parents Project, funded in part by the Conner Canadian Foundation)

Mary Claire Saunders, P.E.I.

Michael Bach, GARI (Staff)

Dulcie McCallum, CACL(Staff - Resigned in August, 1992 to become Ombudsman of British Columbia)

Orville Endicott, CACL (Staff and Observer)

* David Vickers was appointed to the Task Force but resigned to join the British Columbia Supreme Court as Superior Court Judge prior to the first formal meeting of the Task Force.

EXECUTIVE SUMMARY

* Guardianship or substitute decision making legislation is based on the misconception that personal autonomy can only be exercised independently

* A new conceptual framework for decision-making is needed which recognizes the reality of interdependence, and respects a person's right to make choices concerning his or her own life with the support, affection and assistance of family and friends.

* An enabling model, which is called supported decision-making is proposed. This model is based on values and principles which recognize that personal autonomy can be expressed interdependently; every person has a will and is capable of making choices, personal support, in its many forms, must enable the individual; the state has an obligation to provide resources, to ensure that those who are isolated are (re)connected

with others in their communities; the interests of third parties must not lead to an infringement of personal rights; and no individual should be assessed to determine his or her competency.

* The supported decision making model will require enabling or equitable legislation to ameliorate disadvantage, and provide a "ramp" from which people can gain access to a wider scope of experience. Such legislation must validate supported decision making as a legitimate means of making decisions, and establish provisions and guidelines that will outline standards of conduct of those who will provide support; recognize support persons for the purposes of the legislation; and validate specific decisions and activities which are carried out pursuant to the legislation.

* Specific areas will require enabling provisions to overcome existing barriers. In particular, decisions concerning financial management, contracts and medical issues require modifications to existing law to accommodate people who are involving others in the decision making process. Such modifications must be designed to achieve participation on the part of the person receiving support.

* The state must recognize and accept its moral duty to take steps to alleviate isolation for those who are isolated from their communities. Facilitation of informal supports must be included in enabling legislation. For those without support who require assistance with decision making, a mechanism should be available to provide support on an interim basis. Where a person's wishes cannot be interpreted or ascertained, limited residual authority should rest with the court to make a decision.

* Various safeguards must be put into place. An external review process must be able to review specific decisions which may be questioned, and to review individuals providing support when those individuals are challenged. Adult protection legislation must impose duties on the state to implement measures to protect individuals who are victims of various forms of abuse or neglect.

Enabling legislation must be accompanied by omnibus legislation aimed at making all statutory law consistent with the principles and provisions of supported decision making.

REPORT OF THE

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ALTERNATIVES TO GUARDIANSHIP

PART I - INTRODUCTION

This report represents the deliberations of the Task Force on Alternatives to Guardianship. The Task Force was established in October, 1991, has met together three times for three day meetings and has had thoughtful discussion by telephone throughout.

From the beginning, Task Force members were unanimous in their belief that merely tinkering with the traditional guardianship model would not remove the disparate result of guardianship laws. These laws place people who have been labeled "mentally handicapped" in jeopardy; lead to or cause further labeling, and infringe on fundamental rights to liberty and equality. It was clear that such laws do not contribute positively to the personal dignity, equality and integrity of those it might affect. New laws which reflect a new way of thinking were required.

As the deliberations of the Task Force continued, our thinking evolved and the necessary shift emerged. What was needed was a law that would enable people rather than disable them on the basis of declarations of incapacity or incompetency. Fundamentally, law must recognize the inherent value and dignity of all persons and respect the reality that decisions are often made with the support and affection of others. This report reflects this ethic by proposing the adoption of principles and laws that offer a positive and enabling alternative to guardianship.

PART II - A NEW PARADIGM FOR DECISION-MAKING

The resolution which led to the creation of this Task Force spoke of the need to develop "alternate models to guardianship for decision-making and personal support for all persons that reflect the underlying values and principles of personal dignity, equality and integrity" (1991 AGM Resolution #8). The wording of that resolution, as well as the terms of reference for the Task Force, made it clear to the participants that we were addressing the issues of decision-making for people labeled mentally handicapped in a fundamentally different way than in the past. Our "task" was to develop recommendations that will promote inclusion by enabling people who have been marginalized to make choices affecting their own lives, and to participate in decisions and activities with others in the community.

The development of a model of decision-making that is enabling and empowering requires a critical re-thinking of our laws and social policies. To date, these laws and policies have been vehicles of denial to the majority of people who are labelled on the basis of particular characteristics. In order to challenge the discriminatory effect of these laws and policies, their underlying assumptions must be challenged and replaced by a new set of assumptions that respect the equality and dignity of everyone.

This report proposes a "new paradigm" for decision-making. A paradigm is a "framework of thought" or a "scheme for understanding and explaining" certain concepts (The Aquarian Conspiracy, 1984). A new paradigm involves a new way of thinking about a particular issue. It also involves letting go of the old set of assumptions that have dictated

the way issues are resolved. A paradigm shift is now occurring in the field of community services for people who have been labelled:

...it is apparent that the original plan for community service systems has not been realized despite some obvious gains. These problems, in fact, may signal a failure in the fundamental idea of creating a system to administer comprehensive and compassionate care. Such cracks in the paradigm, or conceptional framework, often appear when the existing paradigm is exhausted and the ground for the acceptance of a new one is in preparation.

Our challenge today is not how to expand or refine the community services system but how to counter it with something completely different by nature. The challenge is to move from the familiar world of trying to build a caring service system into trying to elicit and support caring within the subtle fabric of human relationships.

David Schwartz

In the context of decision-making, the old assumptions have create mechanisms such as guardianship that "replace" the person who is deemed incapable of making his or her own choices. But guardianship is only the by-product of the way in which our society views itself and regulates the conduct of some of its members. It is not enough to challenge guardianship as a model of decision-making. We must also challenge the view of society and humankind that assumes some people are of lesser value and are incapable of making choices about their own lives.

Laws and policies which exclude people and provide for "substitute decision makers" are based on the assumption that individuals are independent as well as separate from one another. Individual rights to self-determination and autonomy are seen as significant from the point of view of being able to exercise those rights independently and without interference. People are categorized and gain status on the basis of their ability to make decisions on their own. Those who may be dependent in some way are categorized differently. Our social and legal systems develop methods of distinguishing people on the basis of their ability to perform to standards which are set by able-bodied "independent" people for the rest of society. Concepts such as "competency" and "capacity" are used to highlight differences and invoke legal procedures and other social responses that deny rights to make decisions and exclude certain people from participating as equal members of their society.

The old paradigm, therefore, is one in which people are classified on the basis of physical or intellectual characteristics. It creates barriers between people ("us" and "them") and by attaching importance to differences and placing people within a hierarchy (a "ladder") according to their ability to perform tasks independently. In the context of decision-making, people are tested so that society can determine "who decides?" and "who does not decide?." It is not surprising that a recent Canadian study of decision-making by

people who are elderly is called "Standing in Their Shoes." The message: if a person cannot stand in his or her own shoes then someone else must take his or her place.

It is also not surprising that guardianship "reform" in recent years has placed much emphasis on procedural protection and the notion of "limited guardianship. The assumptions of the old paradigm have not changed. Respecting rights has meant that before a person's place on the ladder can change, a legal process must be followed. Limited guardianship is invoked to ensure that instead of ending up at the bottom, a person who is having difficulties in his or her life gets placed in the middle of the ladder.

One of the main goals of the old paradigm is the creation of an ordered society where a person's place and status is well known to others. As such, the model satisfies the interests of third parties, such as doctors and service providers, who require an identifiable authority with legal and social status to justify their actions. Consequently, only those people who are deemed to be competent, independent decision makers are recognized as having the right to decide for themselves.

A new set of assumptions must guide our laws and policies. All adults have the right to self-determination and autonomy. This right is expressed in the provisions of the Canadian Charter of Rights and Freedoms which guarantees the freedoms of expression and association, and the rights to life, liberty and security of the person. We believe, however, that a person's inability to exercise these rights independently does not in any way make the right less meaningful or affect his or her status, legally or socially. We propose a new paradigm for decision-making that recognizes that self-determination and autonomy can be expressed in the context of relationships with others, and that interdependence, not only independence, is a valid and meaningful way of making choices and decisions.

This new paradigm is merely a recognition of the way decisions are actually made for many people. We rarely make decisions alone, in isolation. We talk things over with people we love and trust. Mostly but not always, those people are members of our family. The new paradigm does, however, propose to give legal status to the process of decision making which is communal and interdependent. This will require that our laws and policies reflect a new set of assumptions about the way decisions are made and how we support people to make choices affecting their own lives.

PART III - SUPPORTED DECISION MAKING - STATEMENT OF PRINCIPLES

The Task Force proposes that C.A.C.L. adopt and promote a model of decision making known as supported decision making. This model is based on the following assumptions and principles:

- (i) All adults have the right to self-determination and the right to make decisions affecting their lives with the support, affection and assistance of family and friends of their choosing.

- (ii) Every individual has a will and is capable of making choices.
- (iii) Some people desire personal support when making choices or decisions. Support may involve providing advice or information, discussing options and consequences, communicating an individual's wishes or decisions to third parties or interpreting the will of an individual. All forms of personal support shall empower the individual, give effect to his or her wishes and be free from conflicts of interest.
- (iv) People are interdependent, The law must recognize this fact and give status and validation to decisions that are made with the support and assistance of others.
- (v) A person's right to make decisions without support from others must be respected. Likewise, a person must have the right to refuse support from particular individuals.
- (vi) A cornerstone of supported decision-making is the existence of a trusting relationship between a person giving support and a person receiving support. Where a person is isolated from his or her community, the State must provide adequate resources to ensure informal personal networks are (re) established.
- (vii) The law must not discriminate on the basis of perceptions of a person's capacity or competence. Rather, the law must enable all adults to enjoy the benefits of making personal choices, and remove existing legal barriers to participation in community life, including economic barriers. All law must be consistent with the values, principles and provisions of the Canadian Charter of Rights and Freedoms..
- (viii) The interests and concerns of third parties must not lead to an infringement on a person's right to make choices, nor invalidate the supported decision making process. Such interests and concerns must be dealt with in ways which are consistent with these principles.
- (ix) No individual should be assessed to determine his or her "competency." Only individual decisions should be reviewable by an outside party to determine (a) whether the will of the person is being respected; (b) the decision has not been made under undue influence; or (c) the persons providing support are not benefiting from the decision without the knowledge and permission of the person receiving the support.

PART IV - THE NEED FOR ENABLING LEGISLATION

Our existing legal framework does not recognize the interdependent nature of relationships and decision-making. Instead, it reflects an ideology that assumes independence and separation. In its reliance on concepts such as competency and capacity it is elitist, limiting and discriminatory. This ideology of separation and limitation and the laws which reflect it have created systems "in which there is no reason to try and discover" another person's "choices, thoughts or feelings" (C.A.C.L. Brief to the Standing Committee on Administration of Justice (Ontario), March 1992).

if people think of you as a person who has many possibilities, they will create a space for you to grow. If people think of you as a person with limits, they usually do not give you as much space, and you grow less. All living things are like that. A plant in good earth with water and sun will bear much fruit; a person in a healthy surrounding will grow fully.

Justin Clark Entourage, Fall 1991

(Justin Clark successfully challenged an application to have him declared incompetent so that he could be forced to remain in an institution. His case clearly demonstrates the potential damaging consequences of guardianship and the ideology which underlies it).

It is not enough to eliminate the existing legal framework. We believe that it must be replaced with a framework which reflects an ethic of equality, compassion, understanding and interdependence. While laws on their own cannot shape a society, they can be a springboard or "ramp" from which people can overcome disadvantage and gain access to a wider scope of human experience.

Building codes are the laws that require these ramps. People with mobility restrictions have become active and contributing members of our communities because we have taken the necessary steps to include them physically. The ramp for a deaf person might be seen as an interpreter. We need to build a legal structure that will act as the ramp for inclusion for people with mental handicaps Only when we include them through such a mechanism will we fully appreciate their capacity to participate. The law must do more.

CACL Brief to the Standing Committee on Administration of Justice (Ontario)
March, 1992

Enabling legislation for supported decision making should be developed to ameliorate disadvantage for all people. In legal terms, such legislation would be seen as equitable legislation similar to other types of legislation designed to overcome systemic disadvantage (for example, marital property legislation, employment and pay equity legislation, and duties to accommodate under human rights legislation). The Task Force proposes that the essential ingredients of supported decision making legislation include:

- * A statement of intent or purpose outlining what the legislation is designed to achieve. In legal terms, this would likely be part of the "preamble" or introductory statement of the legislation.
- * A statement of principles under which the law will operate. The statement of principles should be consistent with those outlined earlier. They would also form part of the preamble of the legislation.

- * A validation / recognition of supported decision making as a legitimate means of making decisions.
- * An explanation of supported decision making, including provisions which establish how those providing support, will be legally recognized. The legislation should also set some general parameters for supported decision making, as well as outline some of the basic duties, obligations and rights of those providing and receiving support.
- * Other enabling provisions to overcome specific existing barriers to decision making and participation. Of particular concern to the Task Force are issues of economic and financial rights and decision-making as well as medical issues.
- * Provisions for the establishment of state funded mechanisms to (re)connect people who are isolated from their communities. The social policy goal will be the re-establishment of informal networks of support that will assist with decision-making and community participation. The legislation must also outline a positive duty of the state to maximize the availability of communication mechanisms.
- * An outline of how decisions will be made by people desiring/requesting support but who have no one to assist them.
- * Provisions for making this process accountable. Such provisions will allow for the review of decisions and the actions of those providing support. Individuals receiving support will not be accessed or reviewed.

In addition to enabling legislation, federal and provincial governments will need to undertake an audit of existing legislation to remove barriers to decision-making for people who are presently excluded. Moreover, since the enabling legislation will be legislation promoting and enhancing personal rights, it will have the status of "quasi-constitutional" or primary legislation. We believe that all other legislation should be made to conform with the principles and objectives of the enabling legislation.

Many of the components of the proposed enabling legislation outlined above received extensive discussion during the Task Force meetings. Members of the Task Force were able to reach a consensus on many of the specific components of supported decision-making as a model for inclusion. The sections below outline the results of the discussions on these issues.

PART V - HOW SUPPORTED DECISION MAKING WOULD WORK

Supported decision making as a model of self-determination must be theoretically and practically sound. It must be designed to accomplish the objectives of inclusion and participation. Moreover, it must be accessible and straight-forward, with clear guidelines. There are three basic elements that need to be established and recognized in enabling legislation:

(i) The recognition of decision-making within the context of relationships as a valid means of self expression and the legal validation of decisions which are made in a supportive context. In essence, the enabling legislation will give status and legal validity to decisions which are made in accordance with the legislation.

(ii) An outline of specific substantive or ethical duties and guidelines for those who will act in a supportive role.

(iii) An outline of procedural guidelines that will validate supported decision making. In other words, what steps must be followed by individuals giving or receiving support before the decisions which are made will be seen as valid and binding?

Duties and Guidelines For Individuals Providing Support

The Task Force views the development and expression of clear duties as an essential part of the new legal framework. Such duties and guidelines will serve to establish the nature of the role of supporters, as well as identify the responsibilities that will be need to be met.

Apart from the obvious education value of duties and guidelines, they will also be significant for those who may be called upon to review decisions as part of the accountability process. Some of the duties and guidelines listed below should be part of the legislation itself, while others may be appropriately placed in regulations or guidelines under the legislation. (Legislation or statute law is primary law, whereas regulations are known as "subordinate legislation." Guidelines made under legislation are not law. We indicate those duties which should be included in the enabling legislation). The main duties and guidelines include:

- * The supporter's role is to give effect to, and if necessary, interpret the desires, wishes, choices of the person whom he or she supports. (Legislation)
- * The supporter shall take all practical steps necessary to determine the will of the person, including interpreting the person's communications by words, gestures, conduct, aids to communication or by any other means. (Legislation)
- * The supporter shall make all reasonable efforts to make available to the person all aids and resources of communication including, but not restricted to PIC Boards, Blissymbolics, computers, facilitated communication, alternate format, Braille, interpreters (including signers), audio equipment and experiential decision-making.
- * The supporter shall respect the individual's wishes as to when and how much support is provided from time to time. (Legislation)
- * The supporter shall owe a duty of utmost loyalty to the person he or she is supporting. (Legislation)

* In accordance with the duty of loyalty, the supporter shall only act as a supporter, communicator or interpreter for the other person, and not as an agent or substitute decision maker.

* In accordance with the duty of loyalty, the supporter shall not make any personal gain while fulfilling his or her role without the knowledge and permission of the person receiving support.

* While acknowledging that the role of the supportive decision maker is to promote the self determination of another individual, the supportive decision maker shall not assist in giving effect to a decision that is otherwise illegal or is in violation of the principles expressed in the Charter of Rights and Freedoms.

* Where it is considered prudent and advisable, the supportive decision maker shall make information and expertise available to the individual to assist him or her in making an informed choice or decision without unduly influencing the decision. The nature of any information or expertise made available must be consistent with the values and principles outlined earlier, and the rights articulated in the Canadian Charter of Rights and Freedoms.

Procedural Framework For Supported Decision Making

Validating an interdependent framework for decision making will require a set of ground rules. These ground rules will establish a framework for acknowledging the participation of persons providing support as well as the necessary steps to be followed to give legal status to specific decisions. The procedural framework will be significant from the point of view of third parties who will want assurances that their inter-action with people who are receiving support will lead to decisions or agreements that are authoritative and binding.

The Task Force was particularly wary of over-formalizing a process which is supposed to take place in the context of natural and informal relationships. A model must be developed that respects informality while providing enough formality and certainty to give it legitimacy from the point of view of third parties (for example, doctors, bankers, service providers, etc.).

The procedural framework must accomplish two tasks:

(i) Provide guidelines for determining who will be recognized as a supportive decision-maker and how this recognition takes place; and

(ii) Provide guidelines setting out what steps must be followed to give legal validation / status to specific decisions. The guidelines must also establish under what circumstances will adherence to these steps be necessary.

Recognizing Individuals Who Will Provide Support

The new model must be accessible. Traditional tests for entering into arrangements such as powers of attorney are exclusionary. We propose that the selection and legal recognition of persons providing support be achieved on any one of the following bases:

- (i) by a designation in writing identifying the person(s) who will be providing support. The designation might be a prior one that is conditional upon an event occurring in the future. The designation document should be very basic, use plain language, and be validated by independent witnesses;
- (ii) by indicating a desire to have someone (or more than one person) act as a supporter. This desire can be expressed by non-traditional forms of communication which is expressed through or interpreted by others, documented, and validated by independent witnesses; or
- (iii) by recognizing the existence of a trusting relationship between the individual and another person or persons. The existence of a trusting relationship must be documented and validated by independent witnesses. The witnesses must be satisfied through personal knowledge and belief that the trusting relationship does exist, and swear an affidavit outlining the basis of their knowledge and belief.

The above criteria for recognition of supportive decision makers are inclusive. People with severe disabilities who have limited communication abilities do have the capacity to trust other people. That capacity must be recognized as a legally valid way to be part of a process that will give effect to a person's desires and choices.

The legal recognition of trusting relationships has a long history. Perhaps the most common example is the recognition of relationships that are known as "fiduciary relationships." These have been described as relationships in which one person places "trust and confidence" in another person who agrees to act in a way that does not breach that trust. A fiduciary relationship can exist where one person is in a position of influence over another person, and there is evidence of some vulnerability or dependency. Such relationships are recognized by the law because the law expects certain people to act with utmost loyalty towards others. If a person who is in a position of trust acts improperly, the law can make him or her accountable for his or her actions.

The recognition of trusting relationships is a logical and legitimate way to legally validate supported decision making. It is anticipated that the process of demonstrating and documenting trusting relationships will have built-in safeguards. The preparation of legal documents will likely involve lawyers who will have to satisfy themselves that the people involved are pursuing a legitimate activity. We propose that witnesses be at least 18 years of age and be prohibited from having any interest which is in conflict with the person who will be receiving support. Moreover, supporters will be under strict obligations to give effect to the will of the individual and avoid conflicts of interest and undue

influence. Accountability measures will be available to address and protect against potential abuses.

The Task Force recommends that the follow-up process to this report further explore ways in which we establish that trust exists between two people in a supportive relationship. Particularly, we will need to determine what kind of evidence will satisfy the recognition provisions of the enabling legislation.

The Task Force debated whether persons providing support should be registered through an independent public agency. Most of the reaction to this idea was negative. We are of the view that registration requirements will over-formalize a process that is natural and informal. Public recognition of individuals providing support can be achieved through less formal means such as providing certified copies of documents to doctors, hospitals, service providers, bankers, etc. The onus should rest with third parties to challenge the validity of the support process if there are perceived problems or concerns.

Validating Specific Decisions and Activities

In some circumstances it may be necessary to undertake procedures in order to make a decision or activity authoritative and binding in the eyes of the law and third parties. Such procedures should be limited to situations where people providing support are either communicating or interpreting the wishes and decisions of another person or are performing support duties that involve the administration of property or financial resources. The following procedure is one possible option that could be recognized in enabling legislation:

Individuals providing support in the nature of assistance with the communication or interpretation of another person's wishes, or assistance with the administration of assets, swear an affidavit (or declaration) indicating:

- (i) an acknowledgement and disclosure of the role of the supporter as communicator, interpreter, or financial administrator;
- (ii) an acknowledgement of the existence of authority to act as a supporter through one of the avenues recognized under the enabling legislation;
- (iii) an acknowledgement of the standards of conduct, including the role of supporting the individual to give effect to his or her choices, wishes or desires, and that the supporter has not unduly influenced the decision and is not in a position of conflict with the individual; and
- (iv) a statement indicating the nature and substance of the decision, choice or activity being made or undertaken.

We propose that enabling legislation provide that a person providing support:

(i) never provide a signature for the person receiving support other than as his or her supporter (communicator interpreter, administrator) and acknowledge that role by written declaration; and

(ii) never act as a witness to the signature of the person receiving support for any purpose other than as his or her supporter and acknowledge that role by written declaration.

It is also proposed that enabling legislation provide that any document which is signed by a person and/or his or her supporter in accordance with the above rules be considered validly executed by the person receiving support.

Decisions Which Cannot Be Made In The Context of Supported Decision-Making

It may be necessary to recognize some limitations regarding the types of decisions which will be possible under the supportive decision making model. This issue may require further review in the follow-up process to this report. The Task Force believes limitations should apply where the risk of misinterpretation of the person's intention would result in decisions which would offend human dignity. The most obvious examples involve sterilization and experimentation.

PART VI - ECONOMIC AND FINANCIAL RIGHTS AND DECISION MAKING

The Task Force spent considerable time addressing the issues of economic integration and self-determination in the context of financial decision making. There was widespread acknowledgement that the right to participate in typical economic and financial activities, with or without support, was largely affected by the existence of systemic barriers. These barriers marginalize people with disabilities to the extent that economic and financial self-determination is difficult to achieve.

The Task Force believes that the model of supported decision-making will have some impact in overcoming these barriers to participation. Some barriers, however, are well-rooted in our economic and social fabric and will require substantial commitments from individuals, governments and communities to effect real change.

Barriers To Economic and Financial Participation

It is well known that most people with disabilities are poor. Self-determination in the context of economic and financial matters presumes that a person has financial resources over which he or she can exercise choices. The theme of economic integration acknowledges that in a society which revolves around the activities of production or consumption, those who are denied participation in the marketplace are fundamentally marginalized.

Some of the well known barriers to economic and financial participation include:

- * the exclusion of people with disabilities from the labour force and traditional employment markets.
- * inadequate income support benefits and laws which permit provincial governments to appoint trustees to receive benefits on behalf of a person deemed to be "incompetent." The same laws prohibit people who receive benefits from owning assets beyond nominal levels.
- * disability support programmes and services which provide bloc or programme funding which places decision making power over resources in the hands of service providers and professionals.
- * the lack of any control over resources that may be inherited from family and friends. Most often, such resources are placed in trust under the control of trustees. If the trust is attempting to preserve entitlement to income support benefits, the trustee's authority is uncontrolled and absolute.
- * laws that set standards of competency in order for individuals to enter into contracts.

Overcoming Barriers

it is beyond the mandate of this Task Force to address in detail all of these systemic barriers to participation. It is clear that our laws and social policies require fundamental changes to adequately address the causes of disadvantage. From the perspective of promoting the right to self-determination and supported decision-making, the Task Force proposes the following:

- (i) Each provincial government review its service delivery programmes to determine what changes are required to give those who use these services control over the financial resources that will meet individual needs. Provincial governments must also recognize supported decision making as a valid way of making choices about the use of resources to purchase services as they are required by the individual;
- (ii) As part of a statutory audit (see Part X), provincial governments remove provisions under income support legislation that allow government of officials to appoint trustees for or benefits for individuals who are considered incapable of managing their own affairs;
- (iii) Enabling legislation for supported decision making recognize an individual's right to control his or her own financial resources with the support and assistance of others;
- (iv) Enabling legislation for supported decision making validate contracts entered into by individuals who are receiving support from people who are recognized under the enabling legislation.

Supported Financial Management and Decision Making

One area in which people require assistance in their daily lives is the management of money and other assets. While acknowledging support is needed, many people may not have the desire to transfer their legal authority over financial matters to others (as is the case under Powers of Attorney and inter vivos trusts). Support with financial management and decision making can be accomplished within the context of the supported decision making model. In view of the particular issues that arise with the use or transfer of personal assets, separate procedural guidelines may be required under enabling legislation. It is anticipated that some of the roles a financial supporter would play include:

- * giving advice and information to enable the person receiving support to make decisions;
- * assisting with the management of money and other property according to the wishes and desires of the person receiving support;
- * interpreting choices and wishes which are made through traditional or non-traditional forms of communication, and communicating those choices and wishes to third parties;
- * ensuring that a person's wishes and choices are acted upon accordingly.

It is proposed that a person providing support on financial matters be recognized in one of the three ways outlined earlier. Where an individual makes a designation in writing, or is able to express his or her wishes or desires in other ways, he or she may specifically outline what the supporter's role will be. A copy of any document which appoints a supporter may be left on file with a financial institution or other third party as notification that the supporter is available and authorized to assist with financial management and decision-making.

The Task Force also proposes that the following procedural guidelines be included in enabling legislation:

- * where a supporter is involved in decisions or activities which affect the use or transfer of assets, he or she must sign a declaration acknowledging his or her role;
- * where a supporter is involved in decisions or activities which affect the use or transfer of assets, he or she must keep records (e.g. receipts, bank forms, declarations, etc.) of the transaction.

Supported Contractual Decision-Making

The opportunity to make decisions and enter into contracts is clearly linked to economic participation. Nevertheless, contract law currently provides that before a contract will be considered valid and binding, a person must have the required mental ability to

understand the nature of the agreement, along with its terms and conditions. As a result, many people with challenging mental disabilities are systematically excluded from economic life. At stake is the right

of many individuals to enter into a lease for a home, apartment, or business, sign a contract, obtain a loan or grant, qualify for a credit card or bid on a tender.

In reality, some people with handicaps do enter into contracts because individuals and agencies overlook strict legal requirements. In such situations, people are putting themselves at risk since their ability to enforce a contract against a person with a disability may not be recognized. In some respects, the law is out of touch with current practice. It is difficult to justify a situation where a person with a challenging mental disability owns a business and employs non-disabled people yet his or her actions are not considered valid in law because he or she does not have the legal capacity to make contracts.

The law is a barrier to participation. Nevertheless, we recognize that legal tests requiring the need to understand the terms of a contract meet a legitimate economic and social goal of making people accountable for the contracts they enter into. We recognize that contract law cannot be completely re-written. Yet the law must accommodate people with disabilities so they can participate in this aspect of social and economic life.

The model of supported decision making must be recognized as a means by which individuals can enter into contracts. We propose that enabling legislation outline the following:

- * A contract is deemed to be valid and binding if entered into by an individual with the support and assistance of a support person(s) recognized in one of the three ways outlined in the enabling legislation;
- * The contract will be valid and binding if either the person receiving support or the person(s) providing support understand the terms and conditions of the contract;
- * The contract will be considered to be an agreement between the person receiving support and a third party. A person who provides support will not be required to be a party to the contract;
- * The contract will be in writing or otherwise recorded and wherever possible use plain language;
- * The contract may be signed by the individual receiving support (in any way he or she normally "signs" or acknowledges his or her name) and witnessed by the person providing support. If the person receiving support is unable to sign the contract, the person providing support may sign it on his or her behalf;

* If required, the person providing support will sign a declaration acknowledging his or her role;

* Unless there has been fraud, gross negligence or wilful misrepresentation or misconduct on the part of the person providing support he or she shall not be liable under the contract;

* Any contract which is entered into on the basis of fraud, gross negligence, wilful misrepresentation or misconduct on the part of the person providing support may be voidable or considered frustrated.

PART VIII - SUPPORTED MEDICAL DECISION MAKING

Another major area of discussion for the Task Force centered around the issues of decision making for medical treatment. In particular, the Task Force questioned how the model of supported decision making could be applied so that people could make decisions affecting their own bodies.

As with other areas of decision making, the law poses serious barriers to participation for people who are labeled as having a mental disability. The law requires that prior to a doctor (or other health professional) undertaking diagnostic, medical or surgical procedures, he or she must have the informed consent of the patient. In order for a person to give a valid consent, the law requires that the following criteria be met:

(i) the patient must be legally competent to consent;

(ii) the patient must have the mental capacity to understand information and authorize care or treatment;

(iii) the patient must receive proper information from the doctor (or other health professional) so that the consent can be "informed";

(iv) the patient's consent must be specific to the procedure to be performed

(v) the patient must have the opportunity to ask questions and receive answers he or she can understand;

(vi) the consent must be given without undue influence and coercion;

(vii) the consent given must be done without misrepresenting any material information.

Adapted from Rozovsky, The Canadian Law of Consent to Treatment

The core of the concept of informed consent is the respect for all individuals to have their right to have personal goals, choices, values and wishes honoured. The concept is not

strictly a medical or legal question, but also includes what is important to a particular patient and his or her family. Individual circumstances, therefore, play an important role.

Barriers and questions arise when the process requires that a person have a particular level of understanding of what is to be done and the risks that are involved. It is up to the health care professional to determine whether this "mental capacity" is present. For many people labeled mentally handicapped, whose very label is defined by reliance on an intelligence quotient, the tendency has been to ignore the possibility of obtaining informed consent.

Nevertheless, there are some doctors and other health professionals who take the time to satisfy themselves that consent has been given or withheld by allowing the individual to express his or her choices and wishes, however he or she can, often with the input from family members and close friends. This practical and natural approach to decision-making generates respect for the individual while including those people who are likely to be the main sources of caring and support. Nevertheless, in some circumstances both professionals and those who provide support are placing themselves at some risk since the legal tests and criteria may not be fully satisfied.

Enabling legislation must endorse and codify the natural and inclusive approach to decision making on medical issues. We recognize, however, that the legitimate goals of legal criteria for

informed consent must be respected. We do not propose to completely re-write the law of informed consent, only to modify it to allow people to participate with the assistance of others.

In legal terms, when a person gives his or her consent to medical treatment, he or she is actually entering into a contract with the doctor for the provision of services. The criteria listed earlier establish the basis for making a valid contract. The Task Force proposes that in situations where a person is in need of support, a different set of criteria be established to validate the consent and process. These criteria would include:

- * Consent for diagnostic, medical or surgical procedures will be deemed to be valid if it is given by an individual with the support and assistance of a support person recognized under provisions of the enabling legislation;
- * Consent will be considered valid if either the person receiving support or the person(s) providing support understand the nature of the procedure and the risks involved that are made known by the attending physician or other health care professional;
- * The consent (or refusal) will be considered to be the consent (or refusal) of the person receiving support;

- * The attending health care professional shall be under an obligation to make all reasonable attempts to communicate with the person who may undergo diagnostic, medical or surgical procedures. The health care professional must take all reasonable measures to confirm that the will of the person is being respected;
- * The means by which an individual could communicate his or her consent (or refusal);
- * The consent form may be signed by the individual (in any way he or she normally "signs" or acknowledges his or her name) and witnessed by the person providing support consent. If the individual receiving support is unable to sign the consent form the person providing support may sign it on his or her behalf;
- * Where consent is being given to diagnostic, medical or surgical procedures which are not routine, and the person(s) providing support communicates or interprets the wishes or choices of the individual, the support person shall be required to sign a declaration acknowledging his or her role (including the standards that must be adhered to), as well as the nature of the decision which is being communicated or interpreted.

Questions and challenges concerning health care decisions may arise from time to time. There must be a way to review such decisions in a sensible and practical way. One option may involve the local review committees discussed in the section on Safeguards and Accountability Measures. Another option would involve using specific hospital review committees (perhaps ethics committees) to resolve challenges or procedural issues. We believe that there should be some limited residual authority in the court to make decisions, if a person's support network and doctors are unable to interpret or determine his or her wishes concerning commencing or discontinuing medical procedures.

PART VIII - FACILITATING NETWORKS OF SUPPORT

Supported decision making will only be relevant and effective if people who have difficulty with decision making have access to others who want to support them. Caring family members and friends will likely provide most of this support, as they do presently. Yet there are individuals with handicaps, or who are elderly, who are isolated from their communities and therefore lack caring relationships. Others, such as some disabled sons and daughters of aging parents, risk isolation. Often the only connections of isolated people with disabilities are those with people who also live with disabilities or people who are providing a service for which they are paid.

As our communities continue to accept people with disabilities as people first, isolation will decrease. Integration within our schools, workplaces, neighbourhoods and recreation activities will provide people with opportunities to develop relationships with others. That process will take time. In the meantime, the Task Force believes there is a need for our governments and communities to recognize they have a moral duty to create ways of connecting people who are isolated with others, and encouraging the development of informal networks of caring people who will provide support to those who are labeled.

Governments must acknowledge this moral duty in enabling legislation, and provide adequate resources to overcome the disadvantage of isolation through the facilitation of informal supports. This acknowledgement would be based on the understanding that our society has been designed in such a way that personal relationships for many people have been systematically undermined and destroyed, mainly by our service systems. Moreover, since our laws recognize an individual's right to liberty and self determination, people requiring support have the right to resources to enable them to enjoy these rights.

The actual facilitation should be carried out in local communities, preferably by non-government boards or agencies who are embedded in the community. Facilitation could include attempts to maximize relationships with families and friends, establishing networks of support, and volunteer advocacy.

The Task Force also proposes that public resources be committed to maximizing communication mediums to enable those with communication difficulties to express their wishes and choices.

Interim Solutions For People Without Support or Whose Wishes Cannot Be Interpreted

A lack of adequate personal relationships and supports should not be justification to invoke traditional legal responses (i.e., guardianship) where difficulties with decision making and communication are present. The first duty of our legal and social systems is to facilitate informal personal support where they are desired or required.

Situations will arise in which decisions will have to be made by individuals who do not have support and assistance. These situations could be dealt with by a public official (perhaps called a Public Facilitator) who could undertake the following functions:

- * Make all reasonable attempts to arrange for the facilitation of informal personal support for an individual. It is proposed that the Public Facilitator utilize existing community facilitators rather than be personally responsible for specific individuals.

- * Where attempts to facilitate informal personal supports are unsuccessful, or if a matter requires an immediate decision or action, provide support or assistance to the individual through:

- advice and information; - providing aids to communication; making all reasonable attempts to determine the wishes or desires of the individual in the circumstances;

- if necessary, communicate or carry out the decision which is made by the individual (including signing of documents on behalf of the individual).

- * Where attempts to determine the wishes or desires of the individual are not successful, apply to a court of superior jurisdiction to have a decision made by the court.

Under this process, any decisions which are made by the individual with the support of the Public Facilitator in the second stage will be deemed to be valid decisions under the enabling legislation. We recognize that supported decision making under this process will not be based on trust between the person being supported and the Public Facilitator. Nevertheless, these steps will be necessary to avoid the risk that people who are isolated end up with substitute decision makers. All of the checks and balances outlined in the next Part can also apply to supported decision making performed by the Public Facilitator.

It is proposed that applications to a court under the third stage be issue limited. The court will not be called upon to determine a person's competence. It will review the situation from the perspective of the particular decision that must be made and whether the person's wishes or desires can be ascertained. The court will, therefore, be under an obligation to determine whether the Public Facilitator has done everything reasonably possible to ascertain and effectuate the wishes of the person. If the court determines that the person's wishes cannot be ascertained (for example, a comatose patient who has not made prior declarations) it will have the authority to make a decision.

It is anticipated that the role of the Public Facilitator as a supporter will be a limited one, and that the use of the judicial process will be even more limited. One issue for further consideration is whether the judicial process should also be available to an individual providing support who is unable to ascertain or interpret the wishes and desires of the person receiving support.

The Public Facilitator should also be given jurisdiction to oversee the activities of local community attempts to facilitate informal personal supports for people who are isolated. The Office should also be equipped to assist people providing support with understanding the rationale and principles of supported decision making, what their roles are, and how these roles can best be played. In particular, the Public Facilitator should provide guidance in the following ways:

- * educating those who provide support so that they keep the person receiving support at the centre of decision making;
- * educating people who provide support so that they respect the trust of the position by not violating the person in any way;
- * provide information and guidance on how to facilitate decision-making;
- * provide information on various aids to communication, and how to access and use them;
- * educate people who provide support so that they know that their role is not a substitute decision maker.

We do not believe that the Public Facilitator should be involved with the review mechanisms outlined in the next Part. Furthermore, appropriate safeguards must be put in place to ensure the Public Facilitator is not a substitute decision maker.

PART IX - SAFEGUARDS AND ACCOUNTABILITY MEASURES

Supported decision making is embedded in the belief that decisions can be made within a process of interdependence, sharing and support. A cornerstone of that process is the existence of trusting relationships between the person receiving support and those providing it.

We recognize that trust and people can be abused; people who provide support may not "listen" to the person being supported; an interpretation of another person's wishes may be questioned or challenged; and conflicts may arise between people within relationships. It is important to acknowledge that there is no perfect model. The process we are proposing will fail from time to time. We believe, however, that these potential negative outcomes do not justify suggesting that supported decision making is unworthy or unworkable. We also believe that the model must be accountable to the people who will receive support, and that clear and effective checks and balances must be developed to ensure people are protected.

The Task Force proposes that safeguards and accountability measures under supported decision making take three forms:

- (i) safeguards which are built into the process itself through standards, procedures and other requirements;
- (ii) incorporating in legislation a review process so that specific decisions and people providing support can be questioned;
- (iii) incorporating in legislation adult protection provisions which place an onus on the State to take appropriate steps when reports of abuse or neglect are made.

Built-In Safe Guards

In earlier parts of this report, various proposals were outlined that are designed to ensure supported decision making respects the dignity and wishes of people receiving support. A starting point is the Statement of Principles that will form part of enabling legislation. Those principles recognize everyone's right to make choices affecting their own lives; that every person has the ability to express choices and desires; and that decision making is often an interdependent process. The recognition of supportive decision makers will be based on the need to demonstrate trust. This demonstration can simply be a declaration or designation by one person that they wish another person to provide support; or it can be a recognition of the existence of a trusting relationship between two people that is verified by independent witness.

Built-in safeguards will also be provided by a series of duties and guidelines by which supporters must adhere. These duties and guidelines will be designed to ensure there is no conflict of interest on the part of supporters by virtue of the power relationship. They will also help ensure that the supporter gives effect to the desires wishes and choices of the person being supported, and takes all reasonable steps to ascertain the will of the person. The legislative framework will need to be supplemented with programmes that will educate people about supported decision making and the need to adhere to standards of conduct.

Finally, the enabling legislation will also set out procedural rules and guidelines that will apply in some situations (for example, when a supporter is interpreting the wishes of another person and is consenting to a medical procedure). These rules and guidelines will reinforce the nature of supported decision making and the role of those providing support.

External Review Process

The Task Force believes that enabling legislation must include provisions for a review process that will perform two main functions:

- (i) Review specific decisions which are questioned or challenged;
- (ii) Review the individuals who are providing support when those individuals are challenged, and resolve conflicts regarding decision-making or between people claiming authority to act as supporters.

Under this review process, specific decisions will be reviewable to determine whether:

- * the will or desires of the person are being respected;
- * the decision has not been made under undue influence;
- * the person(s) providing support have failed to act; or
- * the person(s) providing support are not benefiting from the decision without the knowledge and permission of the person receiving support.

The review process will have authority to overturn a decision which is not consistent with the will, choices or desires of the person receiving support, or where there has been undue influence or conflict of interest on the part of the support network.

Challenges to individuals providing support may come from the person receiving support, other persons within a support network, or from persons outside the support network. The review process will have the authority to decide if individuals providing support should

be recognized for the purpose of the enabling legislation. It will also be able to mediate conflicts.

Under both aspects of the review process, the onus will rest with the person making a challenge to prove any allegations being made. Moreover, the challenger must have the onus of proving the validity of the challenge through appropriate evidence. The only exception to the onus of proof will be when the review process is initiated by the individual receiving support.

The Task Force proposes that the first level of review rest with local committees or boards established under the enabling legislation. The local review committees can be formed on a regional basis within each province to limit cost and bureaucracy. Persons appointed to the review committees must be knowledgeable about, and committed to, the principles of supported decision-making.

The Task Force believes that an avenue of appeal of review committee decisions should also be available. There are two main possibilities. Appeals could be made directly to courts or to a high level government official (perhaps a Minister) who is not responsible for the provision of services to the public. If the appeal process involved a government official, the courts could be the last avenue of appeal.

Adult Protection Legislation

The third safeguard is adult protection legislation which places duties on the State to implement measures to protect individuals who are victims of various forms of abuse or neglect. Several provinces currently have some form of adult protection legislation. It is perceived that such legislation should be independent of enabling legislation for supported decision making.

The Task Force proposes that the basic components of adult protection legislation must include:

- * a broad definition of abuse and neglect (including sexual, psychological, physical and financial);
- * a limit on the extent of any intervention by the state. In other words, intervention would be limited in time and scope and be on a voluntary basis (unless the person's life is in imminent danger);
- * a duty on the state to investigate all allegations of abuse and neglect;
- * a duty on the state to provide necessary supports and services whenever an allegation is substantiated;

* a duty on the state to provide supports and services that will limit the likelihood that vulnerable persons will be victims of abuse and neglect;

* appropriate appeal mechanisms.

PART X - STATUTORY AUDIT AND OMINBUS LEGISLATION

Enabling legislation establishing a model of supported decision making will have to be accompanied by omnibus legislation. This legislation will amend other provincial statutes affecting decision making, and implement the supported decision making model in various areas. For example, elections legislation will need to be amended to provide that a person can exercise his or her right to vote with the assistance of a recognized support person under the enabling legislation. Evidence laws will need to recognize the right of a person to give evidence with the support and assistance of other individuals through various forms of communication.

In addition, legislation that uses language that is potentially inconsistent with the enabling legislation must be reviewed. Terminology that limits participation (e.g. "mental incompetency", "mental disability", "guardian", "committee") must come under strict scrutiny. Where the terminology is limiting, it must be changed to reflect the ethic of inclusion and interdependence which underlies supported decision making legislation.

The Task Force recommends that as a follow-up measure, CACL undertake a project to research provincial and federal legislation to identify legislation that will need to be included within comprehensive omnibus legislation.

PART XI - CONCLUSION

This report presents a valid and positive alternative to traditional decision making legislation in which individuals lose their rights to make decisions affecting their own lives. The alternative is based on the principle, which is recognized by our Constitution, that all adults have the right to self-determination. Where people have difficulties exercising this right, laws and social policies must find ways to encourage and enable them to do so. Fundamental to our recommendations is the belief that it should be possible for all people to have the opportunity to make decisions in the context of caring relationships. Our laws must give expression to this kind of decision making through enabling legislation.

The Task Force is proposing changes to our legal system which represent a departure from existing law. Many provinces are now reviewing these laws with a view to reform. We believe the recommendations in this report should be given serious consideration since true reform can only happen when laws are consistent with the values of personal dignity, inclusion and participation. Anything less will only continue the legacy of denial and exclusion for many Canadians.

APPENDIX B PEOPLE FIRST OF CANADA RESOLUTION ON GUARDIANSHIP BECAUSE GUARDIANSHIP AND ORDERS OF SUPERVISION TAKE AWAY THE RIGHTS OF INDIVIDUALS: THEREFORE BE IT RESOLVED THAT PEOPLE FIRST OF CANADA OPPOSE ALL LEGISLATION PUTTING PEOPLE UNDER THESE ACTS (Adopted at the founding convention of People First of Canada, Saint John, New Brunswick, April 7, 1991)

APPENDIX C PEOPLE FIRST OF ONTARIO (Principles and beliefs relating to decision making) Important Principles

1. The right to self-determination is fundamental to all human beings. No law should ever take away this right on the basis of disability.
2. It's okay to have help making decisions. If we need more help making decisions than other people, we shouldn't lose our right to make decisions.
3. People need to be given the power to make decisions and choices. Society must help us get the support we need to make decisions.

People First of Ontario Believes:

- * that no-one is completely without ability and that the law should guarantee the right for all people to use their abilities to contribute to decisions made about their lives;
- * no law should allow a person to be legally replaced as they would be under the Substitute Decisions Act;
- * decision making must be interpreted within trusting relationships and that it is essential for the law to meet this need;
- * doctors and other service providers may need protection but this protection should not require taking away the rights of people who can't speak for themselves.

TASK FORCE RECOMMENDATIONS TO BOARD

The Task Force on Alternatives to Guardianship recommends that the Board of CACL:

1 create continuing working groups or committees to carry forward the proposals of the Task Force on Alternatives to Guardianship;

2. acknowledge that the guardianship reform process is under way in several provinces/territories that may lead to laws that will adversely affect the rights of people with disabilities and recommend that resources be allocated to work with provincial/territorial associations to promote supported decision making;

3. prepare and circulate a Benchmark Statement that will establish the parameters for provincial/territorial associations regarding supported decision making. The Benchmark Statement should include:

1. Principles for supported Decision Making

2. Contents of Enabling Legislation

3. Omnibus Legislation

4. encourage a coalition approach in each province/territory between CACL, the provincial ACL, national People First, and provincial People First. Priority should be given to provinces/territories that are involved in a guardianship reform process;

5. establish an intensive research project to determine the implications of the proposed model. Applications for funding to be made to Health and Welfare Canada and the federal and provincial Departments of Justice or Attorney General;

6. make application for developmental money for training resources on supported decision making (possible corporate donations ie Apple Computers). Training materials should be produced on issues such as recognizing and demonstrating trust, aids to communication, and methods to carry out supported decision making.

REPORT OF THE CACL TASK FORCE ON ALTERNATIVES TO GUARDIAN SHIP SUMMARY This report is based on the position developed by People First of Canada that guardianship takes away people's rights and should not be permitted by law.

The task force worked out a way that governments would be able to support people to make and communicate their own decisions without having guardianship.

The task force's model would mean that governments would have to pass new laws and change some old ones so that people would get the support they need and not lose any rights.

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Last updated 01/05/04

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