

Audrey Cole

May 1989

BRIEF

OF THE

ONTARIO ASSOCIATION FOR COMMUNITY LIVING

TO THE

ONTARIO GUARDIANSHIP AND ADVOCACY REVIEW COMMITTEE

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PREPARED BY
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OACL TASK FORCE ON ADVOCACY AND GUARDIANSHIP

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This OACL submission was prepared with the assistance of the Task Force on Advocacy and Guardianship and approved by Nancy Stone, Vice President, OACL, as authorized by the Board of Directors, January 26, 1989.

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SUBMISSION TO BERNARD STARKMAN, ADVOCACY AND GUARDIANSHIP REVIEW COMMITTEE

Section 1 — Introduction:

On November 22, 1982, in Lanark County Court, the Honourable Judge John R. Matheson was pondering the question of how to balance "protection" and "liberty". "In all my years I never thought of the Mental Incompetency Act as having stigma, until this case. Usually," he said, "it has a kindly purpose." Earlier in the proceedings, he had remarked on the frequency of mental incompetency applications and had noted that they were invariably seen as "beneficent" acts.

Justin Clark, the Respondent in the case, is one of the few people in Ontario to have challenged an application for a declaration of mental incompetency, the expected consequence of which would have been the appointment of a guardian (Committee) of his person.

Judge Matheson was not convinced beyond reasonable doubt by the affidavit evidence supporting the application and he ordered that the issue as to whether Justin Clark was mentally incompetent be tried. He was similarly unconvinced by expert evidence of Justin Clark's mental incompetency at the trial, despite the lesser requirement of its proof on a balance of probabilities. Judge Matheson was, however, persuaded by evidence to the contrary. He found Justin Clark to be mentally competent.

There is much to be learned from Justin Clark's experience. Some of the lessons are about freedom and protection and control, about beneficence and stigma, about competence and incompetence, but they are also lessons about advocacy, friendship and community, and about information and communication and about strength and power and integrity.

Even as Justin Clark's legal victory did much to raise public consciousness of the rights and dignity of people with significant disabilities so was it instrumental in reminding the government of Ontario that its laws relating to substitute decision-making and guardianship must be reviewed. Coincidental and fortuitous was the requirement that all provincial statutes be reviewed to ensure compliance with Section 15 of the Charter of Rights and Freedoms. As noted by the Advisory Committee on Substitute Decision Making for Mentally Incapable Persons (the Fram Committee), it is essential that the values expressed in the Charter inform any review of the law relating to substitute decision making. Consequently the values of "no unnecessary intervention" and "self-determination" underlie the Fram Committee's recommendations. Recognizing that Section 15 of the Charter "affirms a commitment to protection from discrimination and segregation...promotes a society of equal worth and respect for all individuals...[and]...demands tolerance and invites mutual respect", the Fram Committee expresses its third underlying value as:

"that mentally disadvantaged persons, needing and wanting help to be part of the community, have access to assistance now unavailable to many of the mentally disadvantaged, in support for their personal self-determination and assistance in remaining part of the general community." (Fram, p.42-43)

Similarly, these values and the many issues brought to light by Justin Clark's experience, together with a rapidly accelerating capacity to recognize and to understand what hurts and what helps people who are vulnerable, force the Ontario Association for Community Living (OACL) to scrutinize its own values and

beliefs about guardianship and mental incompetency as those matters relate or might relate to people who have been described as "developmentally handicapped". Contributing to this scrutiny is OACL's participation and interest in the various activities leading to those Reports now subject to review by Mr. Bernard Starkman (see Section 2 for related activities). Of particular interest to OACL was the meeting on March 8, 1989, between Mr. Starkman and certain members of OACL's Task Force on Advocacy and Guardianship.

Section 2 — About OACL:

The Ontario Association for Community Living is a provincial federation of 121 local Associations with approximately 14,000 members. The Association has a long history of advocacy on behalf of people identified as having developmental disabilities. This advocacy has been coupled, at the local level, with the development of community based services. Most community based services for people with developmental disabilities in Ontario have their origins within OACL initiatives.

In its 35 year history, OACL has had three names. Each change of name has reflected the evolution of the Association's understanding of people identified as having developmental disabilities. The heart of the Association is firmly rooted in the community. As a voluntary organization OACL has always remained committed to the development of supports within community settings. Originally incorporated in 1954 as the Ontario Association for Retarded Children by parents and grandparents who wanted educational opportunities in their home communities for their sons, daughters and grandchildren, the Association changed its name in 1965 to the Ontario Association for the Mentally Retarded. Children grew quickly into adults and local Associations were becoming more involved in the provision of vocational services. At the same time, the fact had to be faced that appeals for help for pitiful children was an unlikely foundation for the achievement of full community citizenship (Anglin, Braaten, 1978). The "eternal child" image and the responses it engenders are not beneficial to people with developmental handicaps. As OACL's experience has grown, so has its recognition of what community means and the kind of security it offers to those who share it. The Association's most recent change of name, in 1987, to the Ontario Association for Community Living, reflects the goal and purpose of its membership which is: "That all persons live in a state of dignity, share in all elements of living in the community and have an opportunity to participate effectively." Although rarely called upon to articulate it, few people would deny the importance in their lives of "community". The more we share that sense of community the more complete our community becomes, the more it cares, and the less at risk are its vulnerable members.

Consistent with OACL's Goal is its pursuit of better ways to support people who have difficulty understanding the consequences of decisions relating to their personal care and well-being and who are vulnerable as a consequence.

To this end, OACL's involvement in activities relating to the current Review of Advocacy and Guardianship by Mr. Bernard Starkman, include:

- OACL representatives served on the Advisory Committee on substitute Decision Making for Mentally Incapable Adult (ref. Fram Report, 1987) and also on the Attorney General's Advisory Committee on the Estates of Persons Incapable of Managing Their Property, the Report (1985) of which was treated as an Interim Report by the Fram Committee.
- OACL provided input for the Review of Advocacy for Vulnerable Adults, conducted by the late Reverend Sean O'Sullivan.
- Matters raised by Dr. John Lord and Professor Manson in the Review of the Psychiatric Patient Advocate Office (1987), relating in particular to people identified as having "dual diagnosis" and to people who may be unable to communicate effectively in instruction-based systems of advocacy remain of particular concern to OACL.
- OACL is currently represented by its Legal Counsel, Mr. Rod Walsh, on the Committee for the Determination of Criteria for the Assessment of Mental Capacity, chaired by Professor David Weisstub.
- In the early 70's, OACL, together with representatives of the Ministries of Health, Community and Social

disabilities. The more sensitive we become, the less sure we are of the meaning of words with which we were once familiar. Not only do we no longer use words such as "retarded" to describe certain people, we no longer have a clear image of what those words used to mean to us. We are being taught daily by the very people to whom we have attached those labels in the past.

Sterilization is a matter involving decisions that few people would willingly allow others to make for them. Nevertheless, a right to make such decisions for certain other people, with or without their knowledge, has often been presumed in the past. There has been much to learn about dignity and integrity of purpose in the unwavering pursuit of justice by people with developmental handicaps in this deeply personal matter, a pursuit that was not simply validated but was enhanced by the Supreme Court's decision in the Eve case. That decision embraced all the arguments made before the Court by Counsel for the Consumer Advisory Committee (CAC) to the Board of the Canadian Association for Community Living (CACL). It was the Consumer Advisory Committee, consisting solely of people identified as having developmental handicaps, which sought and was granted status as an intervener in the case. The Board of CACL, when challenged to define its position on sterilization (as a prerequisite to possible intervention in the case) had been constrained by conflicts of opinion and interest and unable to state its position clearly. Although CACL ultimately endorsed the position expressed so convincingly by members of the Consumer Advisory Committee, without their leadership there might never have been an Eve decision as we now know it. That same clarity of direction and unity of purpose has been evident as people who have lived with the labels we have attached to them have struggled for more than half a decade to convince the Association that it must change its name to one that reflects its beliefs rather than the label and that not to do so was to contribute further to the social handicaps that people with developmental disabilities were trying to overcome. Although successful at national and provincial levels, that struggle still continues in some local associations. It is not easy for parents, family members and professional care-givers to discard assumptions that they know what is in the best interests of people with developmental handicaps. Learning to listen to those on whose behalf one had organized, although a slow and sometimes painful process, is also one of growth and understanding for all who participate. It is a process that informs the present deliberations on guardianship.

In discussion on March 8 with members of OACL's Task Force, Mr. Starkman said that he wanted to see guardianship redefined. He expressed his concern about the current perception of guardianship as something that is "bad" that should be used only as a last resort. He said he was of the opinion that guardianship is "good" and that since there is general agreement that the Mental Incompetency Act must be repealed we now have the opportunity in Ontario to make guardianship into anything we want it to be. As Mr. Starkman noted, none of the issues raised by mental incompetency and guardianship are black and white, they are, in fact, all grey. It is questionable whether a concept that has been understood in a particular black and white way for more than six hundred years can have its meaning changed whilst retaining the same name. The more important question, however, centres on how to serve the noble purposes of guardianship in the most supportive and least restrictive manner without discrimination. OACL welcomes the opportunity to share in reshaping the concept.

From its very beginnings, no matter whether held by the King or, as it has evolved, by appointees of the court, guardianship's essential characteristic has been that it removes rights and choices from one person and vests them in another person who is expected to have the other's interest at heart. In an earlier era that concept was understood to be "good". Today, OACL believes that guardianship can be "good" only if it has neither the effect nor the appearance of removing rights that would typically accrue to a person on reaching the age of majority. In a democratic society such as we believe ours to be, the essence of our rights and freedoms is that, subject only to reasonable and justifiable limits, they attach to us by reason of our being. That they are vested in each one of us is not predicated on our exercise of them. We retain our freedom of speech, for example, even when we choose not to speak out; it is curtailed only if we abuse it by slander, libel, messages of hatred, etc. To be unable to speak by reason of disability, however, is not justifiable reason

for removal of the right to do so. That our rights and freedoms are so inviolate contributes to our social status as citizens of equal value and to our image as whole persons of inherent dignity and worth. No concept of guardianship that is or would appear to be detrimental to that social status is acceptable to OACL. Similarly, any concept of guardianship which would require that a person be defined as mentally incompetent, mentally incapable or any other description that adds a demeaning label to that person would, in OACL's opinion, contribute further to the handicaps of people so identified and could not be supported by OACL.

That being so, the question of whose interests are served by guardianship becomes crucial. Guardianship is "bad" if implemented for any reason other than that of clear and unequivocal benefit for the vulnerable individual. The present Mental Incompetency Act which provides for an application for a declaration of mental incompetency to be made by a creditor, illustrates the fact that the interests of the subject of the application have not been paramount. Perhaps it is the emphasis on guardianship as a process to provide for substitute decision-making that opens its motivation to question. Guardianship that serves primarily to provide the protection of legally valid consent to contracts with a third party is arguably not "good" guardianship. Would it not be more appropriate to look at why and in what circumstances legally valid decisions (informed consent) on behalf of the vulnerable individual are necessary and to what extent that need could be addressed by qualifying the requirements of other pieces of legislation? It is a fact that for many, perhaps most, people who at no time in their lives could have been found to be legally competent by today's standards, such occasions rarely arise. When they do, as for example with respect to medical consent, it is surely not beyond the bounds of possibility that the same laws that provide protection in the case of life saving emergency treatment could be adapted to ensure treatment in the absence of informed consent and the presence of any medically indicated intervention. To institute a process to declare a person to be mentally incapable of consenting in order to provide a guardian (partial or plenary, public or private) to give the consent must not be the only option.

The prevailing belief that temporary guardianship or partial guardianship offers a less restrictive alternative owes more to appearance than fact. Although each presents itself as less intrusive than plenary guardianship, each in effect tends to be total within its respective area of relevance or period of time. That will continue to be so as long as guardianship itself maintains its traditional meaning. Had there been provision for partial guardianship at the time, the probability is that it would have been granted to Justin Clark's parents by a Judge sympathetic not only to their concerns for their son's well-being but also to the evidence of his extreme dependency and his consequent vulnerability and the implication that only a "total care" facility could provide the necessary safeguards and security.

In the presence of legislated safeguards such as mandatory reviews or absolute time-limits, orders for forms of limited guardianship assume a relatively benign appearance - "after all, it's only for a couple of years" are words that can make a solution appear less restrictive. But if new guardianship legislation is to be practical and implementable and well-used as a consequence as Mr. Starkman suggests that it must be, one can readily envisage jurisdictional and administrative pressures stretching periods between mandatory review of guardianship orders considerably, over time. The mandatory review period under the Alberta Dependent Adults Act was, originally, two years. Today, less than thirteen years later, it stands at 6 years, raising some obvious questions. First, how long will it be before "partial" becomes "permanent", or "mandatory" becomes "should circumstances so dictate"? More significantly, any procedure or modifications to procedures designed to accommodate administrative convenience must be questioned. If such a modification has the effect of making the guardianship more restrictive or reducing the built-in safeguards, it is clearly "bad" guardianship legislation. No interests or benefits other than those of the vulnerable person must be served by such legislation.

Most significantly, perhaps, any fair and thorough process to determine the need for temporary or partial guardianship will serve also to signal the apparent need for longer term response in some cases. Whereas OACL would say the signal is to the presence of vulnerability and the need for support to be provided in the

is that played by parents of minor children yet there one can find illustrations of situations in which conflict of interest may have played its part in decisions. The authority of parents as guardians has caused the death by starvation to some infants with Down Syndrome and digestive tract blockages or other complicating impairments: without parental consent the usual and necessary surgery has not taken place. Prior to the moratorium in Ontario parental authority has resulted in sterilization of minors identified as having developmental disabilities. Parents have been known to have obtained legal guardianship with the ultimate purpose of making the same decision for daughters over the age of majority not only for purposes of prevention of conception but sometimes for personal care reasons. In Ontario's institutions there are hundreds of residents who have not only spent most of a lifetime but who remain there on the initial authority of parents as guardians. In Justin Clark's case, although there was no testimony to the fact, the clear inference was that guardianship was sought in order to ensure that he remained within the safe and protective walls of the institution.

People whose lives are dominated by services whether in an institutional setting or elsewhere need advocates. Although there is an expectation that guardianship would provide for such a function, without clear limits on the authority of guardians there is no guarantee. It cannot even be assumed that legal guardianship means close and continued contact with a ward to ensure that the ward's best interests are served. One might expect that legally appointed guardianship of a person in an institutional setting - or any residential service - would at least guarantee contact and consultation prior to any programme change, behavioural intervention, medical or research procedure, but such is not necessarily the case. It is common for legally appointed guardians and natural parents to give blanket authorization to the facility administration to carry out any programme or care deemed to be necessary. When Dr. Ruth Wiens was found guilty of assault after conducting and allowing her students to conduct unauthorized rectal examinations of adolescent residents of Ongwanada in Kingston, the administration suggested that all that would be required in future would be authorization from parents and guardians, yet the procedure was clearly not in the interests of the residents and was to the benefit only of the medical faculty and the students who were being trained in the procedure. Researchers have expressed in public their concern that they have no access to "citizens of the world" in institutions to carry out research on the relationship between Alzheimer's disease and Down syndrome since such people are "mental incompetents not so found" who do not have guardians to authorize research procedures. Although such research can be argued to be for the greater good the actual benefit to the individuals themselves is questionable, at least. The important point is that decisions to participate in any such research are personal. Participation can be at some inconvenience - regular and thorough medical examinations which of themselves are intrusive and which might continue for life. Unless clear benefit and total absence of harm to the individual can be proven such consent should not be within the legal authority of another person to give. With all due respect to the Public Guardian, such matters are not the kind that most people would want a government appointed official or any other person to make for them.

Such examples alone are sufficient to justify the limitations on guardianship authority that would be in place under the recommendations of the Fram Report. OACL would add that it should never be within the power of a Guardian (substitute decision-maker) to delegate blanket authorization for unspecified treatment, research, training and care to the administration of any facility or service. Nor should it be within the power of a substitute decision-maker to authorize admission of a person identified as having developmental disabilities to an institution without a court order. No such order should ever be made in the absence of representation on behalf of the subject of the order. In this context an institution is defined as a Schedule I or Schedule II facility, chronic-care facility, nursing home or home for the aged.

Representatives of People First in Ontario and the National Self-Advocacy Project have expressed their beliefs about these concerns to the OACL Task Force in the statement that "no-one should have the authority to make decisions for others that they would not be prepared to make for themselves".

Can Guardianship be redefined to support rather than limit freedom?

The belief that guardianship should be redefined is not new. In 1968, the International League of Societies for Persons with Mental Handicap talked of "mentorship" to indicate the role of wise counselor rather than controller of a person. Michael Kindred (1976) talked of "facilitative guardianship" which would have the function of assisting a person to achieve his or her own goals rather than a function in which the decisions of a guardian could be substituted for those of a ward. David Vickers described a kind of guardianship that does not seek to control decisions or be paternalistic but seeks to understand and protect where protection is necessary. Paul McLaughlin (1979), concerned about traditional "legalistic" guardianship models, suggested professional guardians, more extensive social supports, more advocacy mechanisms and a clear philosophical base of normalization underlying human service delivery. The need to think of guardianship in a social relations context rather than a legalistic one is the considered conclusion of the Centre for Research and Education in Human Services (1988). This is the context in which OACL sees the possibility of solutions.

Great emphasis is placed on improved services and supports in these considerations of a different kind of guardianship. Experience shows that the more supported one is the less need there is for legal guardianship. It is significant that a major finding in the Hamilton Guardianship Project (Webster, 1972), the pre-cursor of the Adult Protective Service Worker programme in Ontario, was that many requests for guardianship literally resolved themselves and were no longer pursued when alternative supports and services were made available. Similar observations were made elsewhere by Kindred in his study.

In examining the legalistic model, Paul McLaughlin notes that it looks at guardianship "with some alarm and attempts to restrict its use as much as possible" (McLaughlin, p. 79). That same sense of alarm is evident in the recommendations of the Fram Committee in which guardianship is seen as something to be avoided at all cost since once the point at which it is unavoidable is reached all freedom is removed in order that protection can be provided. By inference and in somewhat contradictory fashion, guardianship - restrictive as it is in the traditional sense - becomes the least restrictive alternative once it is seen as inevitable, that is once the person is found to be mentally incapable. As long as guardianship means what it has meant in the past, OACL shares this sense of alarm but to an even greater extent than Fram. That is because OACL fears that in the desire to create a summary, inexpensive, non-judicial process for uncontested guardianship the Fram Committee is suggesting a process that could quickly become a form of "express check-out". OACL is concerned that for some people the process will become a first resort. Adding weight to this fear are statements made recently (April 13/89) at a public forum on Guardianship in Kingston, Ontario. There, a representative of the Policy Division of the Ministry of Community and Social Services stated that in anticipation of new legislation such as is proposed by Fram, the Ministry will be looking at the residents in its facilities to determine who will need guardianship and in what order of priority. At the same forum in answer to a question from the floor about the complications of a process whereby temporary guardianship might have to be sought each time a person with profound handicaps required hospital treatment, Hugh Paisley, Public Trustee for Ontario, said it was important to operate on a practical level: his office already acted as guardian for many such people with respect to financial affairs and they would "all require guardianship and it will be permanent". He said the need would be identified at the outset so a separate process would not be necessary each time there was a requirement for consent. These statements again raise the question of whose interest and benefit guardianship legislation is designed to satisfy. In view of them it would seem that the convenience of the administration and the service system would be well-served. But if the definition of guardianship remains the same, it is hard to imagine how the new proposed legislation will be an improvement over the old legislation for those who can never be found to be mentally capable.

OACL is not denying that there are people who have intellectual impairments so severe as to always require that decisions are made on their behalf. There are people who are not able to comprehend the consequences of choices or decisions, that decisions are necessary or even what decisions are. What we are learning, slowly

but surely, is that there are fewer such people than we used to believe and that there are many ways in which choices, preferences and even decisions can be expressed, indicated and understood. Few of these ways would meet the requirements of legal definitions of informed consent as we have previously understood it. Typically, if our authority and capacity to make informed decisions is not challenged, we rarely analyze the processes by which they are made. It is a fact, nevertheless, that most people use whatever resources they feel they need to use in reaching decisions. Some decisions are reached solely on the basis of one's own resources, some necessitate a search for additional information, some are made with the help, influence or support of others to one degree or another. Because most people initiate their own search for whatever resources they require in reaching a decision they are rarely called upon to account for how the decision has been made. OACL believes that given the necessary support all people irrespective of disability can participate to indefinable degrees in the decision-making process. OACL would take the principles underlying the Fram recommendations on presumption of capacity and carry them through into new and different levels and kinds of decision-making that will validate the process not just the product.

It is essential that the law be made to recognize different levels of "informed consent". Kindred (1976) notes that there are examples of court orders which recognize lesser levels of intellectual participation than is implied by informed consent. Although discussing sterilization consent specifically, he refers to the level of "a clear desire" included as valid consent in one court order. But even such a level as "clear desire" will have as many modes of expression as there are people. People who have extremely limited intellectual skills may well be expressing a "clear desire" not to be living where they have been placed by the decisions of others or not to be doing what others have decided they should be doing, by display of what tends to get identified as inappropriate behaviour. Would that we could conjure up an image of Ministry officials spending time with those who are in their care and getting to know them well enough to be able to determine how each one expresses wishes, dislikes, preferences and "clear desire". But no, the image and the reality is that the proposed identification by the Ministry of who will need guardianship and in what order of priority is based solidly on the assumption that guardianship and substitute decision making is what is needed for people who are mentally incompetent and that those are the people who would be "mentally incapable" under proposed changes in the law. This is guardianship as a first resort. Identification of those people in the Ministry's care who will "need" guardianship will be made by either a perusal of the clinical records of residents or by a new round of cognitive assessments or both. Influencing the identification will be information about who is already receiving (and therefore presumed to be in need of) tranquilizing medication, restraints, behaviour modification, or Depo Provera, all of which speak more to traditional "care, supervision and control" and administrative convenience than to the more noble guardianship purposes of protection and support for a vulnerable person.

Learning to listen to the person who cannot speak or communicate by typical means is something we have to do better if we are to avoid discrimination in guardianship legislation. A cognitive assessment that determines mental incapacity by traditional standards contributes nothing to that learning process, it simply reinforces the barriers to understanding, many of which are ingrained and attitudinal in nature.

OACL believes that we can and must redefine guardianship in terms of a more co-operative, facilitative function that requires a sharing rather than a paternalistic relationship. It must provide a mechanism for reinforcing and legitimizing decisions made preferably by and clearly in the interest and to the benefit only of the vulnerable partner in the relationship rather than providing a mechanism that allows for the decisions of the guardian to be substituted for what could be the wishes of the vulnerable partner were he or she able to express them in a legally acceptable manner. Guardianship must encompass and give validation to the many dimensions of the decision-making process and above all it must reflect the obligation of the guardian and of the state to respect and support the need and the right of the vulnerable person to be presumed to be the owner of his or her own decisions. Not only will such redefinition require imaginative approaches to legislative change, it will require clear safeguards against abuse, issues that can be identified in the context of discussion on the remaining question.

Can freedom offer protection and if so, how?

Members of the movement of which OACL is a part, have learned much in the past two decades about the importance of image and social status to the self respect and well-being of people identified as having developmental disabilities. The membership has been taught that amongst the most damaging of handicaps placed on people with disabilities are those that stem not from the impairment itself but from the beliefs and attitudes of others and from the reluctance of society to make reasonable accommodation and provision of appropriate supports to compensate for the impairment. The membership is also being taught that it can not, itself, plead innocent to charges of contributing to these handicaps. It is learning more each day about how people can and should be supported to enhance their status and their participation in community life. Most importantly, it is learning that fundamental to any lasting change in societal outcomes for people with disabilities is the necessity for each one of us to examine how we think about and how we relate to those amongst us to whom we have in the past attached labels for legal, medical and social convenience.

The Justin Clark case provides lessons in this respect, also. One of the difficulties in using his experience to illustrate issues relating to guardianship is that Justin Clark is not incompetent and was found not to be so through due process. It can therefore be argued that the case is not a good example to use in relation to people who might not be competent and who could not testify on their own behalf as Justin Clark did. Nevertheless, expert medical and psychological evidence purporting to prove without doubt that he was mentally incompetent was presented at the trial by eminent professionals in the field of developmental disability. Had Justin Clark, himself, not challenged that evidence thus forcing the matter into open court, it would probably have been sufficient to ensure Committeeship. Because that evidence focused on his extreme dependence and vulnerability, his lack of knowledge and experience and his I.Q. level which had been determined by tests the validity of which could only be challenged by alternative tests and cross examination, it is unlikely that legislation providing for partial guardianship would have ensured that he got out of the safety of a total care environment such as the institution was believed to provide.

But he was able to challenge the evidence. What the witnesses called by his counsel were able to do very clearly was to question the validity of clinically defined mental incompetency and bring the whole issue into the broader social context of how people live and function and relate to each other in the real world. Specifically, they made the court focus on how Justin Clark could live and wanted to live and on the value and strength of his relationship with his personal friends and others who had taken the trouble to get to know him. In the process, the whole issue of relevancy was brought in the open: Why is mental incompetency an issue, when is it an issue and how important an issue is it? One thing the case did not succeed in doing was to help people to understand what mental incompetency is although it did provide a better understanding of what it is not.

The issue goes beyond the black/white, competency/incompetency argument however. Probably the single most important lesson to be learned from Justin Clark's experience is that no one who knew him, not his friends, his counselors, his teachers, his social workers, his lawyer, had considered him to be mentally incompetent. Although the law allows for anyone with supporting evidence to make application for an order declaring mental incompetency it is inconceivable that anyone knowing him would have done that. It was not that his dependence and need for care and protection was not understood, his very life depended on that. It just would not have been an option for his friends and when it was suggested it just did not make sense to them.

The way we relate to a person, the kinds of things we do together, reveal what we believe about each other and how much we know and understand each other. It is interesting that whereas it is the very aspect of knowing a person well that leads to applications and subsequent findings of mental incompetency in the case of frail, elderly family members and gives guardianship its aura of benevolence, no-one who knew Justin Clark well would have considered it a benevolent thing to do to him. Mental incompetency, like "mental

retardation" might be said to exist mainly in the eyes of the beholder.

Most of our security in life comes from belonging and in that sense security is no more one-dimensional for a person with developmental disabilities, however severe and complex they are, than it is for any other person. Security comes from being valued and knowing that no-one is going to question our right to be treated as an equal. It comes from knowing that society would not tolerate the denial or the questioning of our right to live in the home of our choice on the street of our choice with the people of our choice. It comes from the natural gravitation around us of people who care about us and about whom we care, initially, people amongst whom we belong in the natural family context. It comes from a wider circle of people with whom we go to school, to work and to play and with whom we eventually find ourselves participating in some manner and to one degree or another in the life of our chosen community. And it comes from the many supports we provide ourselves with in those communities and to which we assume access by right of citizenship.

It is a fact, however, that we live in a society that has a history of removing those natural support systems from people identified as having developmental disabilities and replacing them with specialized service systems that have served primarily to label and to isolate. It is difficult for anyone whose life is not dominated by such service systems to understand the power and control they have over individuals and families, and to understand the intimidation they engender. OACL believes that people whose lives are controlled by services need advocates to help them to break out of the segregated environments in which institutionalized thinking has placed them. Some of that advocacy can be provided naturally but much of it will have to be provided by an organized, mandated system (see Appendix I for Statement of Principles, Ontario Advocacy Coalition). By supporting people who are identified as having developmental disabilities to live in more typical fashion, to get to know and to be known by others, to be recognized as members of the community and to be accepted, the more can their capacity for self-determination be enhanced and the less will guardianship be seen as the only option for their security. Protection and security lie in the freedom to belong.

Section 5 — New Approaches to Security & Protection:

Conclusions & Recommendations

OACL has participated in the deliberations which have produced the recommendations of the Fram and O'Sullivan Reports and the issues and concerns addressed in the Manson Report. The more recent opportunity to study these Reports together has now enabled OACL to make a more cohesive assessment of Advocacy and Guardianship as they relate to people identified as having developmental handicaps.

In our discussions on March 8, Mr. Starkman acknowledged that he would like guardianship to be a legal recognition of what people ordinarily do when a person has significant disabilities with consequent limitations on decision-making capacity. As far as OACL can ascertain, the truth appears to be that when such a person is living at home within a family setting, legal guardianship is not an ever present issue. It is a fact that many parents do not even realize that they are not the legal guardians of an adult son or daughter for whom they have maintained care and responsibility. If one has had to make decisions for someone throughout his or her lifetime, there is a natural tendency to assume that the responsibility to do so continues as long as is necessary. In such cases the issue of legal guardianship arises only in the context of the age old question of "what will happen when we are no longer here?" It is during the search for answers to that question that such families learn of the distinctions between matters of the estate and of the person and that it is not simply a matter of passing on responsibility to the next generation.

Guardianship also becomes an issue when the interests, benefits or protection of others take precedence over those of the individual as discussed in Section 4. However, whereas there have been instances where medical treatment has been denied in the absence of a legal substitute decision maker, recent random enquiries by members of OACL's Task Force suggest that, for the most part, the signature of a close family member is usually accepted as authority for treatment that is clearly for the benefit of a person unable to give consent. There are some suggestions, however, that doctors are becoming more reluctant to accept such unofficial substitute consent, probably because of increasing concern about the possibility of malpractice litigation. Similar random enquiries of people providing care in both institutional and community settings produced similar responses with the additional information that although signatures by staff members have usually been accepted, the preference of medical practitioners is for the signature of an immediate family member. OACL does not suggest that these random enquiries constitute anything other than an informal attempt to find out "what people ordinarily do" in these circumstances. It is OACL's belief, as discussed in previous sections, that a process to institute guardianship in order to legitimize consent is inappropriate and that the issue of protection from liability to a third party such as is the case with consent for such necessary medical procedures must be addressed by other means.

Guardianship has been recommended also by some legal advocates in recent years as a process whereby parents could control decisions about alternative placements for a son or daughter when a long term care facility has been closed. The suggestion surfaced on a number of occasions during the period of the Ontario government's "Five-Year Plan" which closed certain institutions for people with developmental handicaps. By means of legal guardianship some parents were able to determine the alternative placement for adult sons or daughters, decisions which might otherwise have been made by the facility deinstitutionalization programme. It is not known how many parents took advantage of these suggestions nor whether the consequence was an alternative institutional placement or a placement in the community for the people concerned. Clearly, under the traditional meaning of guardianship and the Mental Incompetency Act, there could be no real guarantee that the wishes of the parent, rather than the most beneficial and least restrictive alternative for the resident of the facility, would not prevail. Only a mandated advocacy system could have ensured that such decisions were made solely in the interests and to the benefit of the residents in question and that the principle of least restrictive alternative would determine placement.

Mr. Starkman also discussed concepts of shared decision making with members of OACL's Task Force. Specifically, he described a process whereby a person whose capacity for decision-making was diminishing or was likely to diminish would be paired with a co-decision maker, the function of the latter representing the equivalent of that of a present-day guardian. As the capacity of one partner diminished so would the responsibility of the other increase with respect to the proportion of the decision making process to be assumed. Such a concept is totally in keeping with the continuing powers of attorney for personal care suggested by the Fram Committee. Members of the Task Force suggested that the same concept could apply even when the more vulnerable of the partners had such limitations on capacity as to be unable to designate the attorney in a manner that would meet present understanding of legal validity. The fact is that experience indicates that the capacity of a person with an extremely disabling condition for decision-making or indicating preference is more likely to increase than diminish. The more one knows such a person and the more challenged and supported that person is, the more "competent" that person becomes and the more able the partner is to understand what preferences are being expressed. Presumption of capacity is not simply a legal concept. It also has significant developmental and social implications.

There is consensus that the Mental Incompetency Act no longer serves the people of Ontario well: it is no longer considered to be "good" guardianship legislation. Consequently the impetus has been towards designing "better" guardianship legislation. Sensibility to rights and autonomy demands that any legislative changes be based on the principle of the least restrictive alternative. Because guardianship, as we know it from the past, has been an extremely intrusive and restrictive means of providing protection for certain vulnerable people, recommendations have tended to focus on partial or temporary alternatives to plenary guardianship. Whilst admittedly "better" than plenary guardianship, these alternatives remain legalistic in approach and total in effect, at least with regard to their respective areas or periods of time.

OACL believes that the principle of the least restrictive alternative must be carried beyond its legal context into the broad social relations context in which we all exist. Only by doing so can we understand what protection and security mean on a day-to-day basis, what role guardianship could or should play in ensuring that the benefits of security and protection are shared by vulnerable people without discrimination, and how guardianship could be redefined to ensure that the life and the image of the vulnerable person is enhanced by the resulting relationship, should guardianship be the only possible way to serve the vulnerable person's needs.

Admittedly, guardianship, preferably redefined, might act as a safeguard in some critical situations but the crucial issue for OACL is that better guardianship legislation will not necessarily improve the quality of life for people identified as having developmental handicaps. OACL believes that, for the most part, the rights to self-determination and autonomy and to living in the least restrictive environment and the assurance that decisions that must be made by others are solely for the benefit of the vulnerable person, are best protected through the efforts of caring parents, friends and advocates, the latter both paid and unpaid.

The strongest safeguards against the hazards of extreme vulnerability are those that arise from the sharing of natural supportive relationships in a spirit of equality within the broader community. Although his disabilities are primarily physical in nature, Justin Clark again provides an illustration. His opportunity to be free to allow such relationships to develop and to call on the community to be responsive to his considerable needs has resulted not only in the blossoming of his own life and self, but also in the development of a more sensitive community to which he now contributes fully. In the process, the community has enhanced its own capacity to include and to protect all vulnerable people.

Justin Clark's experience also raises another matter. It cannot always be assumed that the natural support nucleus is that of the family. Caring and concerned about his welfare as his parents may have been, they did not know him well and they had not had any day-to-day involvement in his life and care for many years. Justin Clark and his family are not alone in that respect. There are many people who at some point in their

lives have been identified as having developmental handicaps and who, like Justin Clark and his family, are victims of systems that have helped to destroy natural supportive relationships. It must be recognized also that not only do some people have no immediate family support but also that families have no natural immunity to making bad decisions. It is probable that the most vulnerable of all people are those whose personal support networks produce bad decisions that are not for the benefit of the vulnerable person. It is essential, therefore, that a mandated advocacy system be in place to act to the vulnerable person's benefit where such action is necessary, to advocate directly on behalf of individuals for whom no personal supports exist at present or where that personal network is not acting for the benefit of the vulnerable person; to provide a back-up support to personal networks where they do exist, and to support and enhance the development of personal support networks for all vulnerable people. This concept of a mandated advocacy system formed the basis of OACL's submission to the O'Sullivan Review. (See Appendix II.) The attached Statement of Principles of the Ontario Advocacy Coalition (Appendix I) reflect OACL's position.

Ideally, each one of us is surrounded by networks of social support upon which we can call at any time. Because we have gone to our neighbourhood schools and worked and played in and around our own communities, our social networks have developed naturally from amongst our families, our fellow students, co-workers, fellow members of our respective congregations and the community at large. It is inherent in OACL's Goal (See Section 2) that that vision become reality and people identified as having developmental disabilities enjoy those same opportunities to share and to belong, to have control over their lives, to participate and to have that participation respected, and to enjoy relationships that have meaning to them.

OACL is committed to planning its own strategies and activities in ways that will ensure that the outcomes for people with disabilities are as dignified and respected as every one of us would want for ourselves. It is OACL's belief and intention that people identified as having developmental disabilities take their rightful place as equal and respected members of their respective communities (CACL, 1987; OACL, 1988).

Even as OACL accepts the challenges that such beliefs and intentions imply, it recognizes that it cannot succeed alone. Not everyone shares OACL's Goal. There are interests and systems that do not yet accept the nevertheless demonstrable capacity of people with disabilities to assert their freedom and rights alone or with varying degrees of support. There are interests and systems for whom it will be difficult to accept that people with developmental handicaps can or even should make decisions on their own or even with help. It is for reasons such as these, and in particular for the reason of clear benefit and protection for people who are vulnerable because of developmental disability, that OACL believes that a mandated system of advocacy must be in place before any changes to legislation relating to guardianship and substitute decision making come into effect in Ontario. Only a provincial mandate can guarantee an advocacy system with the necessary authority to ensure that guardianship will never be used as a process of convenience for others and particularly not for that of any system including the system of government. Only a mandate requiring that the advocacy system be accountable to those it is designed to serve will provide sufficient authority to ensure that it act as a safeguard against the use of guardianship or any form of substitute decision making legislation to meet administrative, third party or any needs other than those of the vulnerable person. It is OACL's belief that such a system is an essential component of Ontario's broader system of support for people who are vulnerable and that without it, processes designed with protection in mind might well increase vulnerability. People who are able to take some control over their own lives must be given the necessary support to enable them to do so. People who require more consistent and longer term assistance to ensure that decisions affecting them are made only with their benefit in mind must have their ownership of those decisions protected no matter how the decisions are made. Only a system that includes a combination of self-advocacy, advocacy by the natural support system which could include Citizen Advocacy and paid advocacy such as can be provided, for example, by APSW's or by others mandated to exercise it without conflict, can ensure that the various needs of vulnerable adults in the decision making process can be met. All of these advocacy roles are complementary and none can fill the needs alone. Each one represents significant contribution to the security and protection of those whose disabilities place them daily at risk.

My book

- Opening Chapter (BOACI Seminar Series)
- People w/ disabilities, Human Rights & the Impact of ^{new} ~~new~~ ^{technology}
Personal Perspectives as a Partner of a person
with Down Syndrome - Andrew Cole
- Until death do us part - Andrew Cole
- Increasing vulnerability & Invalid Assumptions
about Disability and Incapacity - ADC.
- Seventeen then and now - ADC June 2012

1. The first part of the document is a list of names.

2. The second part is a list of dates.

3. The third part is a list of locations.

4. The fourth part is a list of events.

5. The fifth part is a list of people.

6. The sixth part is a list of organizations.

7. The seventh part is a list of activities.

8. The eighth part is a list of resources.

Vulnerable people deserve no less than such a system to support them in their struggle for recognition as equal members in their own right of Ontario society.

Consistent with its belief that protection and security can be most properly and effectively ensured by extending the principle of the least restrictive alternative into the broad social relations context in which we live, OACL recommends:

1. That any legislative changes relating to protection and substitute decision-making honour the personal supportive networks within which the wishes and preferences of a vulnerable person are most likely to be determined with the most possible accuracy.
2. That an independent, funded advocacy system designed to support, strengthen, develop and, if necessary, substitute for such a natural system be established according to the Principles of the Ontario Advocacy Coalition (Appendix II).
3. That the principle of the least restrictive alternative underlie any legislative change and accordingly require that avenues of personal support and mandated advocacy take precedence over the establishment of guardianship, however defined.
4. That guardianship be defined as a co-operative, facilitative function, wherein the guardian shares responsibility for decisions that are made only for the benefit of the vulnerable person, rather than controlling or substituting for such decisions.
5. That no form of guardianship or shared decision-making function be used to provide consent for:
 - 5.1 confinement as aversive conditioning; (Fram p.163)
 - 5.2 restraint as aversive conditioning; (Fram p.163)
 - 5.3 electric shock as aversive conditioning; (Fram p.163)
 - 5.4 any medical/psychiatric or psychological service where the intended effect is not therapeutic; (Fram p.163)
 - 5.5 any blanket authorization for unspecified treatment, training, research or care;
 - 5.6 admission of a person with developmental disabilities to a Schedule I or II institution, chronic care facility, nursing home or home for the aged except by an order of the court after a hearing at which the vulnerable person is independently represented.
6. That the use of any guardianship procedure as a means of providing consent for medical procedures that are clearly for the benefit of the vulnerable person, and would be performed were the person able to consent be prohibited and that any and all third party interests such as protection from liability be addressed by other legislated means.
7. That whereas extreme vulnerability may in some circumstances call for guardianship procedures, no such procedure be allowed to add labels to a person which could be detrimental to the social status and image of that person.
8. That no guardianship procedure have the effect or the appearance of removing rights and freedoms from a person and that the capacity of a person to exercise such rights and freedoms not be a consideration, and any such person be presumed to be the owner of his or her own decisions.

9. That lesser levels of consent such as "clear desire" however expressed, be recognized as valid "consent".
10. That clinical assessments of competence be replaced by processes that expose vulnerability and that response be in terms of support rather than guardianship in the first resort.

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APPENDIX I

ONTARIO ADVOCACY COALITION

STATEMENT OF PRINCIPLES

It is the position of the Ontario Advocacy Coalition that the Government of Ontario must take immediate action to establish an independent, fully funded, advocacy system for vulnerable people in this province.

It is also our position that this system must be operational prior to the introduction of substitute decision making legislation.

Failure to introduce an advocacy system before legislation on substitute decision making would, in our view, lead to abuse of the process and further abrogation of the rights of vulnerable people.

The Government of Ontario has an obligation to designate the financial and human resources required to establish a system which would support the progressive legislative and policy initiatives of recent years. An unwillingness to do so will leave thousands of vulnerable people stranded on the fringes of a society which claims to be progressive while it relegates them to second or third class status.

The Coalition has adopted the following Principles as basic to an effective advocacy system:

A) PHILOSOPHICAL PRINCIPLES:

The Advocacy system must:

1. Promote and support, as its first priority, the concept of self-advocacy.
2. Recruit and support volunteer advocates, and encourage the efforts of volunteer advocacy organizations.
3. Have strong individual and systemic advocacy components.
4. Use client-directed or client-centred, rather than an imposed best interest approach.
5. Ensure access to advocates by those who need them, and avoid the denial of assistance through the use of stigmatizing labels and criteria.
6. Ensure that communication between an individual and the advocate is privileged.
7. Ensure the vigorous pursuit of the wishes of an individual, including an adversarial approach if other approaches have not been effective.
8. Require that advocates act on behalf of individuals or their designate rather than the state.

B. OPERATIONAL PRINCIPLES:

The Advocacy system must:

1. Function at arm's length from government.
2. Be fully funded through a provincial advocacy commission.
3. Have a provincial commission chosen from a list of names submitted by consumer advocacy organizations.
4. Have a provincial advocacy commission comprised of a majority of consumer representatives.
5. Have a core complement of carefully screened, paid professional advocates.
6. Ensure an individual and/or his/her advocate, the right of access to relevant records. Informed consent must be obtained from the individual or their designate.
7. Have an in-house means of obtaining legal advice where required.
8. Have an effective community development component which would enable the system to assist in the development of local advocacy initiatives, and respond to requests for assistance from local communities.
9. Have professional and volunteer advocates.
10. Encompass the existing Psychiatric Patient Advocate Office.
11. Have a legislated mandate.
12. Report to a Standing Committee of the Legislature. It is felt that the most appropriate jurisdictional responsibility in Cabinet would be through the Attorney General, not the Ministries of Health or Community and Social Services; however, caution is required on this point since the Attorney General is also likely to hold responsibility for the substitute decision-making system.

APPENDIX II

A D V O C A C Y

**Supporting the Rights, Autonomy and Dignity
of the Individual**

**A Submission to the Review of Advocacy for
Vulnerable Adults
April 1987**

**Ontario Association for Community Living
180 Duncan Mill Road, Ste. 600**

**Don Mills, Ontario
M3B 1Z6**

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I. INTRODUCTION:

The Ontario Association for Community Living is a federation of 121 local associations with a membership of 14,000 persons. OACL represents some 90,000 people with developmental handicaps throughout the Province.

OACL has had a long-time interest in advocacy and guardianship issues, participating over the last several years on the Advisory Committee on Substitute Decision-making for Mentally Incapable Persons, and has been a leading force in supporting the development of forms of voluntary advocacy including parent advocacy, citizen advocacy, and self-advocacy (see Appendix A).

II. ADVOCACY: WHAT AND WHY?

Advocacy is the act of speaking for or on behalf of someone or something. Advocacy is important in all our lives but for persons who are unable to effectively represent themselves without support it is particularly important to have other forms of representation to enhance the individual's own efforts.

There are several reasons for this:

1. People with developmental handicaps are not always able to articulate wants and needs through a typical communication system;
2. They are frequently dependent on a complex, fragmented, and often unresponsive service system;
3. Human service systems have tended to cut people off from their natural networks and thus exacerbated the problem even further;
4. Serious gaps in current human service systems exist. Advocacy functions include: support to deal with problems of access to community supports and services; creating pressure to fill the gaps in services; the protection of rights within service systems; and ensuring individual self-determination and autonomy.

The power of human service and other systems to infringe upon an individual needs to be counterbalanced by an advocacy system to ensure the individual's rights are protected and their needs as individuals are met. Advocacy also functions as a means of dealing with the inherent conflicts in any collective service arrangement, such as institutions or group homes.

Advocacy also functions as a stimulus to systems change.

III. A SYSTEMIC CONTEXT FOR ADVOCACY:

Quality advocacy can improve any system but it can not compensate for a poor system; it is not a panacea for a bad system. Fundamental changes in our system are required in order to make the system more responsive and effective. The most important of these is a reorientation of the system from collective services and programs to a focus on the individual and their specific needs and wants. The central elements of a system based on empowering the individual would include, at a minimum, mechanisms for:

A. INDIVIDUALIZED FUNDING

B. IDENTIFYING INDIVIDUAL NEEDS AND CREATING LINKAGES TO SERVICES (I.E. SERVICE BROKERAGE)

C. BUILDING, STRENGTHENING, AND EMPOWERING PERSONAL SUPPORTS OR NETWORKS

Advocacy is a necessary component of this type of system. Without effective advocacy and personal representation an individualized system becomes an academic alternative for management of funds and programs.

Case Management is often discussed in relation to Advocacy. While the two are strongly linked they are distinct elements of an effective system. Where the two are directly equated, the check of an advocate on the case manager's activity is lost. This can also lead to the case manager usurping the role of voluntary advocates and the exchanging of the control of one component of the system for another. In a brokerage style system the need for an advocate independent of the service broker is crucial to ensure the autonomy and rights of the individuals are protected.

IV. THE ROLE OF A PAID ADVOCACY SCHEMA:

In all cases the ideal advocates are individuals who have a personal bond and commitment to another person and who will support the individual's right to autonomy and self-determination. This personal network is crucial to ensure decisions being taken truly reflect the wishes of the individual. Individuals who cannot articulate their wishes directly through speech or other formal communication systems are often denied their right to self-determination because they lack a personal network empowered and supported to help them interpret their wishes and needs. This lack has usually resulted in the individual's life situation being determined solely by professionals who base their judgments not on the individual's uniqueness, but on the collective perception of the profession regarding a particular class of labelled individuals.

For many people with a mental handicap personal networks have either been stripped away or the natural opportunities for developing and strengthening personal networks have been denied them. Without this personal representation many individuals with developmental handicaps cannot effectively exercise their right to self-determination.

Therefore a primary role of a paid advocacy schema must be to promote, support, and enhance the development of voluntary personal support systems including the provision of resources (monetary and technical) to those groups.

While voluntary groups have attempted to develop citizen advocacy programs, they have not evolved to the extent that many people anticipated in the early 1970's. More recently concepts such as support circles have been developed as another means of fostering personal support networks. To date these have not had wide application. This emphasizes the need for some method of enhancing the development of personal support networks.

A paid advocacy system can also act as a back-up for individuals, their families and friends, and citizen advocates who find they are unable to negotiate effectively through normal channels. The limited development of voluntary forms of advocacy also points to the need for a back-up system when these networks are not in place or as yet undeveloped. Paid advocates have to be available to people who currently do not have existing personal networks or representation. Paid advocacy must not, however, usurp the role of voluntary personal support networks.

In summary then, there are three roles for a paid advocacy scheme:

1. To support and enhance the development of personal support networks;
2. To provide a back-up and support to personal networks where they do exist; and
3. To directly advocate on behalf of individuals for whom no personal supports exist at present.

V. KEY PRINCIPLES:

There already exist several systems to safeguard the rights of individuals and protect them from unreasonable decisions of government. These include the Office of the Ombudsman, the Human Rights Commission, and our legal system itself.

What is not now available is a more personal and flexible form of advocacy, one which is not constrained to breaches of legal or human rights, nor simply reactive to unreasonable decisions of government. By personal and flexible, we mean that such a system could be:

- ongoing, not specifically problem-oriented
- personal and individualized
- broad in focus
- proactive, not reactive
- a means of reducing the need for recourse to more formal systems

VI. INDEPENDENCE:

The primary concern about the organizational structure or context is the need for independence and freedom from conflict of interest. The two primary sources of conflict of interest in the existing system are:

1. If the advocate is an employee of a service delivery agency, his/her ability to function as an advocate will be compromised; or
2. If the advocate is paid by the Ministry who is responsible for funding needed services, his/her ability to advocate will be constrained or inhibited.

Therefore it is reasonable to assume any valid advocacy system must be:

- a) independent of the service delivery system; and
- b) not directly linked to the ministries which fund health and social services.

There is, however, another inherent form of conflict of interest in a paid system of advocacy. That is, advocates representing more than one individual must inevitably make trade-offs as to time and resource allocations, thus bringing the interest of more than one client into conflict. Therefore the goal of the system must be that each person who is at risk has a personal network or one-to-one relationship for support.

Until this goal is achieved, a paid system of advocacy which is independent of service delivery organizations and ministries which fund health and social services can address the first two forms of conflict of interest. The system will, however, still be susceptible to the third. This can be to some extent controlled by maintenance of reasonable limits on the number of people any one advocate can represent at any one time.

VII. MANDATE:

An effective advocacy system requires a clear and strong mandate, empowered by legislation and resources. There are several ingredients which must form the basis of the system's mandate in order to safeguard and enhance the rights of the individual without supplanting these rights.

The relationship between the individual and the advocate is voluntary in nature. The advocate shall only act with the actual or implied consent of the person. Where a legally appointed substitute decision-maker has been named, the advocate may convey the individual's wishes and preferences to the substitute decision-maker. Where there is a conflict between the substitute decisions-maker and the advocate, the advocate would be at liberty to make representation, on the individual's behalf, to the Public Guardian or Trustee. The advocate does not assume the rights of those whom he or she represents. The individual continues to have rights equal to and in accordance with those guaranteed to all citizens.

Finally, in order for advocates to be effective, there must be assured rights of complete and unimpeded access to the individual, and to pertinent records and information. This would of course be at the individual's discretion.

VIII. CONSUMER CONTROL:

Consumer control must be maintained at both the individual level and the organizational level in order to maintain the fundamental integrity of the system and its accountability to the individuals it seeks to serve.

IX. ORGANIZATION:

In order to ensure continuity, effectiveness and minimize conflicts related to funding sources, a provincial advocacy system should be fully funded by the Provincial Government.

In order to minimize conflict of interest inherent in government funding we are proposing that a voluntary, non-profit transfer payment agency be established to fulfill the mandate of the proposed advocacy system. A voluntary transfer payment agency provides initial arms length protection from government.

Recognizing that government is a major service provider and funder of services, yet acknowledging government's need for fiscal accountability, we propose that the advocacy agency not report to a ministry which provides or funds health or social services. Reporting responsibility should be to the Ministry of the Attorney General. The Ministry of the Attorney General is best suited structurally and would give the system a voice in Cabinet.

We propose that a board of directors consisting of a majority of representatives from primary consumer organizations be established. The primary consumer organization representing people with developmental handicaps in Ontario is People First. We suggest that a majority of the board be drawn from primary consumer organizations; the remainder, members at large appointed by the board. Several considerations should guide the nomination of members at large. Firstly, while People First is recognized by the Ontario

Association for Community Living as the primary consumer organization representing people with developmental handicaps, parents have also had a long history of advocating for their sons and daughters. This is particularly important in relation to individuals who have significant needs such as those with multiple handicaps. In recognition of this we recommend that parents of individuals with a mental handicap be given special consideration for "at large" membership.

Secondly, we suggest that the People First representative(s) have the option of having an advisor present at all board meetings. Such an advisor must have access to all information the board is considering in execution of its mandate. This is an essential element for the advisor to be effective.

The board members must meet the following conditions:

1. Representatives of service delivery organizations should not be eligible for membership on the board.
2. Board members must have a demonstrated commitment to the principles and mandate of the organization.
3. Members at large should be initially nominated by the board members representing primary consumer organizations. Subsequently, members at large would be nominated by the board as a whole.

The role of the board of directors includes development of policy to carry out the mandate of the advocacy system. The board will be responsible for overall implementation of the provincial system of advocacy, including hiring senior managers, and ensuring fiscal accountability.

X. ORGANIZATIONAL STRUCTURE AND FUNCTION:

In order to fulfill the mandate of the provincial advocacy system, the following structure is proposed:

A provincial office would be established to:

1. disburse funds to regional offices;
2. ensure adherence by regional and local offices to organizational mandate and principles;
3. provide consultation and expertise to regional offices in the following areas: community development, public education, training and evaluation, and legal services; and
4. conduct policy analysis and lobbying for systems change as identified at the local and regional levels.

Regional offices would be established to:

1. support community advocacy initiatives through the provision of financial and technical resources;
2. foster the development of local advocacy and personal support networks through public education and community development;
3. ensure adherence by community groups receiving financial support to the mandate, principles, and values of the advocacy system;
4. provide direct assistance and advice to promote self-advocacy; and

5. provide individual advocacy services.

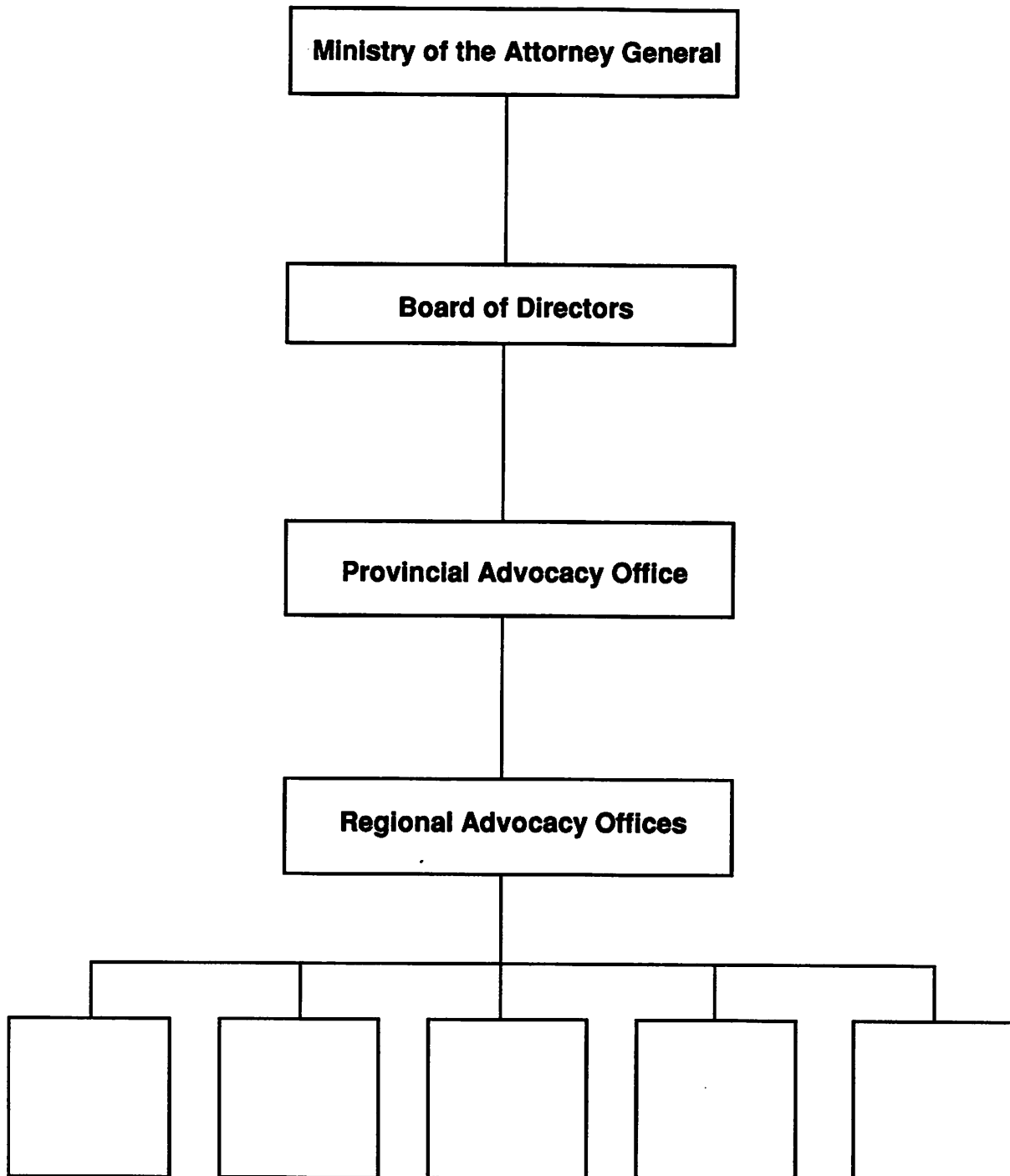
XI. COMMUNITY INITIATIVES:

Community groups receiving financial support from the provincial advocacy body must meet the following conditions:

- A) demonstrated commitment to the mandate, principles, and values of the provincial advocacy body;
- B) have as its exclusive function the provision, promotion, or enhancement of advocacy and/or personal support; and
- C) must be a voluntary, non-profit organization with a board elected from the membership.

Financial support should not be limited to groups providing direct advocacy services but also should be available to groups supporting the development or enhancement of personal support networks such as support circles, family support groups, or Citizen Advocacy. This is essential to represent the diversity of individuals within communities and their need for personal support to enhance their participation in society.

STRUCTURE OF A PROVINCIAL ADVOCACY SYSTEM



APPENDIX A

GLOSSARY:

Adult Protective Service Worker (APSW)

The APSW program is funded by the Ministry of Community and Social Services (MCSS) but APSW's may be employed by a variety of community service agencies. APSW's provide personal support, referral to needed services, advocacy, and counselling to persons over eighteen years of age who have an intellectual handicap.

Advocacy

Advocacy is the act of speaking on behalf of an individual or a group. (See Corporate Advocacy, Personal Representation, and Advocacy Resource Centre as well as Parent Advocacy for discussions of particular forms of advocacy found in the field of intellectual handicap.)

Advocacy Resource Centre for the Handicapped (ARCH)

ARCH was the first legal clinic for disabled citizens to be established in Canada. Direct legal services, monitoring of relevant legislation, preparation of briefs to government and public education are among the activities of ARCH.

Case Management

Case Management refers to the co-ordination of an individual "package" of services through needs identification, linkage to services and funding co-ordination. A Case Manager is usually the key point of contact between the individual and the system and is usually attached to the funder (government) or a service provider organization. (See Service Brokerage.)

Citizen Advocacy

A mature individual, called an advocate, is matched with a person with an intellectual or other handicap, the protege. This is a one-to-one relationship, on a volunteer basis. The advocate is not only a friend to the handicapped person, but represents his rights in society as well. Staff required for citizen advocacy are responsible for matching individuals, handling problems in the matches, publicizing the program, and community relations. (See Personal Representation.)

Corporate Advocacy

Groups (particularly at the provincial and national levels) act on behalf of persons with a mental handicap as a group, by lobbying government for needed legislation affecting them, by public education programs to improve community acceptance of people with handicaps, and other related activities.

Guardianship

The term "guardianship" (1) refers to a legally recognized relationship between a specified competent adult and another specified person, the "ward", (2) who, because of his tender age or because of some significant degree of mental disability, judicially verified, is considered to lack legal capacity to exercise fully some or all of the rights pertaining to adults generally in the country of which he is a citizen. The guardian is specifically charged with protecting his ward's interests and, for certain purposes, exercising essential

rights on his behalf. (*Symposium on Guardianship of the Mentally Retarded*. ILSMH 1969.)

Joshua Committee (See Support Circles)

Individualization

To individualize is to distinguish a person from all others by his/her own particular characteristics. Applied to the field of human services, "individualization" would require that every person served would have the right and freedom to have their needs, capabilities and potential considered on an individual basis. Individualization in human services would require flexibility and a range of options, to ensure the well-being of each individual in programs.

Monitoring

As used in the field of intellectual handicaps, monitoring is the systematic observation of services offered persons who are mentally handicapped, by an independent citizen or group. It is intended that the provision of feedback from the observer to the service provider will assist in improvement and maintenance of program effectiveness, and the quality of life of the individual.

Parent Advocacy

Parent Advocacy has two definitional aspects, that is: advocacy on behalf of parents and advocacy by parents on behalf of their children. This may involve monitoring of services. (See Pilot Parents, Parent Support Group.)

Parent Support Group

A parent support group is a self-help group of parents who come together to support and advocate on behalf of each other. This may include developing and monitoring of services. (See Pilot Parents.)

People First

People First is an organization made up of people who have a mental handicap. They have joined together for mutual support and to speak out on behalf of all people with this handicap, including those who are unable to speak for themselves. In Ontario, People First of Ontario is an incorporated non-profit organization.

Personal Representation

Personal Representation is one-to-one support by an unpaid volunteer to a person who has a mental handicap. The form of support is determined by the need of the individual and can include friendship, advocacy, or practical help. Citizen advocacy is an effective form of Personal Representation. (See Advocacy, Citizen Advocacy.)

Personal Support Network

A personal support network is a support network of persons who are committed and bonded to the individual which will support, sustain and enhance the autonomy of that individual. Families are usually the core of a personal support network. (See Support Circles.)

Pilot Parents

This program is one in which parents of handicapped children help other parents who have recently learned that their child has a handicap, or who require the assistance of supportive experienced parents in meeting the needs of their handicapped child.

Primary Consumer Organization

An organization of persons linked through their collective, direct use of a given service or service system. (See People First.)

Self Advocacy

Self Advocacy refers to the act of singly or collectively advocating one's own interests. (See People First.)

Service Brokerage

Service Brokerage refers to the process of empowering individuals and their personal networks to: identify their needs; negotiate for required funds and services to meet these needs; where necessary, develop new ways and means of meeting these needs; monitor the ongoing provision of services to ensure needs are met on an ongoing and sustained basis. The broker is the fixed point of responsibility for the system and acts as the agent of the individual through the provision of ongoing technical support. The broker must be independent of service providers, accountable to the individual and his/her network.

Support Circles

Support circles refer to a group of concerned and committed persons who "circle" an individual to provide support, advocate on their behalf and ensure their needs are met on an ongoing basis. Each circle is unique and may or may not involve "professional" or "technical experts", provide direct support and co-ordination and advocacy around specific issues. The purpose of the support circle is defined by the circled individual. A "facilitator" may be used to develop the initial circle around an individual. (See Personal Support Network.)

Trusteeship

Trusteeship involves the management of money or property by one person on behalf of another. The office of the Public Trustee is responsible for the financial management of the assets of most adults residing in mental retardation facilities and Homes for Special Care. Trusteeship for administering the assets of a person with a mental handicap who is living in the community (usually FBA) may be shared with another individual, if the situation warrants it.