THE PROBLEM OF AUTOMOMY: INFORMED CONSENT IN SOCIAL WORK

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THE PROBLEM OF AUTONOMY: INFORMED CONSENT IN SOCIAL WORK

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Dedicated to Social Work 6010 Where it all started to make sense.

Abstract

This study represents an attempt to deal with the problems posed by the social work profession's adherence to the value of self-determination by refocussing the energies of the profession toward a commitment to autonomy rather than self-determination and applying the doctrine of informed consent in social work as a way to avoid diminishing autonomy.

The efforts of this study to deal with the problem of selfdetermination have resulted in a double focus. The first is on an analysis of self-determination in the literature and on the meaning of autonomy and its relationship to personhood. It is through this analysis, coupled with an understanding of the particular nature of social work, that the rationale for refocussing the profession's energies toward a commitment to autonomy emerges.

The second focus of this study is on the doctrine of informed consent. An historical analysis of the evolution of the doctrine of informed consent reveals an increasing emphasis on the duty of society to safeguard autonomy and the important part the doctrine plays in ensuring that the duty is carried out. The purpose, functions and requirements of informed consent point to the centrality of autonomy in the doctrine.

An analysis of the requirements of informed consent and the requirements for the existence of autonomy shows that the doctrine of informed consent is an important vehicle in ensuring that the profession's commitment to autonomy is upheld.

Finally, this study explores some of the implications that the commitment to autonomy and the application of the doctrine of informed consent in social work practice would have for the client, the practitioner, the educator and the profession.

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THE PROBLEM OF AUTONOMY: INFORMED CONSENT IN SOCIAL WORK

Susan M. McConnell

A review of the social work literature reveals a strong, emphasis on the concept of self-determination as a.m. as or value of the profession. As early as 1928 at the Milford Conference, client self-determination was recognised as one of the highest contributions made by social casework (American Association of Social Workers, 1939). Nearly thirty years later Biestek (1957) stated that:

one of the firmest convictions of the profession of social work is that/the person has an innate ability for self-determination and that a conscious, willful violation of the client's freedom by a caseworker is an unprofessional act which transgresses the client's right and impairs casework treatment or makes it impossible. (p./101)

Bartlett (1970) has noted that the emphasis which the profession places on self-determination is a distinguishing characteristic of social work. She points out that the value of selfdetermination tr implicit in the 1958 N.A.S.W. Working Definition and is expressed therein as the "maximum realization of each individual's potential for development throughout his lifetime" (p. 65).*

*Reader's Note: In order to offset specific gender assumptions implicit in the literature's use of solely masculine terms such as "he" and "his", the terms "she" and "her" are used throughout they'text of this thesis. Pumphrey (1961) acknowledges the importance of self-determination in social work and explains that adherence to this principle arises naturally from social work's participation in a democratic society which espouses self-determination as-s major value. While Perlman (1976) agrees that self-determination is not a concept exclusive to social work, she implies that social work has a special relation to self-determination and other values.

I Goldstein (1973) states that self-determination as expressed in "the principle of autonomous action" is the philosophical base which underlies the profession and the practice of social work (p. 12). Soyer (1975) refers to the right of self-determination as "a most pregious casework axiom" (p. 53) and "basic to casework" (p. 55). McDermott (1975) refers to the consistent theme of self-determination in the literature and states that it is "revered as one of the most fundamental of social work values" (p. 118).

Although these and other authors point to the fundamental importance of the concept of self-determination and its mear universal acceptance within the profession, the concept remains problematic in a least three ways, and as a result its significance for practice is diminished.

The first problem is that the meaning of the concept of self-determination is confused. The second problem is whether self-determination is viewed as ah end or as a means to some end. Third; the social work literature is virtually silent on the important question of how the social worker would demonstrate the existence of this value in practice.

In order to address these problems, several steps are suggested. Pirst, a clear statement of the difference between self-determination and autonomy is required. Second, the relationship between self-determination and autonomy must be clarified. In so doing, it will be shown that it is really autonomy that the profession desires because it is tied to a higher moral ideal, and that an understanding of this higher moral ideal will lead to a partial resolution of the means-end problem. Last, it will be shown that it is through the application of the doctrine of informed consent that the possibility for autonomy is created.

In short, what is intended here is to show that the doctrine of informed consent is a valuable tool for the profession, to use in justifying its commitment to one of its primary values.

Statement of the Problem

The concept of self-determination is generally acknowledded to be a central value in the profession. However an examination
of the literature reveals some serious problems with this concept.
The first of these problems is the diverse meanings connoted by the
term 'self-determination'. The second problem is whether self-determination can be properly viewed as a means to some other social
'work goal or whether it is an end in itself. Third, there is the
unanswered question of what constitutes an adequate test to point
to the existence of self-determination in practice.

Diverse Meanings

Despite nearly universal agreement that self-determination is a grimary value in social work, the literature is mixed and unclear in the way he term is used. Self-determination has been used interchangeably with "freedom to act" (Reamer, 1979; p. 236), "autonomy" (Abramaon, 1982; p. 20; Levy, 1983; p. 904; Siporin, 1975; p. 73), "self-direction" (Hollis, 1964; p.*13; Stalley, 1975; p. 102), and even with "self-fulfillment", and "self-realization" (Bartlett, 1970; p. 65);

When the term 'self-determination' is used, more often than not the literature is silent on what the term means, and its use in the literature seems to presuppose a common understanding. For example, the Working Statement on the Purpose of Social Work (1981) declares that 'transactions between Individuals and others.

in their environment should enhance the dignity, individuality, and self-determination of everyone" (p. 6) and the CASW Code of Ethics (1977) states that "each person has the right to self-determination with due regard to the interests of others" (p. 12).

The absence of a clear definition of self-determination has been recognized by Levy (1973) who states that there is "tendency in the social work literature to list routinely and indiscriminately a series of so-called social work values as if nothing more need to be said for all to understand" (p. 37). Perlman (1976) has recognized this problem and notes that the concept of self-determination is "so general and abstract that [it] may be subject to radically different interpretations" (p. 381). Keith-Lucas (1975) has called self-determination an "clusive principle" (p. 51), and Pumphrey (1961) states that "each of us carries into his job his own social work translation of such concepts as...self-determination" (p. 70).

McDermott (1975) points out at least three ways in which

self-determination is used in the social work literature. The ordinary or literal meaning of self-determination is "that condition in which an agent's behavior emanates from his own wishes, choices and decisions" (p. 3), in other words, behavior that is self-caused. The second meaning of self-determination is one of negative freedom or "absence of constraints" (p. 3). Third, self-determination is used to connote positive freedom, or liberation "from the bonds of ignorance, prejudice and passion...or from the crippling and distorting effects of a repressive economic and social system (p. 5). McDermott points out that the failure to distinguish between these

meanings "leads to considerable confusion about the import of the principle of client self-determination" (p. 6).

Several examples of the use of different meanings for self-determination can be found in the literature. Biestek (1957) defines the principle of self-determination as "the practical recognition of the right and need of clients to freedom in making their own choices and decisions in the casework process" (p. 103). He appears here to be referring to self-determination in both its literal sense and in the sense of megative freedom. Rein and White (1980) also appear to use the term self-determination both in its literal sense and as negative freedom. They state that the value of self-determination means that social workers "help people realize their own purposes as they define their purposes...[and] do not impose purposes upon them" (p. 13).

On the other hand, Bartlett, Reamer and Bernstein appear to view self-determination as positive freedom. Reamer (1983) states that "a key mission of the profession is to help clients achieve what they want to achieve and to assist them in the formation and pursuit of meaningful goals" (p. 628). It is this reference to assisting clients in forming and pursuing meaningful goals that makes the use of the term one of positive freedom. Bartlett (1970) is more explicit in the use of. self-determination as positive freedom.

She states that self-determination has been "expressed variously as 'self-fulfillment' or 'self-realization'. The subcommittee on the Working Definition expressed it as "maximum realization of each

individual's potential for development throughout his lifetime"

(p. 65). Bartlett's use of the term implies more than an absence of constraints, and includes all of the elements described by McDermott as positive freedom.

In his analysis of self-determination, Bernstein (1975) has included all three meanings of self-determination but appears to prefer the view that self-determination is almost akin to positive freedom. He states that self-determination means not only that social workers "should help people to do what they want to do and not stimulate them to go beyond their wishes" (p. 30), but that adherence to self-determination also means recognizing ambivalence and non-verbal communication in the client, recognizing those aspects of reality that cannot be changed, accepting the social responsibility incumbent upon the individual and including a rational approach to solving problems. Bernstein concludes that his view of self-determination is "a pretty high level of high social-functioning" (p. 39).

There is a fourth interpretation of self-determination which has been expressed by Siporin (1975) and Abramson (1982).

Both of these authors discuss the principle as self-determination or autonomy, and both are explicit in their assumption that respect for self-determination or autonomy must include providing the client with alternatives. Siporin (1975) states that "respect for the client's autonomy or self-direction is a troublesome, much discussed principle. It meets the client's needs for self-realization and growth, for competence and the development of his own powers in

responsible decision-making" (p, 77). Abramson (1982) states that self-determination means "that social workers must present clients with viable alternatives, and the opportunity to choose freely without undue coercion" (p. 20).

Perlaan's (1975) work provides an example of the confusion that results when different meanings are attached to a single term. At one point, she describes self-determination as "the expression of our innate drive to experience the self as cause" (p. 79), and at another point she different manners and that "man's exercise of choice rather than his coercion by his own blind impulses, is what builds in him his sense of effectiveness, of identity and selfhood, and responsibility" (p. 20).— The first statement appears to refer to the literal meahing or self-caused behavior, whereas the second statement appears to refer to a combination of negative freedom and positive freedom.— The effect of using these diverse meanings is that while it is clear that Perlman believes that self-determination's should be included in practice, it is not clear what self-determination is.

Although the profession has treated self-determination as a "banner" sround which it can rally (Toule, 1985; p. 18), the profession is divided and unclear as to what that banner is. Whittington (1975) has pointed out that the controversial nature of self-determination remains because "the gulf between the theoretical definitions and their application in practice is often wide, and rife with inconsistencies...the concept has so many limitations that

a serious re-examination of its position in professional social work ideology is essential" (p. 81).

The result of using a single term to convey such diverse meanings is that the profession is left confused and tied to a value which it does not properly understand.

Means or End

The lack of a more precise definition of self-determination affects a second and independent problem, which is whether self-determination should be treated as a means or as an end. McDermott (1975) has posed the problem quite nicely when he says, "whether the obligation to refrain from coercing or manipulating The client should be regarded as stemming from a fundamental right of the client as a human being, or merely as a pragmatic or technical principle for achieving certain social work goals is the point at which controversy breaks out" (p. 7). Stalley (1975) makes the same point but carries it a step further by noting that treating clients as self-determining has been viewed by some authors as "a means to the more effective pursuit of other casework goals" (p. 100) and by others "as in some way determining the goals of casework" (p. 101). For example, Bernstein (1975) has argued that while selfdetermination is not the supreme value in social work, it is nonetheless an important value in that it is a means to demonstrate social work's supreme value, respect for human worth. This is in contrast' to Perlman (1975) who seems to view self-determination

as valued in its own right, and as an end in itself in that it is "the very essence of mature humanness" (p. 70).

Although according to McDermott (1975) the dominant conception is that self-determination is an instrumental means to other goals of social work such as growth and development, Stalley (1975) claims that self-determination is most often seen as an end. He says that social workers "value the principle partly because it is a means of achieving beneficial results such as the reduction of the client's fears and timidities, but chiefly because self-direction is something which is valued for its own sake" (p. 102). The result of the continuing means-end confusion is that practitioners cannot be clear under what, if any, circumstances self-determination should be set aside.

Implementation

Aside from the ambiguity and confusion surrounding the concept of self-determination the profession is also left with the problem of translating this principle into action and constructing a test to demonstrate its inclusion in practice. At this point it bears emphasizing that the literature is virtually silent on how the concept is actually put into practice. The problem for the practitioner is one of being expected to act on a principle without any means to do so.

Recognition of the need for practical steps has come from a number of quarters in the social work literature. Steiner (1979) points out that values such as self-determination have not been "operationally defined, critiqued and refined relative to evolving social work knowledge and specific practice behaviors" (p., 524). According to Pumphrey (1961), the "problem lies in seeing how these and other expressed values operate in the solution of specific problems in practice...how they help make what the social worker does different from what a well-meaning non-social worker might have done" (p. 68). Levy has made a plea for a "set of axiological rules which would serve as a series of guides, expectations, and criteria for evaluation against which the individual and collective actions of social workers may be weighed and appraised" (p. 41).

Perlman (1976) argues that a link must be forged between what the profession believes and how its practitioners act. She states that "this task is an essential condition for a profession's wholeness, and, certainly, it is a condition for the mental and emotional wholesomeness of its practitioners" (p. 390).

At this point in time there are basically two schools of thought which suggest ways that self-determination can be demonstrated. The first approach would suggest that certain attitudes of the social worker such as warmth, acceptance; recognition of the client's feelings and tolerant understanding of the client's behavior (Bartlett, 1964) are indicators that self-determination is being acted upon. Perlman (1975) identifies the mutual supportive exploration of the client's problem as well as the client's situational and emotional relation to it as a first step toward fulfilling the practitioner's commitment to client self-determination.

— If would seem however, that while such attitudes of warmth, acceptance and support are important, they do not constitute a sufficient basis for proving that self-determination is in fact being acted upon. In the first place, whether a practitioner has such attitudes towards clients can not be objectively established. This would leave a subjective report from the worker and the client as the only possible basis for evaluation. Another problem with using attitudes as the only criterion for evaluating adherence to self-determination is that it would make it difficult for a worker to be confrontive towards a client, thus denying the possibility for the use of certain therapeutic techniques.

Finally, using worker attitudes alone as a basis for operationalizing self-determination might well lead to competition between different therapeutic camps. The social worker who operates from a Rogerian framework can legitimately point to the subjective attitudes of acceptance, warnth and support as part of a broader theroretical perspective; however the practitioner who operates from a behaviorist perspective can not make the same claim since behaviorism relies on objectivity. Although there is no reason to believe that a behaviorist could not also evidence warnth, support and acceptance, these are not fundamental requirements of the theory.

The emphasis on the worker's attitudes as the only criterion to evaluate adherence to this fundamental value of social work could conceivably lead the profession to choose sides, endorsing only those theroretical models that are implicitly compatible with its values, and rejecting other equally valid and useful forms of

therapy. Such a competition might unnecessarily restrict practitioners. It would seem that given the diverse theoretical orientations held by practitioners, proving adherence to self-determination or any other value on the basis of attitudes alone is insufficient.

A second approach that has been suggested for putting self-determination into effect is through worker-citent contracts (Pincus and Minshan, 1973; Compton and Galaway, 19'9). While the value of contracting per se is not Peing disputed here, it would appear that there are some problems which are overflooked in such a solution. These include the often necessarily dependent position of the client on the agency for services, the imbalance of power and possibilities for worker manipulation, both through the exercise of "his legitimate authority and the pseudo-authority with which he is often accredited" by the client (McDermott, 1975; p. 135), the lack of any client recourse should the contract be broken by the social worker, and the lack of opportunity on the part of the client to opt out of the contract.

The combination of these problems would suggest that contracting, while it may be useful for other purposes, is not an adequate test in itself to ensure the promotion of client self-determination.

Purpose

Clearly the profession needs a resolution to the problems posed by its commitment to self-determination. This resolution requires a conceptual framework that distinguishes between self-

determination and autonomy and locates each relative to the other and to a larger professional ideal.

What will be suggested in this framework is that it is really the principle of autonomy, not self-determination, to which the profession has committed itself in the service of a higher professional ideal of promoting personhood. The construction of this framework and the substitution of autonomy for self-determination will provide a vehicle whereby the means-end problem can be reexamined and accommodated relative to this professional ideal. This framework will show the necessary conditions required for the existence of autonomy and will show that through the application of the doctrine of informed consent it will become possible for the profession to speak with some justification to its commitment to the principle of autonomy.

Conceptual Franework

In order to get some resolution to the problematic nature of self-determination what is required is a conceptual arrangement that will show that the profession's commitment to self-determination is misleading, and that it is autonomy to which the profession is committed in the service of a higher ideal of promoting personhood. This will require, as a first step, making a distinction between self-determination and autonomy which will demonstrate that autonomy is the preferred commitment. The second step is to demonstrate the developmental relationship between Self-determination, autonomy and personhood and to state the relationship between autonomy and personhodd in terms of moral rules, moral ideals and utilitarian ideals. Third, the requirements of autonomy will be identified. These are the same as the requirements of informed consent, which allows the application of informed consent to emerge as the means by which autonomy can be kept intact in order to create the possibility for personhood.

Distinction Between Self-determination and Autonomy

The first step in developing a conceptual framework that will help to unravel the problems posed by self-determination is to resolve some of the confusion in the meanings of self-determination. It is proposed here that self-determination be limited to mean self-caused behavior, behavior that emanates from the self without external coercion or restraint; and that autonomy be defined

as the exercise of self-determination based on information about one's alternatives and the consequences, of one's actions as well as an understanding of what that information means.

Limiting self-determination to references to self-caused

given the meaning of 'self-determination' in other contexts [e.g., national self-determination], and the function of the prefix 'self' in-marTogous expressions, there is a strong resemption that the concept of individual self-determination should be interpreted as essentially a defical that the action of of an interpreted in the context of the conte

Autonomy on the other hand, is generally used with a broaffer meaning, and it has been defined as "the quality or state of being self-governing! (Webster"s Seventh New Collegiate Dictionary, 1969; p. 60). In that autonomy refers to self-government, it implies not only behavior that is self-caused and free from coercion, but also, as Krause (1982) has suggested, responsibility for one's behavior, which can only exist when one is acting rationally, knowledgeably and freely. Thus autonomy includes an element of free informed choice among alternatives and the use of rational thought. Because these are conditions necessary for governing, they are implicit in the concept of self-government, or autonomy. These elements can be, but are not necessarily included in self-determination. One can be self-determining without being aware of alternatives, without rational thought, or without being responsible for one's actions. Animals can be self-determining as long as they are' not interfered with; only persons are capable of autonomy.

Autonomy and Personhood

. Having made a distinction-between self-determination and autonomy, the next step is to show that the special significance of autonomy lies in its relation to personhood. This will require further clarification of the concepts of autonomy and personhood.

Friedlander (1982) defines autonomy as "the ability of freedom of a person to make his own decisions, whether they be purely of an intellectual sort—a thought or a value judgement—or whether they are something that is acted upon" (p. 1712). Autonomy is

the personal freedom that is one of the most, if not the most, highly-valued attributes of our political system. It is the necessary condition for persons to have in order to arrive at a set of values and based on these they can often express their values, and they can always make mental judgements about their values. Autonomy can even permit persons to elect to give up their autonomy except, perhaps; those elements which are supposed to be 'inalienable'. (Friedlander, 1982; p. 1712)

Autonomy is particularly problematic because individuals
live within a society, nor alone. Autonomy is not such a problem
for the person who lives alone on an island, it is only when the
person lives with others that the possibility exists for his autonomy
to be impaired.

Friedlander (1982) has developed an analogy, which is helpful in shedding some light on an important aspect of autonomy;
autonomy not only requires actual freedom but also the feeling of
freedom. He describes a man, John Smith, who voluntarily fences
his backyard to give himself some privacy "so he can feet he is free
to conduct himself as he wishes... He desires autonomy, he wants to

control without outside interference his own intellectual and physical activities" (p. 1710). The actual degree of freedom Mr. Smith has is not at issue here, for in fact he can act as he wishes regardless of the nature of the fence between him and his neighbor. What is important is that Mr. Smith feels he is free to do as he pleases. Thus, the individual must not only be free, he must understand that he is free and feel free in order to be truly autonomous.

Friedlander (1982) concedes that personhood is a difficult concept to define but notes that the central and most commonly accepted feature of personhood is the presence of self-awareness, that "the entity known as a person has the characteristics of being aware of itself" (p. 1710). Personhood as used in this framework would imply an awareness not only of the boundaries and limitations of the self but an awareness of the existential meaning of that self. This is a higher order of self-awareness and might be considered similar to Maslow's concept of the self-actualized person. As such, it is an ideal to which individuals might properly be said to assire.

In describing the way the relationship between personhood and autonomy is experienced by the individual, Berlin (1969) states:

I wish, above all, to be conscious of myself as a thinking, willing, active being, bearing responsibility for my choices and able to explain them by references to my own ideas and purposes. I feel free to the degree that I believe this to be true, and enslayed to the degree that I am made to realize that is in the form.

A Developmental Model of Personhood

The process of attaining personhood or a sense of self and an awareness of the meaning of that self can best be described developmentally. This process begins with the exercise of control over one's body and one's environment. The newborn infant perceives no difference between herself and her mother; as she gains mastery over her body and learns to manipulate her environment, she begins to perceive the difference between herself and others, and to recognize her boundaries and limitations. At this stage, she has achieved a limited self-awareness which enables her to exercise further control over herself and her environment.

As she grows, the child gains further mastery which comes in part from her awareness of the boundaries between self and other; she requires less interference from others in her actions, and she begins to have some capacity to be self-determining:

The exercise of self-determination provides the child with information about the consequences of her actions and she begins to have an understanding of what her actions and their consequences will mean for her—For example, the child may exercise her self-determination by jumping off a fence. She learns that if she jumps off a fence that is too high, she will get hurt.

As the individual continues to mature, exercising self-determination and increasing and integrating her knowledge, she becomes capable of autonomy. She makes choices, develops beliefs and acts on those choices and beliefs based on the information and understanding she has acquired thus far. The individual's capacity to be autonomous is dependent not only on the exercise of her self-determination but also on the amount of information and understanding she has acquired.

It is the exercise of this autonomy which enables the individual to develop a sense of self and the boundaries, limitations, possibilities, and existential meaning of that self. In other words, by being autonomous, the individual is able to move toward personhood.

While a description of this process appears to be linear, in fact, the exercise of autonomy and the attainment of personhood is not accomplished at a single point in time but is instead an ongoing and ever-increasing spiral process with the individual's capacity for, and exercise of self-dètermination and autonomy constantly influencing her capacity for personhood. Personhood is not achieved at any discrete point in time, rather it is a process of becoming.

If at any point during this process the individual is denied the right to self-determination or denied the access to autonomy, her ability to move toward personhood will be diminished. Thus, the child raised in extreme isolation, unable to exercise her. self-determination, grows up with little understanding of the consequences of her actions or of the limits and potentials of her person. Less severe is the case of the overprotected child who, because she is denied the right to be self-determining, grows up afraid to test herself.

In short, the exercise of self-determination and autonomy are developmental prerequisites for personhood. Because violations of self-determination or autonomy diminish the individual's potential for personhood, it is critical that violations of self-determination and autonomy be reduced to an absolute minimum. It is only in this way that the possibility for the individual to achieve personhood can exist.

Autonomy and Personhood in the Context of Moral Rules and Moral Ideals

A profession's commitment to autonomy and personhood can best be seen in the context of Gert's (1973) enalysis of moral rules, moral ideals and utilitarian ideals. A moral rule requires that one avoids causing evil. It must be understandable by all rational men and requires universal application. Because moral rules involve the avoidance of causing evil, they are usually couched in negative terms (e.g., "don't cause pain"), and are not ordinarily a burden in that one-can-obey the rules by non-action pronon-interfarence. The only justification for violating a moral rule, or causing an evil. is if doing so will prevent a greater evil.

Moral rules are applied in the service of a moral ideal, which encourages the prevention of evil. Because following moral ideals requires action, they are usually couched in positive terms, for example "prevent pain". Although following a moral ideal is encouraged, it is not required that it be universally applied. Gert (1973) has pointed out that "it is impossible to follow the moral ideals with regard to all men equally; thus each man is allowed to

choose toward whom he will conceptrate his efforts, though, of course, it is best to help those most in need" (p. 133).

Utilitarian ideals encourage the promotion of good and are stated in positive terms, for example "promote pleasure". They do not require universal application to all people or by all people, nor is it realistic to expect that they can be universally applied. Adherence to a utilitarian ideal does not justify the violation of a moral rule or a moral ideal, in other words, causing an evil cannot be justified on the grounds that it will produce a good. The realization of utilitarian ideals can only be justifiably accomplished through obedience to the moral rules and moral ideals.

In terms of autonomy and personhood, the utilitarian ideal for social work, or the professional ideal, might be said to be "promote personhood". This would be consistent with, although not exactly the same as, what has been called the ultimate value of social work: "the maximum realization of the individual's potential" (Sartlett, 1970; p. 65). In order to create the possibility for achieving personhood, the moral ideal becomes "prevent the loss of autonomy" or, stated another way, "safeguard autonomy", and the moral rule which follows from this is "avoid diminishing autonomy".

The utilitarism ideal, promotion of personhood, does not require universal application by all persons at all times. Nor can an individual's autonomy be yielated in order to promote that individual's or another individual's personhood. Thus, an individual cannot be forced to engage in family therapy unless it can be shown that

by not being involved in therapy an evil greater than the diminishment of the individual's autonomy will result.

The moral ideal of safeguarding autonomy is encouraged, but the ideal also does not require universal application to all people at all times. Although social workers have a particular commitment to uphold this ideal because of their profession, it is not possible for them to do so with equal regard to all people or at all times. They can thoose those toward whom they feel most committed to direct their efforts at safeguarding autonomy.

The moral rule however requires universal adherence. No person has the right to diminish another individual's autonomy; autonomy is an inalienable right. Adherence to this rule is even more important for social workers and others in professions who are committed to human growth and fulfillment because of their implicit commitment to the professional ideal of personhood, and also because of the special status and powers these professions enjoy.

Thus the central task for the social worker is, that she must avoid diminishing the autonomy of the individual. It is only by implementing the moral rule of not diminishing the client's autonomy that the profession can uphold the moral ideal of safeguarding autonomy and create the possibility for the client to move toward attaining personhood.

Requirements of Autonomy

In order to keep the moral rule intact, the practitioner

must understand the necessary conditions for autonomy. These are competence, voluntariness, information and understanding.

Capacity or minimal competence is a sine qua non for autonomy; the individual who is mentally incompetent will be less able to make decisions and to act autonomously than the individual who is fully competent. Autonomy requires that the individual be free from external coercion, and able to act voluntarily. Voluntariness or freedom of choice requires not only lack of coercion but also alternatives from which to choose. If there is only one possible course of action open to an individual, she can not be said to be acting voluntarily or autonomously if she chooses that course of action, since she can choose no other. Autonomy not only requires choice among alternatives, but an awareness that alternatives exist, knowledge about what those alternatives are, and an understanding not only of the consequences of one's choice but that one is free to make a choice.

Without the presence of all of these elements, autonomy cannot exist. It is only when the individual is sufficiently compatent to choose a course of action, is free to choose voluntarily, has information about her alternatives and their consequences and an understanding of what those alternatives and consequences might mean for her that it is possible for her to be autonomous.

The necessary conditions for autonomy are also the requirements of the doctrine of informed consent. By inclading these requirements as a prerequisite to intervention in practice, the application of the doctrine ensures that the autonomy of the client will not be diminished. Thus the doctrine of informed consent becomes the vehicle for ensuring that the moral rule is not violated. Through the application of informed consent, the profession not only avoids-diminishing autonomy, but, by doing so, will be better able to uphold the moral ideal of safeguarding autonomy in the service of promoting personhood, thus fulfilling its commitment to its professional ideal.

Evolution of the Doctrine of Informed Consent

This section will examine the evolution of the doctrine of informed consent from its earliest beginning to the present time in order to demonstrate the increasing emphasis placed on the duty of society to safeguard autonomy and the importance of the doctrine in ensuring that this duty is carried out.

At the heart of the doctrine of informed consent lie the values of self-determination and individual autonomy. An historical analysis of the evolution of the doctrine in experimental and non-experimental medicine will show how society, through the law and the courts and to a lesser extent the professions, has come to view the question of autonomy vis-a-vis the consent issue.

Historical Antecedents in Experimentation

The doctrine of informed consent as it is presently understood and applied in both medical experimentation and treatment is a relatively recent concept, however its historical antecedents in experimentation date back to the eighteenth century. The earliest case pertaining to consent in medical experimentation was <u>Slater</u> v. <u>Baker and Stapleton</u> which was decided by a British appellate court in 1767. This tase involved the first use of a device to rebreak an improperly healed leg; when after four months the petient had not recovered, he brought suit against the physician and his associate and was awarded damages by the court. The court affirmed the original verdict on two grounds. First, since the device had not

been used before "ic was a rash action, and he who has acted rashly acts ignorantly" and is responsible for the consequences of his actions; and, second, the patient should have been informed of the surgeon's proposed action so that he could "take courage and put himself in such a situation as to enable him to undergo the operation" (Annas, Glantz and Katz, 1977, p. 2).

The significance of <u>Slater</u> lies in its introduction of the issues of rashness and consent. Although the present rationale for these issues differs from that of <u>Slater</u> in that the prohibition against rashness is no longer based on the assumption that any experiment is a rash action and therefore improper, nor is the question of consent considered for the purpose of enabling a patient to prepare himself to undergo a procedure, the question of consent and rashness remain critical in contemporary medical experimentation (Annas et al. 1977).

In the United-States, the first case dealing with experimentation was <u>Carpenter v. Blake</u> in 1871. This concerned a deviation from standard medical procedure for the treatment of a dislocated arm where the physician failed to advise the patient to either keep his, injured arm in a sling or on a pillow. The court considered this deviation an experiment and ruled that there should be no departure from the established mode of treatment "unless the surgeon who doen it is prepared to take the risk of establishing, by his success, the propriety and safety of his experiment. The rule protects the community against reckless experiments while it admits the adoption of new remedies and modes of treatment only when their

benefits have been demonstrated, or when, from the necessity of the case, the surgeon of physician must be left to the exercise of his own skill and experience" (Katz, 1972; p. 328). Although the court addressed the issue of rashness in <u>Carpenter</u> it did not introduce the operation of consent.

From 1871 until 1935, fewer than a dozen cases concerning medical experimentation were brought to court; none of these cases dealt with the question of consent, and almost all of them dealt with experimentation as a departure from standard medical practice and, as such, improper (Annas et al, 1977). The 1926 decision in Ovens v. HcCleary illustrates the courts' view at that time of the illegitimacy of experimentation with its statement that "a failure to employ the methods followed or approved by his [the physician's) school of practice evidences either ignorance or experimentation on his/part. The law tolerates neither" (Annas et al, 1977; p. 4).

In Fortner v. Koch in 1935, medical experimentation was considered for the first time by the court to be a legitimate undertaking, as long as the experiment did not vary too far from standard medical practice and provided that the subject consented to the procedure. Fortner involved the mindiagnosis of bone cancer; the patient, after consulting another physician, was given a Wasserman test and learned he had syphilis (Annas et al., 1977). The appellate court in reducing the amount of damages awarded to the plaintiff stated it recognized that "there must be a certain amount of experimentation; but such experiments must be done with the knowledge and consent of the patient or those responsible for

him, and must not vary too radically from the accepted method of procedure" (Katz, 1972; p. 529). While a misdiagnosis would not be considered an experiment today but would probably be considered gross negligence in that the physician failed to employ an indicated standard diagnostic test (Annas et al, 1977), Fortner is nonetheless significant because it represents the first Legitimation of non-radical experimentation on human subjects. Perhaps of more importance, and more than 150 years after the question of consent to experimentation was introduced by a British court, is that Fortner contains the first introduction of consent as a necessary prerequisite to medical experimentation by a U.S. court.

A 1941 New York appellate court case, Stammer v. Board of Regents further legitimized experimentation; however in this case experimentation was considered closes to its present context, referring not to be deviation from standard medical practice but to the testing of a new medical procedure in the course of treatment. The appellate court reversed the decision by the state licensing board to suspend a physician's license to practice after he had successfully used a topical medication to treat face cancer, having fully informed his patient that the treatment was experimental, might do some good, and would not cause any harm. The court stated that it was not fraudulent or deceitful for a physician "with the consent of his patient, to attempt new methods when all other known methods of treatment had proved futile and least of all when the patient's very life has been despaired of. Initiative and originality should not be thus effectively stifled, especially when undertaken with

the patient's full knowledge and consent, and as a last resort"

(Annas et al, 1977; p. 6). By 1941, the courts had begin to view, medical experimentation as a legitimate enterprise and had established ed consent to experimentation as a necessary prerequisite.

Historical Antecedents in Treatment

The legal foundation for the doctrine of informed consent in medical treatment has its beginnings in Pratt v. Davis in 1905. This was the first appellate court case in the U.S. involving established medical treatment and was also the first time that the question of consent to any medical procedure was raised in an "">"American court. The court ruled that a physician must obtain consent to surgery when Mr. Justice Brown stated that "the free citizen's first and greatest right, which underlies all others—the right to the inviolability of his person, in other words, his right to himself—is the subject of universal acquiescence...this right necessarily forbids a physician...to violate without permission the bodily integrity of his patient" (Katz, 1972; p. 554).

The <u>Pratt</u> decision was cited by Mr. Justice Cardozo in <u>Schloendorff v. Society of New York Hospital</u> in 1914 (Katz, 1972), which was perhaps the most widely known case dealing with the issue of the <u>Midwidual</u>'s right to mastery over his own body (Macklin, 1982). <u>Schloendorff</u>, like <u>Pratt</u>, dealt with consent in the context — medical treatment, in this case the removal of a stomach tumor. The court ruled that any non-emergency operation performed without consent is a battery and the surgeon who performs such an operation

is liable for damages (Annas et al. 1977). In his famous opinion, which is considered to be the root premise for the basic principle. of informed consent (Barber, 1980) bosoff, 1981), Mr. Justice Cardozo stated "every human being of adult years and sound mind has a right a to determine what shall be done with his own body" (Katz, 1972; p. 526).

These early decisions regarding both medical experimentation and treatment represent the evolution of the concept of consent prior to World War II and focused on consent as a means of respecting the patient's right to have control over his or her own body. None of these decisions however addressed the question of the quality of coasent, including voluntariness, the kind and amount of information required, the need for the patient's comprehension of that information (Macklin, 1982), or the right of the patient to terminate the treatment or experiment. Further, Mr. Justice Cardozo's opinion limited the right to consent to an adult of sound mind, leaving open the question of the relationship between a sound mind and the ability to grant consent (Macklin, 1982), a question that continues to be important in the present context of informed consent.

The Nuremberg Code

Although the doctrine of informed consent was applied in the medical experimental setting before it was applied in the therapeutic setting (Annas et al. 1977), the contemporary doctrine does include both experimentation and treatment. The experimental provision has its origins in the Nuremberg Code and the treatment provision originates in Natenson v. Kline (Parry, 1981).

The Nuremberg Code is considered to be the most comprehensive and definitive statement of the doctrine of informed consent in the experimental setting (Annas et al, 1977) and was articulated by the court in 1945 in U.S. v. Karl Brandt during the Nuremberg Military Tribunals that followed World War II. In Re Brandt, 23 German physicians were charged by the U.S. with unlawfully, willfully and knowingly committing "war crimes [and crimes against humanity] ... in that they were principals in, accessories to, ordered, abetted, took a consenting part in, and were connected with plans and enterprises involving medical experiments without the subjects' consent...in the course of which experiments the defendantscommitted murders, brutalities, ruelties, tortures, atrocities, and other inhuman acts" (Katz, 1972; p. 293). These experiments were considered to have constituted violations of international conventions which "departed from every, known standard of medical ethics" and in some instances had as their true object "not how to rescue or cure, but how to destroy and kill" (Katz, 1972; pp. 294-297).

The basis for the Nuremberg Code is "a type of natural law reasoning" (Annas et al, 1977; p. 6), and in its judgement in <u>Re Brandt</u>, the court stated "all agree...that certain basic principles must be observed in order to satisfy moral, ethical, and legal concepts" (Katz, 1972; p. 305). The essence of the doctrine of informed consent is contained in the first principle of the Code which emphasizes the idea that "the voluntary consent of the human subject is absolutely essential" (Annas et al, 1977; p. 6) and states that this consent must have four characteristics: it must be competent, voluntary, informed and

understanding. Thus the Nuremberg Code addressed for the first time the

The significance of the Nuremberg Code for the doctrine of informed consent lies in its specification of these four requirements and in holding the experimenter responsible for ascertaining the quality of the consent obtained. It also addresses the nature of the experiment, the conditions surrounding the experiment and the conditions under which it should be terminated. The Code states that the purpose of any experiment with human subjects should be to yield results "for the good of society unprocurable by other means of study", that its anticipated results should justify the performance of the experiment with the degree of risk never exceeding the importance of the problem, and that the experiment should "avoid all unnecessary physical and mental suffering" and should not be conducted at all if death or disabling injury seems to be the likely outcome (Annas et al. 1977; pp. 279-280). With regard to the conditions surrounding the experiment, the Code specifies that any experiment must be conducted by scientifically qualified persons and with proper preparation and adequate facilities "to protect the subject from even remote possibilities of injury, disability or death" (Annas et al, 1977; p. 280). Finally the Code states that the subject should be at liberty to terminate the experiment at any time and that the experimenter is obliged to terminate the experiment if he has reason to believe that a continuation will result in injury, disability or death (Annas et al, 1977).

The Ndremberg Code marked the acceptance of the ethical standard that the subject's free, informed consent to participate is an essential

part of human experimentation (Annas et al, 1977). It has subsequently become a part of international common law and was adopted by the United Nations General assembly in 1946 (Annas et al, 1977). Although there are some questions regarding the legal standing of the Code in the U.S. in that, it may be making international common law U.S. common law, the Code has nonetheless been adopted and applied in civil and criminal cases by state, federal, and municipal courts (Annas et al, 1977). According to Annas-et al (1977), "no case law, statute, or regulation has been found that is as comprehensive as the Nuremberg Code. The Code requires the competent, voluntary, informed and understanding consent of the sub-ject" (p. 44).

Informed Consent in the Experimental Setting

Therapeutic Experimentation After World Waf II. The Nuremberg Code signalled a shift from the court's view that experimentation was a somewhat questionable practice to the view that experimentation was a reasonable and legitimate scientific enterprise. Thereshave been only a few appellate court decisions involving human experimentation following World War II (Annas et al, 1977), and in those cases, the courts have been increasingly concerned with the quality of the subject's consent. These cases can be separated into two groups: therapeutic experimentation which has as its aim a benefit to the patient, and nontherapeutic experimentation which has as its object scientific inquiry with no therapeutic benefit for the subject (Annas et al, 1977).

Baldor v. Rogers (1955) which involved an experimental freatment of cancer of the lip, is illustrative of the court's view of experimen-

tation as legitimate, and is significant because it represents a majorbreak from nearly all previous cases in the U.S. in its explicit recognition and encouragement of medical experimentation (Annas et al. 1977).

In <u>Baldor</u>, the court found "not only that experimentation is a legitimate
undertaking, but also that it is to be encouraged, at least in areas where
no effective treatment exists", and on appeal held the investigator
responsible for disclosing options to the patient when the experimental
treatment proves ineffective (Annas et al. 1927; p^{*} 10), sptt is
interesting to note that at this point, the court was more concerned with
the <u>fact</u> of obtaining consent, considering it necessary to disclose
options only if the treatment is ineffective, than it was with the <u>quality</u>
of consent obtained at the instigation of the treatment.

The courts' increased concern with the quality of consent to therapeutic experimentation is evidenced in <u>Fiorentino v. Wenger</u> (1966) which involved the death of a minor as a result of a "movel and unorthodox" surgical treatment for scoliosis. The issue before thercourt was not the appropriateness of the experiment, but the necessity of disclosing one risks inherent in the procedure since five of the 35 times this technique had been used, it had "unexpected and untoward results" (Annas et al. 1977; p. 11). The boy's parents had consented to the surgery but were not informed of its experimental nature (Holder, 1978) and the court found the surgeon liable because of his failure to disclose the known risks of the experimental surgery (Annas et al. 1977). In <u>Fiorentino</u> then, the quality of consent in the context of disclosure began to be explored by the court in its consideration that disclosure of the exper-

imental nature and the risks involved in the procedure is a prerequisite to consent.

Karp v. Cooley (1972) illustrates the courts' continued concern with the quality of consent rather than the intrinsically experimental nature of the procedure (Annas et al. 1977). Karp involved the implantation of an artificial heart, which was followed a few days later by a heart transplant. The patient died the day after the transplant and his widow sued on the grounds that there had been no informed consent. The appellate court affirmed the original verdict in favor of the physician when it found that the patient had full understanding of the procedure. This finding was based on a detailed consent form which specified that this was the first use of the device in a human being, that the risks had been explained and that the surgeons could give no assurance of success (Annas et al, 1977; Holder, 1978).

In response to the difficulties of obtaining a valid consent to the experimental implantations of artificial hearts from a dying patient, the 1976 Committee on Ethics of the American Heart Association published guidelines on the use of artificial devices, and recommended the participation of a third party in the consent procedure. This recommendation was based on the "likelihood of a strong mutual dependency between the surgeon and the patient" which might invalidate the ability of the patient to give a meaningful consent Annas et al. 1977; p. 17). In its recommendation the committee stated: "the participation of a third party, which may be more than one person, to mediate the consent process without being caught up in the force of its dependencies ought to make the consent decision more genuine" (Annas et al. 1977; p. 17).

In 1973 the court resurfaced the issue of rashuess in the context of voluntariness in Kaimowitz v. Michigan Department of Mental Health when it took a different approach to therapeutic experimentation in psychosurgery. Kaimowitz involved a proposed experimental amygdalotomy to reduce aggression in an institutionalized person who had been convicted of murder and rape. Although the patient had signed a full ' and detailed consent form, the court forbade the experiment and declared. "psychosurgery should never be undertaken upon involuntarily committed populations...because of the impossibility of obtaining truly-informed consent from such populations" (Brooks, 1974; p. 907). The reasoning of the court appeared to be that signing the consent form proved either that the person did not understand the content of the form or, if he did understand, he was incompetent or coerced (Annas et al, 1977). In forbidding the experiment, the court stated "a person may not consent to acts that will constitute murder, manslaughter, or mayhem upon himself. In short, there are times when the State for good reason should withhold a person's ability to consent to certain medical procedures" (Brooks. 1974: p. 910).

The significance of <u>Mainovitz</u> lies in two issues addressed by the court concerning consent: the questionability of obtaining fruly informed and voluntary consent from involuntarily committed populations, and the right of the State to withhold an individual's ability to consent to procedures deemed rash. Up to the present, the courts have generally shown an increased tolerance toward therapeutic experimentation, considering it a legitimate scientific undertaking, with the exception of experiments the court deems against public policy. The emphasis of the courts has increasingly been on the quality of consent to therapeutic experimentation, considering the requirements of competence, the physician's disclosure, voluntariness and understanding.

Nontherapeutic Experiments After World War II. With the exception of kidney transplants in minors, there have been no post-Huremburg appellate court decisions regarding nontherapeutic medical experimentation in the U.S. (Annas et al. 1977). A Canadian case, Malushka v. University of Saskatchevan (1965), and a case that appeared before the state licensing board of New York, The Jewish Chronic Disease Hospital Case (1965), both ruled that there can be no exception to full disclosure in the nontherapeutic experimental situation and these decisions can be used as a basis for defining the law of informed consent in the nontherapeutic experimental setting (Annas et al. 1977).

Halushka dealt with a normal subject who volunteered to participate in an experiment involving the insertion of a catheter into the arm. The catheter was advanced toward his heart whereupon surgical anaesthesia was introduced; cardiac arrain ensued and the subject required surgery to restore his heart beat. The appellate court, in affirming the original decision in favor of the subject, stated that he had not been adequately informed in that he did not know that the drug to be tested was an anaesthetic and had never been tested before or that there were specific risks involved (Annas et al, 1977). The court ruled that "the subject of medical experimentation is entitled to a full and frank disclosure of all the facts, probabilities and opinions which a reasonable man might be expected to consider before giving consent" and that "there can be no exceptions to the ordinary requirements of disclosure in the case of research as there may well be in ordinary medical practice" (Katz, 1972; p. 572).

The Board of Regents' reached a decision which parallelled
Halushka in the Jevish Chronic Disease Hospital Case in which 22
chronically ill patients were injected unknowingly with live cancer
cells for the purpose of studying the body's immune reaction.
The Board suspended the physicians' licenses for a year on the
grounds that the patient, not the physician, has the right to decide
what factors are relevant to his decision to participate in an
experiment, and that the patient has the right "to refuse to participate
in an experiment for any reason, intelligent or otherwise, well-informed
or prejudiced" (Macklin, 1982; p. 357). The Board declared that
"the physician, when he is acting as an experimenter, has no claim
to the doctor-patient relationship that, in a therapeutic situation,
would give him the generally acknowledged right to withold [sic]
information if he judged it in the best interests of the patient"
(Macklin, 1982; p. 357).

Thus the distinction between the investigator's obligations in therapeutic and nontherapeutic experimentation is that in non-therapeutic experimentation the volunteer can never be considered a patient, so exceptions to full disclosure such as therapeutic privilege cannot be applied. The physician may not withhold for any reason, any information from a prospective volunteer which he knows may influence the volunteer's decision to participate (Annas et al. 1977).

adopted by the 18th World Medical Assembly in 1964 and revised in 1975 (Beach, 1979), is based on the principles of the Nuremberg Code and addresses the issue of both therapeutic and nontherapeutic research, making the necessary distinction between the two.

Regarding therapeutic research the Declaration states that "the doctor must be free to use a new therapeutic measure, if in his judgement it offers hope of saving life, reestablishing health, or alleviating suffering" (Annas et al. 1977; p. 282) with the proviso that freely given informed consent is a necessary

prerequisite. Experimentation combined with professional care is considered permissible only to the extent that the experiment is justified by its therapeutic value to the patient (Annas et

al. 1977).

Declaration of Helsinki. The Declaration of Helsinki,

The Declaration is more specific with regard to experimentation in the nontherapeutic setting and sets out the following requirements:

- The nature, purpose and risk of the research must be explained to the subject.
- The research requires the free informed consent of the subject or if the subject is incompetent, of his legal guardian.
- 3. The subject should be in such a state as to be able to exercise fully his gover of choice.
- 4. Consent should as a rule be secured in writing; however the responsibility for obtaining consent in some form rests on the investigator.
- The investigator must respect the subject's right to safeguard his personal integrity.
- 6. The subject or his guardian should be free to withdraw their consent at any time; if the experiment appears to be potentially harmful to the subject, the investigator should discontinue it. (Annas et al,

The issue of the quality of the subject's consent is thus fully addressed by the Declaration of lateral subject in subject in the consent is thus to Annas et al (1977), it can be introduced in subpractice proceedings as a standard of care.

Current Status of Informed Consent in the Experimental
Setting. While there is no general agreement among courts as to
the precise nature of the risks to be disclosed in order to obtain

imformed consent in experimentation, the general conclusion is

that in the nontherapeutic setting more detailed disclosures are required and no therapeutic privilege obtains (Annas et al, 1977). The courts do seem to be in agreement that the doctrine of informed consent in any experimentation places the responsibility on the physician to ensure that the consent is competent, voluntary and informed as to the nature of the procedure and its risks. While understanding is considered a prerequisite to consent in experimentation, the courts thus the have been more concerned with the facts of disclosure than with the nature of that understanding.

Informed Consent in Treatment

There is a fine distinction between experimental and nonexperimental treatment especially when that treatment is relatively new. Katz (1972) points out the increased awareness of the close relationship between the two. He states:

research and therapy, pursuit of knowledge and treatment are not separate but intertwined. Therefore the focus on experimentation and the concomitant emphasis on 'informed consent' created new difficulties not merely because of the requirements to inform patient-subjects about proposed rebearch, but also because consent raised troublesome questions about what all patients should be told about medical interventions. (p: 319)

While more than 200 cases have been brought before the courts since World War II with the question of informed consent to new and established treatment (Holder, 1978), only a few of the most influential will be discussed.

(Salgo v. Leland Stanford Board of Trustees (1957) was the first post-Nuremburg appellate court decision regarding treatment, and one which set the tone for later decisions by requiring that there be disclosure of the risks involved in treatment. concerned a relatively new procedure which had resulted in the permanent paralysis of the patient. Neither the patient nor his wife were informed of the risks involved nor of the fact that the procedure was relatively new at the time. Despite the novelty of the procedure, the issue before the court was not one of experiment ation, but of consent to treatment. The court found the physician liable and ruled: "A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of ag intelligent consent by the patient to the proposed treatment. Likewise, the physician may not minimize the known dangers of a procedure or operation in order to induce his patient's consent" (Holder, 1978; p. 228).

A 1958 decision similar to that of Salgo is Bang v. Charles T. Miller Hospital which concerned a patient who was not informed that a proposed bladder operation would also entail having his sperm cords cut in order to reduce the risk of infection. In its decision, the court declared that where no emergency existed, the patient had the right to be informed so that he could weigh the risks of infection with the risks of sterility and decide whethen to consent to the procedure (Katz, 1972).

Until 1960, two major issues had been considered by the

or not consent to the particular procedure was obtained at all and, second, whether the partient was informed of the known risks inherent in that procedure. During the 1960s, the court looked beyond the question of whether consent was obtained to the quality of the physician's disclosure and thereby the quality of the consent, considering failure to infore adequately to be negligent disclosure (Romotf, 1981).

Natanson v. Kline. In 1960, the decision in the landmark case of <u>Natanson v. Kline</u> laid down the basic principles of the present doctrine of informed consent in medical treatment. <u>Natanson vas a malpractice action wherein the patient alleged that although she had consented to the radiation therapy which had resulted in her lajury, "the nature and consequences of the risks of the treatment vare not properly explained to her" (Katz, 1972; p. 531).</u>

The appellate court ruled that the burden rests on the patient to prove both absence of informed consent by the physician's negligence in disclosing risks that a competent physician would where identified in a similar situation, and that the injury sustained was due to the undisclosed risks inherent in or as a consequence of the treatment received (Kats, 1972). In his decision, Mr. Justice Schroeder referred to the right of the individual of sound mind to determine what shall be done to his body and, citing Salgo, the court held the physician liable, stating "the physician has the legal obligation to disclose and explain to the patient the nature of the proposed typetent, the probability of success, alternature of the proposed typetent, the probability of success, alternature of the proposed typetent, the probability of success, alternature of the proposed typetent, the probability of success, alternature of the proposed typetent, the probability of success, alternature of the proposed typetent, the probability of success, alternature of the proposed typetent.

natives available, and the possible dangers known to the physician" (Parry, 1981; p. 538).

Thus Natanson is significant in three respects. First it set out the duties imposed by the doctrine of informed consent by introducing the requirements of the physician's disclosure: the nature of the proposed treatment, its risks and likelihood of benefits, and the alternatives available to the proposed treatment This was the first time that any information other than the risks/ of the proposed treatment was considered relevant. Second, Natanson treated the lack of informed consent as negligent nondisclosure rather than battery on the grounds that battery is intentional and negligence is nonintentional (Katz, 1972; 1981). Third, the court applied the standard of the professional community to the necessities of disclosure in that the amount of disclosure required for a legally valid informed consent was based on what a reasonablepractitioner would do in similar circumstances, leaving the burden of proof on the patient to show by expert medical testimony that the physician was negligent in his or her disclosure (Rosoff, 1981)

The court described and upheld the standard of the resonable medical practitioner in 1965 in Aiken v. Clary, wherein the
petient alleged that he had not been warned that insulin shock
therapy could lead to a come with resultant brain damage (Rosoff,
1981). The court stated that the issue was not "what, regarding
the risks involved, the juror would relate to the patient...or
even what a reasonable man would ralate, but what a reasonable
medical practitioner would do" (Kats, 1972; p. 538).

Ressonable Man Rule. The "reasonable practitioner rule" was the standard regarding facts of disclosure adhered to by the courts until. 1972, when in the landmark case of Canterbury v. Spence, the court rejected the physician's claim that it was not the practice to disclose the risk that a laminectomy might result in paralysis. The court stated that "the touchstone for the law on informed consent is the patient's right of individual self-determination" (Rosoff, 1981; p. 38) and it is this right of self-determination that "shapes the boundaries of the physician's duty to disclose all material risks, all serious inherent and potential hazards, alternative methods of treatment, and the likely results of nontreatment" (Holder, 1978; p. 222).

In <u>Canterbury</u> the standard of disclosure is based on the patient's need-to-know and includes the disclosure of any risks which might be material to-the patient, decision. Mowever, the court ties materiality of risks not to the particular individual involved, but to those risks which "a reasonable person, in what the physician knows or should know to be the patient's position, would be likely to attach significance to...in deciding whether or not to forego the proposed therapy" (Rosoff, 1981; p. 54). Thus the standard of disclosure set by <u>Canterbury</u> is patient-based rather than physician-based.

Canterbury marks the beginning of what is now known
as the Reasonable Man Rule and represents a philosophical shift
away from reliance on the professional community to determine the

necessities of disclosure (Rosoff, 1981). A practical result of the <u>Canterbury</u> decision is that it relieves the patient-plaintiff of the burden of producing expert testisony as to the standard of disclosure of the professional community, thereby hipproving the patient a strategic position vis-a-vis the physician (Rosoff, 1981) and moving journel qualizing the doctor-patient relationship (Annas et al., 1977).

While the Reasonable Man Rule has not been followed in all states and has been rejected outright in some as leading to a plethora of malpractice suits and placing too heavy a burden on the physician, this approach "seems to reflect the trend in judicial thought" (Rosoff, 15-1; p. 41).

Using either the old reasonable practitioner standard or the new standard of the reasonable man, the onus is on the patient to prove causality in order to show negligence; that is, the patient must prove that a duty to diclose was breached and that the breach caused injury. Under the Reasonable Man Rule, the patient has to prove that the undisclosed risks would have been material to his or a reasonable man's decision. While expert testimony may be required to show what the known risks are regarding a procedure, the patient is not required to provide expert testimony regarding the practice of disclosing those risks.

In Cobbs v. Grant, also decided in 1972, the court endorsed the Reasonable Man Rule and, recognizing the abject dependency of the patient on the physician for information on which to base his decisions (Hannah, 1981), the court regarded certain information

to be fundamentally necessary in all cases, stating: "a medical doctor has a duty to disclose to his patient the potential of death or serious harm, and to explain in lay terms the complications that might possibly occur. Beyond the foregoing minimal disclosure, a doctor must also reveal to his patient such additional information as a skilled practitioner of good standing would provide under similar circumstances" (Rosoff, 1981; p. 79). Requiring the explanation to be covered in lay terms increases the possibility of the patient's underestanding.

Current Status of Informed Consent in the Treatment

Setting: While traditionally lack of informed consent has been to considered a battery, as in Schloendorff, the general tendency is for the courts to consider battery only when the patient is in total ignorance of what is to be done or if the patient consents to one intervention and receives another.

Because of the pejorative nature of the tort of battery and the assumption that the physician acts in good faith, the courts have increasingly tended to view the act of nondisclosure of tisks as a breach of duty and therefore consider it negligence (Annas et al; 1977). The recent trend in the judiciary is to use a patient-based standard of disclosure, resting on what a reasonable person would need to know in order to decide whether to undergo a particular intervention. Despite this standard however, the courts have continued to recognize the physician's therapeutic privilege in the acknowledgement that "there are situations where

a full disclosure to the patient is not medically sound" (Rosoff, 1981; p. 54).

Since the mid-1970s, many state legislatures have joined the courts in their attempt to define a legally valid informed consent; however, there is still much uncertainty in the concept (Rosoff, 1981). Generally, it can be assumed that the physician must provide the following information:

1. diagnosis

p. 265).

- 2. nature and purpose of the proposed treatment
- 3. risks and consequences of the proposed treatment

6. prognosis if the treatment is not given. (Rosoff, 1981)

- 4. probability of success
- 5. feasible treatment alternatives
- The issue of voluntariness has been somewhat problematic with regard to treatment that violates a person's religious freedom. However, except in cases of emergency, the court has chosen to safeguard religious freedom and allow the patient to refuse treatment, citing the 1976 case, In the Matter of Melideo "the general rule that an adult person of sound mind cannot be compelled to submit to medical treatment against his or her will unless the

Lack of competence to consent to treatment has generally been resolved by the courts' requiring a proxy consent from the person's legal guardian. the courts have not questioned the right of parents to consent to treatment for a sick child fannas et al,

state can show a compelling overriding interest" (Rosoff, 1981;

1977). However, in a substitute consent situation, Since there
is no reason to fear that disclosure to the person acting on the
patient's behalf will have any adverse effect on the patient, therapeutic privilege does not apply; a complete and frank disclosure
is required (Rosoff, 1981).

Most court cases involving informed consent in treatment have been based on the physician's failure to distiose the risks and consequences of the proposed intervention (Boooff, 1981), thus the issue that have been most often addressed is whether the consent is informed. While in the experimental setting undeat anding is considered a prerequisite to consent, it is only recently that the patient's understanding in the treatment pontent is becoming more accepted as a requirement of a legally valid informed consent (Somerville, 1979). In both treatment and experimentation, the courts thus far have been more concerned with the issue of disclosure, still leaving undefined the question of the evaluation of the subject's or patient's understanding.

Summary

Throughout the evolution of the informed consent doctrine the courts have focused on the question of self-determination and the related concept of individual autonomy. There is a trend in the courts, as agents of society, towards an increasing emphasis on and recognition of individual autonomy and a decreasing villingness to delegate control to the professions.

This could be viewed as a signal to the professions that, while they have been granted special status in many ways and can consider themselves immune to certain requirements, society, through the courts, will not allow them to take advantage of their status or nower to override the autonomy of the individual.

The Nuremberg Military Tribunals disclosed the atrocities that took place during World War II and demonstrated the horrific possibilities of what can happen when professions and the society in which they work have no restraints. It was at least in part this extreme abuse of the individual's autonomy and of humanity itself that led to the recognition of the profound importance that must be placed on safeguarding individual autonomy. The courts have recognized the potential that the doctrine of informed consent has for providing a practical means whereby this autonomy can be safeguarded.

Description of the Doctrine of Informed Consent

This section will examine the doctrine of informed consent in terms of its purpose and underlying assumptions, the functions served by the doctrine and the elements required for consent to be considered valid. A number of issues related to the purpose, functions, requirements and possibilities for meaningful consent will be identified and explored in an effort to understand both the complexities and potential value of the informed consent doctrine.

Purpose and Underlying Assumptions of Informed Consent

The doctrine of informed consent is the legal principle which recognizes the right of the individual to determine his or her own destiny by providing the individual with sufficient information to make a free and rational choice about participating in a proposed intervention. At the heart of the doctrine lies the belief in the idea of individual freedom, which is the "cornerstone of the Western concept of man and society" (Katz, 1972; p. 521). Macklin (1982) has suggested that the ethical principles which underlie the purpose of informed consent are twofold and "réflect the dual purpose behind the informed consent acottjne" (p. 349).

The first of these ethical principles is derived from utilitarian theory which holds that "morally right actions or practices are those that result in a positive balance of pleasure over pain, happiness over unhappiness, or other beneficial consequences over undesirable ones" (Macklin, 1982; p. 349). This ethical precept gives rise to the purpose of beneficence or protecting people from

harm and is expressed in the risk-benefit ratio used in informed

The second ethical principle emphasizes the rights and duties of individuals rather than the consequences of their actions, and is derived from the work of Immanuel Kant. This principle can be expressed in terms of the primacy of the value of individual autonomy and human dignity which leads to the basic rights of life, liberty and autonomy and from which "the patient's right to decide arises" and it is this ethical principle which gives rise to the purpose of showing respect for an individual's autonomy (Macklin, 1982; pp. 349-350).

According to Macklin (1982), while the dual purposes of beneficence and respect for the individual's autonomy carry the seeds for potential conflict, they can also work in concert. For example, informing the individual of the risks and benefits of a proposed intervention and giving her the opportunity to weigh them relative to each other and to her situation allows the individual the possibility of being autonomous in protecting herself from Incressary or unwanted harm.

The conflict between these dual purposes arises when it becomes necessary to override an individual's autonomy in order to protect her or others from harm. This potential for conflict is one that philosophers view as being inherent in the dichotomy between the individual and society and it is a dilemma that posses one of the great difficulties of the human condition. As Macklin (1982) points out, the-conflict between beneficence and autonomy

is not a conflict between good and evil but rather a conflict between
two morally good principles and for this reason it is essential
that a continuing dialogue take place so that each principle may
be understood relative to the other vistarvis the use of informed
consent.

Functions of Informed Consent

Webster's Dictionary (1969) defines function as "the action for which a person or thing is specially fitted or used, or for which a thing exists" (p. 338). The functions of the informed consent doctrine are necessarily related to its purposes in that it is through the functions that the purposes or ends are achieved.

Traditionally, the function of informed consent was to separate legally permissible touching from unauthorized touching (Katz, 1972); however, it can be seen from the cases in the previous section that, as the doctrine has evolved historically, more emphasis has been attached to the concept of autonomy both as a purpose and as a function.

Katz (1972) has identified three major functions of the modern doctrine: promoting individual autonomy, encouraging rational decision-making and protecting the experimental process. However, Annas et al (1977) state that the doctrine serves only two functions: promoting autonomy and encouraging rational decision-making. Annas et al (1977) do not include protection of the experimental process as a function separate from encouraging rational decision-making. Anna they believe that promoting autonomy and encouraging rational

decision-making are part of the larger function which is the "promotion of equity and fairness among parties who otherwise have inherently unequal bargaining positions" (p. 33).1

According to Gadow (1981) there are two aspects to the first function of promoting autonomy: autonomous agency which involves freedom of choice, and autonomous action involving "freedom from interference in action upon one's choice" (p. 859). When autonomy is promoted in both of these ways through informed consent, freedom is safeguarded, the individual is protected and fraud and duress are minimized (Kats, 1972).

The second function of the doctrine is based on the assumption that "rational decisions are more likely to be made if they are left in the hands of those who bear the risk of those decisions rather than those who might have ulterior motives...in making the decision" (Annas et al, 1977; p. 37). In order for this function to be carried out properly, the individual must know the nature and purpose of the procedure, its risks, benefits and alternatives and be allowed to decide her course of action.

The ability to make rational decisions is determined by
the amount and kind of information available to the individual and
by individual's capacity to comprehend the information. Comprehension
can be aided or interfered with in two ways. The first is in the
amount of information provided and the second is in the way the

The difference between Katz and Annas et al is probably not as important as its might seem and may be explained in terms of the concern of Annas et al with informed consent in the non-experimental setting as well as the experimental setting.

information is provided (Katz, 1972). In a study by Gray (1975), it was shown that a failure in communication can undermine comprehension and obscure the decision-making process, making a request for a decision appear to be a request for compliance.

Katz (1972) has identified a number of "barriers" to rational decision-making which impede the individual's ability to rationally use the available information; these are transference, countertransference, dependency and regression. Besch (1979) states that many of these barriers arise from the doctor-patient relationship which is in itself one of the potential impediments to rational decision-making. These barriers include such things as the patient's dependence and the status difference between physician and patient which can lead to a reluctance to ask questions or a feeling of obligation to comply with the request.

Finally, both the level of the individual's understanding and the amount of energy the individual can expend are related to such factors as nervousness, being in an unfamiliar or a crisis situation, or lacking one's usual support systems. These factors also act as further barriers to rational decision-making (Sommerville, 1979).

It is because of these potential barriers to rational decision-making that the onus of responsibility rests with the professional to make sure that the information is not only heard but also comprehended.

The third function suggested by Katz (1972) is the protection of the experimental process. By this Katz means: (1) that the

experimenter is protected from legal liability and (2) that the experimenter is compelled to think through the experiment in order to provide disclosure, thus adding a dimension of integrity to the experimental process. According to Annas et al (1977), the physician cannot always know whether the right treatment is being used, nor can the physician know all of the possible effects of treatment. It is this dimension of uncertainty that makes treatment a kind of quasi-experiment, thus the protection accorded to the experimental process should be extended to the treatment process as well.

It is through the interaction of these three functions of the dottrine that autonomy is promoted and inviolability preserved.

If these functions are not properly carried out, neither autonomy nor inviolability can be realized. As Annas et al (1977) have observed.

only by going through the difficult task of tailoring information to fit the procedure and the paient is it likely that either individual auconomy or rational decision-making will be processed. If neither of these functions is furthered, the process becomes meaningless. (o. 42)

Requirements of Informed Consent

Although the Nuremberg Code was developed to deal with the question of consent in medical experimentation, it has become the standard for consent to treatment as well. This code requires that consent be voluntary, competent, informed and understanding. The Nuremburg Code states that in order for a person to be able to consent voluntarily to a procedure, that person

> should have legal capacity to give consent and should be so situated at to be able to exercise free power of choice without the intervention of any element of force, fraud, deceit, duress/overreaching, or other ulterior form of constraint or coercion and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. (Annas et al. 1977; p. 279)

Voluntariness. In order for consent to be truly voluntary, the individual must be free of force, fraud, coercion or undue influence. The individual must be aware that she has the right to refuse treatment (Hannah, 1981), and has the right to withdraw consent without fear of reprisal or loss of a needed service (Somerville, 1979). Somerville (1979) emphasizes that only if consent is seen as a continuing requirement, will the individual be aware that she is face to hatop consenting.

The problem of ensuring voluntariness in consent arises in two areas. The first and most obvious is that of obtaining voluntary consent from involuntarily detained individuals. This problem was addressed at some length in Kaimovitz, which highlighted the obvious coercive effects of the institution.

The second area in which the problem of voluntariness comes into focus relates to the more subtle coercive elements that exist in any setting where consent is required (Somerville, 1979). These elements exist whenever an individual is in physical or emotional need and is receiving or hoping to receive a service from that

setting. Other elements which can impact on the voluntariness of consent in subtle ways are the manner in which the consent is requested, and the critical question of who is obtaining consent (Somerville, 1979). In this regard, Somerville (1979) warns against paternalism as a potential coercive element; she states that coercion "may be most subtle and difficult to detect and freedom of choice most threatened in a situation in which the most powerful party, believes he is acting for the benefit of the other" (p. 48).

Competence. The question of competence arises most often in the context of interventions with children and psychiatric patients and has recently received increased attention. The courts have struggled with the question of the age of consent and the purpose of consent as it applies to minors. Annas et al (1977) and Macklin (1982) have warned against the current tendency to assume incompetence in institutionalized patients, and Macklin (1982) has pointed out that generally a patient's competence is only called into question when she rejects a proposite treatment.

Appelbaum and Roth (1982) have proposed a hierarchy of standards of competence. The most lenient in this hierarchy is evidencing a choice. With this standard an individual is considered competent to make a decision if she can communicate in some way her willingness or unwillingness to undergo a given treatment. This standard is the most respectful of the sutonomy of the individual in that it does not allow proxy-consent as long as the individual is able to indicate a decision.

The second standard proposed by Appelbaum and Roth, and according to Macklin (1982) the most videly accepted standard of competence, requires a factual understanding of the issues. Competence is assumed and consent is required from that individual if she is either capable of understanding or actually understands the description of the proposed intervention.

The ability to rationally manipulate the information is the third standard, for competence and is the standard embodied in laws regulating contractual capacity. This standard requires that the individual be able to use the information available in the decision-making process in order to be considered competent to give consent.

The strictest standard for competence is the requirement that the individual have the ability to appreciate the nature of the situation. This requires the abstract capacity to integrate all of the information relative to the treatment with what the individual already knows about the situation, and then make a decision based on the integration of that information.

As Macklin, (1982) points out, the standard of competence used for requiring consent will vary according to the intrusiveness of the treatment, but more importantly it will vary according to whether the purpose of the doctrine is perceived as being aimed at autonomy or potention from harm: "the stricter the standard for competence, in the inderests of protecting patients from their own unwise decisions, the more patient autonomy is sacrificed for gain in benevolent paternalism" (p. 364).

Informed. The requirement that consent be informed is tial part of the doctrine. Meisel (1981) states that "The

an essential part of the doctrine. Meisel (1981) states that "Che disclosure requirement...is the heart of informed consent" (p. 2473). At a minimum diclosure must include:

- A description of the proposed treatment, its duration, purpose, and the identification of any experimental procedures (Annas et al. 1977; Macklin, 1982).
 - 2. A description of appropriate alternative treatments or procedures (Annas et al, 1977; Hacklin, 1982).
 - 3. Any inherent risks or disconforts that can reasonably be foreseen (Annas et al., 1977; Macklin, 1982). (Annas et al. (1977) have concluded that no precise definition exists as to the nature of the risks that must be disclosed. Macklin (1982), has suggested that the requirement of risk disclosure depends on the purpose the doctrine is serving. If the purpose of protection from harm is being served, the duty to disclose increases as the risks increase. If however, the purpose being served is respect for individual autonomy, the actual degree of risk makes little difference to the need for their disclosure.)
 - 4. Anticipated problems of recuperation (Annas et al., 1977).
 - 5. Anticipated benefits of the procedure (Macklin, 1982).

- 6. The extent to which confidentiality will be maintained (Macklin, 1982).
- 7. Whom to contact for answers to pertinent questions (Macklin, 1982).
- A statement that participation is voluntary, that refusal will involve no penalty, and that the individual is free to discontinue his participation (Macklin, 1982).

There is general agreement that there are four conditions under which there is no need for disclosure. No disclosure is necessary in an emergency to carry out essential interventions. Therapeutic privilege is also considered a justifiable breach of disclosure if the physician "can reasonably conclude that informing the patient might be detrimental to the well-being of the patient." (Cohen, 1979; p..251). The other two circumstances that can justify non-disclosure are: -if the treatment is a simple one of common knowledge and the danger is remote, and if the endividual has indicated that she does not want the information (Annas et al, 1979; Besch, 1979).

Understanding. It is only recently that attention has been extended beyond the question of disclosure to the issue of understanding (Annas et al. 1977). Somerville (1979) has pointed but the difficulty that lies in ascertaining the nature and level of understanding when obtaining informed consent. Meisel (1981) states that a number of recent atudies have attempted to examine

the question of understanding and have concluded that, in general, the level of understanding in patients is not very high (Meisel, 1981).

Some of the reasons suggested for a low level of understanding are that the language used to inform the individual may be too complex, or the forms used to obtain consent may be too long for easy comprehension. It has also been suggested that not enough time is allowed the individual to assimilate the information; if too much information is given too quickly, it becomes more difficult for the uninitiated to understand. Finally, there is conflicting evidence as to whether the medium used for disclosure affects the level of understanding (Meisel, 1981).

To offset the low level of understanding, some authors have advised the creation of patient advocates to act as third parties with the task of ensuring an opportunity for the patient to ask questions, and ensuring that the patient does not consent to a procedure without having had a chance to understand what undergoing that procedure may mean (Annas et al, 1977; Besch, 1979).

Annae et al (1977) have pointed out that, notwithstanding the exception in law to the requirement of understanding in the therepeutic context, that the requirements that the individual be informed and understanding are crucial to the ability of the doctrine to fulfill its functions, and achieve its purposes. They state, "if full information is not both disclosed and comprehended before the patient or subject is asked to make a decision, the

functions of the doctrine cannot be attained, and it becomes a useless rule" (p. 53).

Summary

The requirements of informed consent essentially constitute the sine qua non of autonomy. Autonomy requires that the individual be free to sict voluntarily, be sufficiently competent to care for herself and make decisions, have sufficient information on which to base those decisions, and understand what that information means and what the action will mean in her life. Without these elements, truly autonomous living is difficult if not impossible. It is important to note that these requirements were enunciated as a direct result of the Holocaust by the Nuremburg Court in order too asfectived individual surpompy.

Although there are many issues surrounding the difficulties of obtaining meaningful consent, and some controversy about the need for and reality of a meaningful consent (Macklin, 1982), the literature appears firm in concluding that the doctrine is a valid means of safeguarding individual autonomy in an inherently unequal relationship such as the relationship between a doctor and patient. Annas et al (1977) and Somerville (1979) have pointed out that informed consent should not be seen as a single event or as an end in itself, but as a means toward the end of achieving autonomy and as an ongoing process of sharing information in order to achieve that end. As Freud (1972) states, "a requirement of voluntary informed consent does have values beyond the symbolic one of respect for individual autonomy and personality. It is far from the be-all and end-all of legal and ethical safeguards, but it is a valuable ultimate check" (p. 604). The doctrine of informed consent acts as a necessary although not sufficient requirement of professional intrusion into other people's lives.

The Status of Informed Consent in Psychiatry and Psychology

This section wild present a brief review of the current status of informed consent in the mental health professions and some of the issues that have been raised in psychology and psychiatry with regard to its application.

The professions, particularly the "helping professions", have special powers and privileges within society. In order to justify these special powers and privileges, professions make two claims: that they will use their powers in the public interest, and that they will maintain effective self-regulation against the possible abuses of power (Barber, 1980).

Katz (1972) maintains that, while the services of a professional are usually initially sought out by the client, once the client has "placed himself in the expert's hands", it is the professional and snot the client who has the power, and who selects the goals and the means and skills he will use to attain those goals (p. 185). This decision-making power is supported by the client's willingness to trust the expert (Katz, 1972). Thus despite certain constraints upon the professional, in the relationship with the client, the professional's autonomy seems to be increased, the client's autonomy decreased, and the power imbalance, between the professional and the client is perpetuated.

In his arbicle on the ethics of physicians and lawyers,
May (1977) comments on the nature of the client's relationship

with the professional and suggests that informed consent can be used as a mechanism to respect the client's freedom. He states:

Clients surrender to the professional sng yet feel 'uneasy about this surrender. The professional, therefore, not only must deliver technical services to offer relief for distress, but also he must be continually on guard, as the controlling actor in the situation, to respect his patient/client for the free man that he was, still is—despite everything—and once again will be. Such respect takes many controlling to the profession of the controlling of coversion for informed consent. (n. a.)

The awareness of informed consent in medicine has extended to the mental health professions of psychiatry and clinical psychology. Despite some controversy over the possibilities for applying informed consent in the treatment context, some clinicians have begun to consider informed consent an essential part of the ethical aspect of their practice (Hare-Mustin, Marsacek, Kaplan and Liss-Levinson, 1979).

The Extension of Informed Consent to Psychiatry and Psychology

Cohen (1979) has identified the issue of control as perhaps the most important ethical question facing the mental health professions today. The centrality of this issue is highlighted by the surfacing of two important trends currently influencing the practice of psychology and psychiatry. First is the recent emphasis on the rights of consumers (Hare-Mustin et al., 1979) and a concomitant recognition of clients as consumers of mental health services (Margolin, 1982). Second is the judiciary's beginning involvement in examining the rights of clients receiving mental health care (Hare-Mustin

Psychology and psychiatry are beginning to look to informed consent as an ethical response to these trends in society and the judiciary (Cohen, 1979). According to Smith (1981), there is now "an unprecedented advocation of informed decisions by clients regarding the goals and procedures of therapy" including provision of information about the psattices and competence of therapists, and the possible alternative sources available for help (p. 22).

The literature in psychology treats informed consent in three contexts (Cohen, 1979). In the first two, the patient's or subject's waiver of confidentiality and the use of informed consent in research, there is little debate. However, the third and most commonly cited context, pre-treatment disclosure of the possible risks and benefits of a proposed therapy, has engendered some controversy. It would be an oversimplification to suggest, despite the increased attention given to informed consent, that the doctrine of informed consent is completely in place in psychology and psychiatry. As Katz (1981) points out, this is not the case, since "any change in professional values and belief systems is a slow process. Therefore, it would be surprising, indeed suspect, if the recent interest in disclosure and consent had already made a significant impact on existing practices" (p. 99).

Ethical Arguments for Informed Consent: the Right to Autonomy

The ethical arguments for informed consent center around three concerns: the obligation of the mental health professional to ensure that the client's right to abconomy is upheld, the related issue of control, and the possibility for the intrusion of values into the treatment process. All of these arguments hinge on the recognition of the client's fundamental right to autonomy, the core of the ethical argument for informed consent.

Rosenbaum (1982) states that the principle of autonomy is recognized by contemporary ethical codes of psychiatry and psychology in their requirement of free and informed consent. Autonomy, as _ Katz (1981) points out, "requires nurture and care which communication and dialogue can provide by bringing into swareness all kinds of acknowledged and unconsidered influences on the choices about to be made" (p: 113).

According to Hare-Mustin et al (1979), the responsibility for nurturing the client's sutonosy and ensuring that the client's rights are not violated must rest with the therapist. They give three casens why this onus is necessarily on the therapist rather than the client. First, prospective clients are in a help-seeking rather than in a self-protective posture, which is a poor position from which to negotiate. Second, the therapy situation is a novel one for most clients; as a result they neither know what role, to assume nor what their rights are. And third, some clients may simply be incapable of protecting their own rights because they are used to, and often resigned to, having their rights denied.

Ethical Arguments for Informed Consent: -the Issue of Control

The issue of control can best be viewed in the context of the recognition of the client's right to autonomy and is based on concern about the exiating power imbalance between the client and therapist. Finkel (1980) has observed that "conditioning, psychosurgery, psychopharmacology and persuasion have all grown in efficiency, variety, and danger... What makes the danger clear, present, and more troubling is the increase in the 'applicability' of these tools to present-day psychological and behavioral problems at a pace that outraces the related, ethical discussion" (p. 17).

Burt (1979) points out the dangers that are inherent when any single party has total control through exclusive decision-making powers: "assigning exclusive decision-making appearing to an exclusive decision-making appearing to an exclusive decision-making appearing to none party...and complementary choiceless status to another in an interpersonal transaction readily leads to paradoxically destructive results for all participants" (p. 134). He advocates a continuing falogue such as that which can take place through the process of informed consent.

Ethical Arguments for Informed Consent: Lest Values Intrude

The possibility for control is implicitly present in the value assumptions of the therapist which are imposed in part through the mode of therapy the therapist chooses for treatment ***Mosenbaum (1982) paintains that "in every instance the personality theory which may have set out to be purely descriptive or even scientific, becomes normative and dictates the goals of therapy" (p. 24).

To offet this imposition of values and the consequent subtle control that ensues, Margolin (1982) recommends that provision of informed consent include informing clients of the personal values of the therapist which are implicit in the mode of therapy used.

Therapeutic Value of Informed Consent

In addition to the ethical obligation to provide informed consent, a number of authors have also referred to the therapeutic value gained from the consent process itself.

Finkel (1980) states that consent is required in behavior therapy in order for the treatment to be effective; without consent there is little likelihood that generalization to environments outside the therapeutic situation will occur. He argues that strictly external control offers fewer possibilities for generalization than control which has been relocated internally. Consent, he contends, is the mechanism by which this relocation can take place; requiring that a client consent to, plan and take responsibility for a treatment plan produces more demonstrable gains and more lasting changes than can be produced by any externally imposed regulation.

Katz (1981) acknowledges the difficulties inherent in the ability of both clients and therspists to tolerate the ambiguity and uncertainty implicit in much of psychiatric treatment, as well as the need for both the client and the therspist to have a certain amount of faith in the outcome of therapy. However, despite these difficulties, he believes that "many patients, if the opportunities

are provided, can and will participate in decision-making. Providing such opportunities will create a much better climate for the entire therspectic process than exists in contemporary practice" (p. 109). Further, Katz (1981) suggests that the ever-present problem of patents' regressing under stress might be reduced "by not keeping patients in the dark, by inviting them to participate in decision-making, [and] by addressing and nurturing the infact, sature parts of their functioning" (p. 1111).

Margolin (1982) underscores the therapeutic benefit that takes place when the client takes responsibility for making the decision to participate. She believes that taking this responsibility makes for more active participation on the part of the client during treatment.

Hare-Mustin et al (1979) state that informed consent has a number of therapeutic benefits. Informed consent "defines the therapeutic relationship as a mutual endeavor to which the therapist contributes knowledge and skill in psychology and to which the client brings specialized personal knowledge and a commitment to work on his or her problems" (p. 7). Through the process of informed consent, the client comes to understand the possible benefits of treatment, which encourages more realistic expectations regarding therapeutic outcomes. In addition, if the client has freely and knowingly consented to treatment, the likelihood of therapeutic impasses and unilateral terminations is minimized.

Issues Emerging from Informed Consent

One of the problems with implementing informed consent in the mental health professions is the question of the client's competence. The claim is made that clients seeking mental health services are incompetent to make informed decisions. However, Katz (1981) argues that therapists should assume competence rather than incompetence "and only in rare and well-specified circumstances meak authorization to override their patients' wishes" (p. 104).

Macklin (1982) opposes the tendency of thereplate to assume that their patients and clients are incompetent and declares that the rationale for lack of disclosure on the grounds that the patient cannot handle the information "is simply an attempt to justify an act of paternalism by clothing it in the mantle of professional judgement and expertise" (p. 368).

Some practitioners claim that the dependency of the client precludes the possibility for real consent since "some therapists can get their patients to consent to almost anything" and consent is therefore a meaningless charade (Macklin, 1982; p. 358), and should not be pursued. Macklin (1982) argues however that, if indeed it is true that the client can be talked into anything, this fact is simply a further testament to the power of the therapist and hence

²This suggestion that comparence should be assumed would appear to be schoold in the recent fulfing of the court in Rogers v. Okin (1979) wherein it was decided that voluntary and involuntary patienty, are comparent for the purpose of exercising the right to return mediation, absent an emergency. An emergency was strictly defined as "substantial likelihood of physical harm" to the patient or others (Rosenberg, 1981; p. 16).

increases the urgency for requiring that the consent process be undertaken in an attempt to redress the power imbalance.

Another issue that has emerged relates to the question of ensuring voluntariness in that involuntary partients among be free of at least subtle, if not overt, coercion when their release from the hospital may depend on their villingness to cooperate (Macklin, 1982). On the other hand, if there is no villalogue present at all, then no possibility exists for informed decision-making. And the potential for oppression in the name of treatpent is assured.

There are several knowledge-related issues that come to light in the context of informed consent in the mental health professions. Practitioners in psychology and psychiatry have access to a variety of possible tynatment modalities; however, there is little reliability as to the therapeutic outcomes and possible sidereffects of these modalities (Cohen, 1979; Mare-Mustin et al, 1979; Macklin, 1982). This indicates a clear need for further research into treatment outcomes and sidereffects (Mare-Mustin et al, 1979). Although uneven knowledge poses sajor problems in describing specific prescriptions for disclosure (Kats, 1981), it can be argued that it be precisely this uneveness that underlines the need for the provision of informed consent because of the quasi-experimental nature of treatment based on uncertain knowledge.

Other knowledge-related issues include the practitioner's lack of knowledge about alternative forms of treatment and the commitment the practitioner may have to her own particular mode of

reatment which may cause her to be reluctant to describe alternative, less favored modes of treatment even if she is aware of them. Congern has also been expressed among some therapists that disclosure of alternative modes of treatment might in itself undermine the clients' trust and confidence, thereby interfering with . the therapeutic process (Macklin, 1982).

The issues that have been presented here do not preclude the implementation of the doctrine in psychiatry and psychology. In fact, just the opposite might be argued. The dangers inherent in the professional's assumptions of incompetence and dependency, along with the limited knowledge on which the professional bases her decisions, serves to make the implementation of informed consent critical to ethical practice.

Summary

It is important to distinguish between the doctrine of idformed consent and the idea of informed consent in the mental health professions. The doctrine of informed consent refers to the legal profession's response to what it perceives as the need for greater communication between physicians and patients or therepists and clients. The idea of informed consent, on the other hand, refers to the quest for a doctrine which takes informed consent sentimentously (Kate, 1981).

Clearly, maither of these is firmly entrenched. The legal profession has only begun to deal in a serious way with the issue of the informed consent doctrine in psychological or psychiatric treatment, notably in <u>Kaimovitz</u> and <u>Rogers</u>. The idea of informed consept, however, has received some attention in recent psychiatric and <u>Asychological</u> literature. The most compelling arguments for informed consent are based on the ethical stance; that treatment without the provision of informed consent constitutes a moral injury because it reduces the client's autonomy. A secondary benefit of informed consent is therapeutic, and includes the possibility that exists in the consent process for nutturing clients' greengths.

Although it may be tempting for practitioners to forego thying a implement informed comment because of the many difficulties and challenges it presents, the ethical obligation incurred by the client's right to autonomy, the awareness of client rights in society, and the increasing involvement of the judiciary make it mandatory that mental health practitioner extend their thinking regarding their ethical standards and seriously examine the idea of informed consent in their practice (Hare-Mustin et al. 1979).

If the principle of autonomy is a valid one in our society, then the professions of psychiatry and psychology are clearly on the right track. They are beginning to examine the possibilities for ensuring that the client's right to autonomy is protected by searching for a way to put informed consent into practice.

Social work requires a means to operationalize its commitment to autonomy. This Section proposes the doctrine of informed consent as the mechanism whereby autonomy can be safeguarded and the possibility for personhood created. The references to informed consent in the social work diterature will be reviewed and some of the possible reasons for the profession's lack of attention to informed consent will be explored. The case will be made that informed consent is especially needed in social work due to the special character of social work clients, the profession's knowledge base and the nature of its interventions. The special relationship among @ the requirements of informed consent when applied in social work . and the relationship of these requirements to autonomy will be described along with an explanation of what is incumbent ugon the speial worker in monitoring these requirements. Finally, some of the possible implications of implementing informed consent will be explored in terms of the client, the practitioner, the educational institution and the profession

Informed Consent in the Social Work Literature,

The literature on informed consent in social work is extremely limited. The few references to informed consent that do exist fall into four categories only one of which refers to informed consent to a social work intervention.

The first category in the social work literature deals

Alth informed consent medicine, and the role of the hospital

social worker as an advocate for the patient to ensure that the patient has had the opportunity to give a free and fully informed consent to a suggested medical procedure (Parry, 1981). The second category in the social work literature refers to the use of informed consent procedures in waivers of confidentiality (Bernstein, 1981) Rosenblast and Waldfogel, 1983). The third category is informed . consent in research. Rosenblatt and Waldfogel (1983), point out in the context of single subject design, that the informed consent of the subject is required in order to carry out such experimentation in social work. The only reference to informed consent to a social work intervention is made by Bernstein (1981) who refers to informed consent as a means for practitioners to avoid malpractice suits when they use a "radical" therapy in their intervention. Bernstein states that the social worker must be able to show "that the treatment used was not negligent under the circumstances. One way to avoid such a pitfall might be to secure an informed consent .. the social worker should explain the proposed therapy or treatment, its advantages and dis wantages, as well as its risks and results that may reasonably be anticipated. The client can either accept or reject the course of treatment" (p. 177).

The subject of informed consent to non-radical social work interventions has been almost entirely ignored in the literature. While there are some statements which might be construed as implicit recommendations for informed consent, such as the suggestion that the client be involved in practice decision-making (Vigilante, 1974), or the acknowledgement that sanction for an intervention must come

from the client (Simon, 1977), it is clear from these statements only that the client should be involved in some Way; the nature of that involvement is left unspecified.

From time to time, more specific statements have appeared in the literature referring to consent, but in the context-of a more general discussion values. Newy (1974), for example, comes close to recommending the inclusion of informed consent in social work interventions by proposing that respect for the client's autonomy requires that "the practitioner should provide or illuminate those facts the client will need to make intelligent and realistic decisions. He should clarify the alternatives available, as well as the anticipated consequences" (p. 212). He does not, however, say anything about consent to the intervention as a prerequisite for action.

Abramson (1982) and Siporin (1975) address the question of uncoerced consent. Abramson (1982) comments that "social workers must present clients with viable alternatives from which to choose, full information about those alternatives, and the opportunity to choose freely without undue coercion" (p. 20). Siporin (1975) makes the only explicit reference to the application of informed consent in practice. He states, "respect for the client's autonomy...is conveyed by permissiveness and by encouragement of the glient to exercise his own free will and active judgement in making informed choices and decisions and by obtaining the client's informed consent for helping actions" (p. 77).

The problem with these statements is that while they recognize the need to include informed consent or something like it in practice, they are isolated statements. They are, for the most part, single sentences found in the context of describing social work yalues and include no further explication of informed consent. As such, these statements probably have little or no impact on practice.

The lack of attention to informed consent in social work is not surprising. In the first place the literature on informed consent has generally been restricted in scope to medical settings; it is only recently that it has been brought to the attention of those professions which are more closely allied to medicine, such as psychiatry and psychology. Second, other than in the context of vaiving confidentiality, the subject of informed consent is not included in the curriculum in schools of social work. Even with regard to confidentiality, the concept of informed consent, if applied at all, is often applied incorrectly, ignoring the requirement that the client be informed of the risks, benefits and alternatives to vaiving confidentiality. It should more properly be called consent to celease information' rather than informed consent.

Finally, the attitude that society has historically held, and to some extent continues to hold toward clients who, avail themselves of social work services may have influenced the profession's lack of attention to informed consent as a routine part of practice interventions. These clients are often in some way disadvantaged, and they receive services that are paid for by society. In a society which places a high salue on the ability of the individual to pay

his or her own way, clients who do not pay for services are often seen as less important or deserving of respect than clients who do pay. The non-paying client is often seen as fortunate to have a service, available at all. Since professions do not operate in a vacuum, but are influenced by the prevailing views in society, it is not difficult to see how such a disparate view of clients would not incline the social work profession to demand that their non-paying clients be accorded the same rights to informed consent as clients of other professions who pay for their services.

Informed Consent as Critical in Social Work

It has been shown that social work's commitment to personhood carries with it an implicit commitment to the autonomy of the
client. The application of informed consent in practice is a practical and measurable way of honouring this commitment. When autonomy
is balanced against the character of the client population, the
nature of interventions used in social work and the knowledge upon
which these interventions are based, it becomes clear that such a
practical means is critical to ensure that client autonomy is not
eroded.

The Client Population. While the problem of autonomy is an issue in many professions, it is even more significant for social work than, for example, medicine or law because of where the indivirgular requesting services stands in relation to her autonomy. In law and medicine, the individual most often requests services because

she feels a threat to her autonomy. The lawyer's client may be accused of a crime and faces the possibility of a prison sentence; she feels a threat to her freedom and autonomy. The patient may request the service of a physician because she is ill and her autonomy is temporarily reduced or she fears that the illness may lead to debilitation, dependency or even death; she fears for the loss or reduction of her autonomy in a physical and perhaps emotional sense. In both cases, part of the motivation to seek the services of the professional is either astemporary loss of autonomy or a perceived threat to autonomy.

In social work, however, when the client requests services, it is often not because she feels a threat to her autonomy but because her autonomy is already distinished. While there is no single category that would adequately describe all of the individuals who seek the services of a social worker, it could be said that the majority of social work clients are in some way disadvantaged, economically, socially or psychologically. This disadvantage is emperienced by the individual as some form of internal or external constraint. In other words, the autonomy of a disadvantaged client is impaired. Often her diminished autonomy is not temporary, but is one that has endured during her entire life, and sometimes in the history of her family as well. It may be at least in part because of her impaired autonomy, and perhaps motivated by the pain that results from a lack of sense of autonomy that the individual has soughtithe services of a social worker.

The individual whose autonomy is impaired or diminished may perceive herself as not being in control of her life or circumstances. She may have few resources at her command and little choice as to how she can resolve her problems or where she can turn to for assistances.

When these problems are considered in light of the profession's commitment to autonomy, it becomes clear that it is critical that every effort be made-to enhance the client's autonomy by increasing the client's range of choices and awareness of the possibility for choice. This can be provided through the informed consent procedure by giving the client information at the outset outlining the choices that exist for intervention or non-intervention and the risks and benefits of each as well as a clear statement that the client has the right to refuse to consent to the proposed intervention. Although this involves risking the possibility that some people may choose not to avail themselves of social work services after having been informed, this course seems morally preferable to treating the client as choiceless thereby further diminishing the client's autonomy.

Intrusiveness of Social Work Interventions. Social work interventions run a wide gamut, from the provision of concrete services to intricate interpersonal and intrapersonal modes of psychotherapy. For any of these interventions, the client is asked to give up a measure of privacy in order, for example, to determine aligibility for social assistance, or to benefit from a service such

as family counselling. Social workers routinely explore the private lives of their clients by such seemingly simple questions related to the client's income or inability to work or by the more obvious invasions of privacy involved in exploring the nature of a marital relationship or the interactions that take place between a mother and child. What all of these interventions hold in common §s a requirement that the client provide information to the social worker that is not usually a part of the client's public self. By giving up her privacy, the client is being asked to make herself vulnerable; it is this demand for vulnerability that constitutes a part of the intrusive nature of the social work intervention.

The second aspect of intrusiveness is the actual acting on this vulnerability. That is, once the client has allowed herself to be vulnerable by providing the required personal information, the social worker often makes a decision to act in a way or ways that potentially or actually have a profound and sometimes devastating effect on the client's life. There is a wast range of such decisions, such as the decimal that a client is ineligible for public housing, or that a child should be removed from her home.

The profession's commitment to sutonomy would dictate that the client has the right to decide knowledgeably to what extent she is willing to allow herself to be uninerable and whether she is willing to engage in any subsequent intervention. The first decision would require an understanding of the kinds of personal information she will be expected to share, the alternatives available to

providing the requisite information and the likely consequences that may follow upon her decision. The client's decision as to whether she will participate in subsequent interventions requires that she know the likely risks and benefits as well as the alternatives of the proposed intervention and their probable outcomes. Clearly there may be times when the interests of society are such that the client has very little choice, as in instances of child abuse. When this is the case, this information should be included in the gdisclosure as well as the likely consequences of the client's non-participation, for example, the loss of parental rights.

The Nature of Social Work Knowledge. The knowledge upon which social work interventions are based has two sources; some is borrowed from other disciplines and bome is developed from the profession's experience (Bartlett, 1964). Each of these kinds of knowledge is problematic in ways that have implications for the use of informed consent.

Several authors have questioned the reliability and usefulquess of the borrowed knowledge (Chambers, 1975; Howe, 1980). Howe (1980) argues that "in terms of their ability to explain, control and predict..social science theories have been disappointingly unsuccessful" (p. 321). It is unlikely then that the social worker can guarantee a.specific outcome from her intervention. In this sense, the practice of social work is no different from that of medicine which faces the problem that: largely because what the physician decides to do (and not to do) on behalf of a patient is based on less than perfect knowledge, it has been said that "in a sense his every tlinical act is an investigation", and that "medjeal experimentation on bhama beings, if its broadest meaning and for the good of the individual patient, takes place continually in-every doctor's officien". (Fox, 1972; p. 707)

The knowledge used in social work is also "less than perfect", thus social work interventions might also be considered to be quasi-experimental in nature. When the quasi-experimental in nature of social work interventions is considered along with the profession's commitment to autonomy, the obligation to provide the client with the means to make an informed decision becomes even more crucial than would perhaps be the case if the social worker could promise that a specific desired outcome would result from the intervention.

The knowledge that is derived from social work experience carries with it a different kind of problem in addition to the foregoing. Werner Boehm (1958) has observed that the knowledge used for social work practice is determined by the profession's goals, functions and the problems the profession seeks to solve. This means that knowledge derived from practice is based on what the profession wants for people rather than what it knows about people. This is true not only on the macro level of the knowledge developed by the profession, but also on the micro level of the knowledge gained in individual practice and used by the individual practicioner. Referring to the micro level, Goldstein (1973) observes that:

the theofts and concepts that the social worker, selects, tests and finds useful are congruent with his own beliefs about the nature, dynamics and transactions of persons, groups, and society, they are, in a sense, core formal elaborations of his basic values about person-to-person and person-to-society relations. (p. 90)

What becomes apparent then, is that the knowledge derived from social work practice is inextricably fied to what both the profession and the individual practitioner value. In this sense, Schwartz (1976) is correct in saying that "everything woo do or fail to do is related to a value base" (p. 393).

The doctyline of informed consent provides a mechanism whereby the practitioner can avoid the accidental intrusion of professional or personal values on the client. This is accomplished by providing the client with a clear explanation of the basis upon which the problem is defined and the intervention is made, including the value assumptions that may underlief the definition of the problem. Providing the client with this kind of information opens up the possibility that, should she decide to confine with the proposed intervention, she is doing so knowingly and, insofar as Axternal constraints allow, autonomously. Without this information, the client and the practitioner may become embroited in the unresolvable value dilemms so often referred to in the literature.

Any one of these characteristics of social work, the nature of the client population, the intrustveness of the interventions, or the nature of the knowledge used would be sufficient to make the inclusion of informed consent necessary. But when all of these characteristics are taken into consideration in light of the

The Special Relationship Among the Requirements of Informed Consent in Social Work

The doctrine of informed consent requires that consent be voluntary, competent, informed and understanding. In order to understand the way informed consent would be applied in social work, it is important to understand the rationale for including all of these requirements, their relation to autonomy, the way in which they are interrelated and the impact that the intrusiveness of social work interventions has on the operation of these requirements.

Rationale For Inclusion of Requirements. In order to undertake this analysis, it would be useful to begin with an examination of the view of the courts with regard to the requirements of informed consent in medicine. The courts have recognized a difference in these requirements according to whether an intervention is primarily therapeutic on experimental (Annas et al. 1977). For a therapeutic intervention, the client's inderstanding is not required and the courts allow a lower standard of competence and volunturiness. This is based on two assumptions: that the intervention is made with the intention of benefitting the client and that the practitioner is setting in the client's base interests. In nontherapeutic experimentation however, the courts require that

consent be understanding as well as informed and impose a higher standard of competence and voluntariness because the subject does not stand to gain any inherent benefit from the intervention, and it can not be assumed that the intervention is made in the subject's best interests. The courts take intrusiveness into account as well as the experimentality or therapeutic nature of the intervention, "the more drastic the procedure and its possible effect upon the patient and the exercise of his rights, the more likely that the stricter standards will apply" (Annas et al. 1977; p. 159).

Although social work interventions are usually made with the aim of benefitting the client and with the client's best interests in mind, they are also made under an agency mandate and with the sanction of society. This means that the goals and pesources of the agency play a part in determining the nature and goals of interventions and that, at times, it is society's best interests that have priority and society that stands to benefit from a proposed intervention. Even if all social work interventions were based on firm knowledge and therefore were strictly non-experimental, and were made solely in the best interests of the client, the minimum requirements for the fulfillment of the commitment to autonomy would be that consent be informed, competent and voluntary. However, since many social work interventions are quasi-experimental because of their non-guaranteeable outcomes and because these interventions are made under an agency mandate and often in the interests of society rather than the individual, the commitment to autonomy

requires that consent in accial work be informed, voluntary, competent, and understanding.

Mobile-of Autonomy. The requirements of informed consent have previously been described as critical to and essentially the necessary elements of autonomy. These elements may be conceptualized as part of a mobile of autonomy that includes the intrusiveness of the intervention as a counterbalance. In order to create the possibility for autonomy, the mobile must be kept in equilibrium; if any element is out of balance, or a threat to the balance, it must be compensated for with one or more of the other elements.

The social worker's task is to monitor these elements so that equilibrium is maintained. If the social worker intervenes with a procedure which is based on uncertain knowledge, the information she will be able to provide will be less solid; while she may be able to indicate what the unknowns are, the "softness" of the knowledge or theory she uses will determine the extent to which she is able to make any accurate predictions of the likelihood of desired outcomes or undesirable side effects. Thus, "softer" knowledge makes for less adequate disclosure which diminishes the possibility that consent will be adequately informed. Referring back to the model of the mobile, the effect of less than adequate information is that the parts are out of equilibrium. In order to compensate for inadequate information and bring the mobile back into equilibrium, a minimally intrusive intervention and a higher standard of voluntariness, competency and understanding are required.

Clearly the social worker has little control over the client's competence or voluntariness; the client comes to the social worker with a level of competence and voluntariness that is already established. What the social worker can control is the nature of the intervention she uses, the level of its experimentality and therefore the amount and clarity of her disclosure. In other words, the social worker has control over, the element of intrusiveness, the extent to which the client is informed and the possibility that exists for the client to understand.

The question of competence or incompetence should not be answered by the social worker. This is a legal question, and one that should be addressed by the courts. If the client is adjudicated as incompetent, appropriate steps to secure informed consent by her legal guardian should be taken. If however, the client is legally competent, it remains for the social worker to assess her relative competence and compensate for any lack of competence by adopting a higher standard of voluntariness, by using an intervention which is based on firm knowledge, relatively simble to provide disclosures for, easily understandable, and less intrusive.

In the same way, the social worker must compensate for a client's level of voluntariness. Clients are frequently mandated to seek social work services, and the social worker may have little control over the extent to which the client has been coerced into accepting services. The social worker does have the power to expand the client's choices within this mandate by offering the client alternatives in treatment that would have the same likely outcome.

As well as expanding the voluntariness involved in mandated treatment, in order to keep the mobile in equilibrium, the social worker must compensate for the lack of voluntariness by adopting a higher standard of information and understanding and by using a less intrusive intervention.

If the proposed intervention is potentially or actually quite intrusive, which happens most frequently when social workers are acting as agents of social control; the knowledge upon which the idtervention is based has to be firm and include a high level of predictability, the standard for disclosure and understanding must be high, and every effort must be made to further compensate for a high level of intrusiveness with high standards of competence and voluntariness.

By monitoring the requirements of information, understanding, competence and voluntariness and the counterbalance of intrusiveness, and by compensating for any elements which are out of equilibrium throughout the informed consent process, the social worker creates the possibility for client autonomy. Insofar as the social worker fails to acknowledge and monitor these elements, the possibility for autonomy will be diminished.

implications of Informed Consent

. The incorporation of the doctrine of informed consent into everyday practice will have numerous implications for the client, the social worker, the social work educator, and the profession as whole. These will be briefly discussed in an effort to understand what meaning the application of informed consent might have for social work.

For the Client. The most important implication for the client, and the main rationale for the inclusion of informed consent, has to do with the client's autonomy. One of the primary functions of the doctrine of informed consent is to promote autonomy, and it would be hoped that, in the long run, this goal would be attained. In the short run, by monitoring the elements of informed consent in-relation to each other and in relation to the intrusiveness of the proposed intervention throughout the interventive process, the provision of informed consent will ensure that, at a minimum, the client's autonomy is not diminished thus keeping the moral rule intact, and that, at a maximum by safeguarding the client's autonomy, her personhood may be promoted.

Requiring consent to interventions will have two immediate practical effects: it will introduce voluntariness to the client's participation and it will clearly locate appropriate responsibility in the client. This does not mean that the client should or will carry all the responsibility but that, through the process of informed consent, the client will be clear as to what share of the responsibility she owns in the treatment or interventive process.

Provision of informed consent will also have the desired effect of equalizing the relationship between the client and the social worker. Because the social worker is sanctioned by society through her agency and her profession, and because she is the

"expert", the relationship between the client and the social worker is necessarily imbalanced in favor of the worker. Providing the client with a mechanism to exercise her rights to choose empowers the client and enables the client to operate on a more equal footing with the social worker. The disclosure aspect of informed consent is particularly important in this empowerment because, by enabling the client to understand what the social worker is doing and why the activities of the social worker are demystified. Providing disclosure to clients has the effect of educating them, giving them their own tools and the means with which to solve future problems. This, along with the appropriate location of responsibility, minimizes the potential for client dependency, which further equalizes the client-social worker relationship.

Finally, implementation of the informed consent process implicitly demonstrates respect for clients which results in an actual increase of the respect that the social worker feels for clients and the respect the client, has for herself. This seems to operate in a circular fashion. Just as it is difficult to respect clients who are seen as choiceless and incapable of exercising their rights, when these same clients are treated with respect by making provision for them to exercise their rights and abilities to choose through the informed consent process, the actual respect the social worker feels increases. In other words, behaviorally operationalizing the value of respect for clients enhances the actual respect felt for clients. When this increase in respect is perceived by the clients, they can begin to have more self-respect.

For the Social Worker. The practitioner, as a member of the social work profession, has carried the difficult burden of being obliged to implement professional values without any guidelines for doing so. The application of informed consent provides a visible and behavioral means for acting on these values which reduces the intolerable and immobilizing burden of trying to translate values into practice without clear guidelines for action.

The disclosure requirement of informed consent will have implications for the individual practitioner's knowledge as well as her values. Providing disclosure will motivate the social worker to understand more clearly what whe is doing because this understanding is essential for provision of adequate disclosure. Implementing informed consent Elterally forces the practitioner to think through interventions and to be aware of the knowledge and assumptions underlying those interventions. The social worker will also be forced to learn about alternative bays of approaching a problem and alternative community resources in order to be able to adequately provide information about the client's options.

By requiring informed consent from a client as a prerequisite to any intervention, responsibility is more clearly located not only for the client, but also for the social worker. A clear location of responsibility for each party hight reduce the social worker's inclination to "rescue" the client by taking a disproportionate amount of responsibility for the client's life. This not only is good for the client but also may ultinately reduce that source of worker burnout which comes from carrying responsibility without control.

Informed consent will also help to alleviate the conflict that arises when the social worker feels-she Is in the position of being forced to choose allegiance butween the agency and the client. By illusinating all the major-risks and benefits of an intervention for the client and by providing the possibility for the client to decide, the social worker will less often be caught in the middle. If the client refuses the service on the basis of the possible risks induced by agency policy, the social worker will have data which she can use to influence policy change. This may remove some of the conflict for the worker, and diminish another source of worker burnout.

Finally, the application of informed consent will reduce the likelihood of malpractice actions. The social worker will be forced to be more careful in her choice of interventions and treatment plans and will be protected from malpractice suits because the client will have knowingly consented to the intervention.

For Education. The way in which the professional schools react to the implementation of informed consent will depend in part on the needs of the profession. It will be left to the educators to teach students the relationship between autonomy and the importance of explaining to their clients what they are doing, and the way in which this explaintion can be provided in the context of a theraphutic relationship. This will involve not only more emphasis

on applied ethics in the curriculum but also a greater emphasis on theory in order that the student will be able to understand the ethical and theoretical bases of her interventions in order to pass on the relevant information to clients.

The student will also have to be taught ways of facilitating and evaluating the client's understanding. It may be that teaching students how to use the doctrine of informed consent effectively, will prove an important vehicle for teaching them methods of establishing a therapeutic relationship.

For the Profession. There are several possible implications for the profession which may follow from the inclusion of informed consent in practice as a means of safeguarding autonomy. These implications can be seen in terms of the profession's values, knowledge and research, understanding of resistant clients and the practical issues which will need to be addressed by the profession.

Self-determination has been recognized by a number of authors as a problematic value for social work. This recognition of the problematic nature of self-determination has resulted in at least three approaches which attempt to deal with the ambiguity of the concept. The first approach begins with the recognition that so many conditions have been placed on self-determination that the concept is of limited or no value. McDermott (1975) refers to holding the principle within its "proper limits" of conformity with law and morality (p. 118). Biestek (1957) argues-that self-determination must be considered in terms of agency functions and the decision-

making capacity of the individual. Keith-Lucas (1975), states that these conditions, and the exclusion of the right to self-determination if exercising this right will be detrimental to the client or others, serve to make self-determination at best highly clusive, and at worst almost meaningless. With so many conditions placed on it, the concept of self-determination is considered nearly empty and of no real value in practice to either the profession or the client (Keith-Lucas, 1975).

The second approach asserts that self-determination is incompatible with the profession's social control and authority function (McDermet, 1975). At the heart of this view is the belief that the controlling function of social work is definitionally inconsistent with self-determination; proponents of this view have suggested that at a minimum the concept of self-determination needs to be re-examined and possibly dropped because it is a value that is impossible to implement (McDermott, 1975).

The third approach is a kind-of realignation to the inevitability of insoluble value dilemans. Schwartz (1976) has noted that given the difficulty in defining social work, the profession's values, the obligations and responsibilities of the social worker, and the agencies that support the social worker, it "must follow that the professional worker will be faced with severe...value problems which are ongoing and inescapable" (p. 394). This analysis offers no solution to the problem, only an admonition that the social worker should be aware of the value conflicts and value dilemans inherent in her work. In this analysis it would seem that being

a social worker carries with it the necessity of facing constant value dilemmas and living with unresolvable coperficit. The worker is immobilized and can only take confort in the knowledge that this plight is shared by other social workers. Clearly this is not helpful to the practitioner.

By refocusing the profession's energies toward the right to autonomy rather than self-determination (which it might be argued is not a right to be given or taken away, but simply a fact of human existence), the problems that were posed by the concept of self-determination are reduced. Because autonomy presupposes responsible action, conditions which are imposed by a commitment to self-determination are no longer necessary, and the social control function, of social work can be seen as compatible with safeguarding autonomy.

The inclusion of informed consent provides a mechanism for operationalizing the value of autonomy, as well as making clear the value assumptions on which any given intervention is based. In this way, the value dilemmas previously referred to become less pervasive and insoluble. Through the application of informed consent, the profession has a clear test for ensuring that its values are working and for justifiably pointing to its commitment to autonomy.

Operationalizing the profession's values is essential for mother reason: if the profession cannot demonstrate its respect for its clients' autonomy, it will be less respected by society, since professions are identified with and are dependent upon their clients for their sense of self. Operationalizing respect for

clients by safeguarding their autonomy through informed consent may thus serve to enhance both the profession's self-respect and the respect it gains from the society it serves.

The refocusing of the profession from self-determination to autonomy provides a way to re-examine the means-end question with regard to autonomy. This question can be approached philosophically and epistemologically. Ehilosophically autonomy has been described in terms of its instrumentality to personhood. Epistemologically autonomy is both a means and an end depending on the paradigmatic orientation of the practitioner.³

For example, the practitioner operating out of an Existential framework may be likely to view autonomy as an end in itself. For the practitioner operating out of a psychoanalytic framework, however, autonomy may more likely be viewed as a means to enable the client to come to terms with his own past. The commitment to autonomy can accommodate either point of view; thus the means-end issue becomes not a problem but an intriguing epistemological question, and not diminishing autonomy through the provision of informed consent becomes an enabling rule leading to a philosophical ideal of the promotion of personbood.

The view that not diminishing autonomy is a moral rule states the conditions for overriding autonomy clear. That is, an individual's autonomy can only be overridden if a greater evil will

This would hold true for self-determination as well. Philosophically it is a means to autonomy. Epistemologically, however, whether self-determination is viewed as a means or an end depends, in the same way, on the orientation adopted by the practitioner.

thus be prevented. For example, a parent's autonomy can be overridden if so doing will prevent the greater evil of abuse of a child. However, her autonomy cannot be overridden in order to provide a more stimulating atmosphere for the child. This does not mean that the social worker should not inform the parent of better parenting skills; in fact, the dectrine of informed consent would dictate that it is the practitioner's duty to inform the parent of the conhequences of continuing to provide an understimulating environment and the benefits of attempting to improve that environment. In other words, the parent can be invited to participate in an intervention, but not coerced (thus overriding autonomy) unless there is a good likelihood that non-involvement will lead to 4 violation of a moral ideal which will, by definition, be perpetrating an evil.

Requiring informed consent will also have an effect on the profession's knowledge. The requirement of providing disclosure and alternatives will mean that the profession itself, as well as its members individually, will have to know more and be more current with knowledge from other disciplines. The experience of its practitioners, who will thus have a strong theoretical understanding of their interventions might open up possibilities for further research. For example, if the practitioner clearly understands the basis upon which she has defined the problem and the basis on which the intervenes, if she has explained this to the client and secured the client's informed and understanding consent, and is the intervention still has an unsuccessful outcome, the-practitioner will have

norf information upon which to evaluate the reasons for failure.

This will impact on the profession because, as more of its practical interpretationers gain a better understanding of the knowledge upon which their practice is based, the knowledge base of the profession as a whole becomes stronger and possibly broader. Further, the profession will have a basis upon which to go back to the disciplines from which the knowledge has been borrowed with information which may bely these to further refine and rework their theories.

The provision of informed consent may also open up new ways for the profession to view "resistant" clients. The profession may be forced to reopen the question of what a resistant client is if, even with consent as a prerequisite, the profession is still faced with resistant clients. Reopening this question may provide further understaphing into the causes of clients' resistance:

It is possible that, because of the obligation to secure informed consent, a number of clients may choose to refuse to participate in social work services. The client's refusal to consent to nonmandated social work interventions might pose some intriguing questions, such as whether some crients refuse to consent because they now have an alternative which was previously unknown to them, or whether some clients refuse to consent because the risks or the discomforts are greater than the Potential benefits. If, in some instances, the latter proves to be the case, the profession will have a clear rationale for insisting that agencies reevaluate the policies under which their services operate.

Finally there are some practical issues with which the profession will have to deal if it is to implement informed consent. Such critical questions as the timing and prescribed content of disclosure as well as the form in which consent is obtained will require resolution.

The question of the enforcement of informed consent willneed to be addressed as well. Shall the profession of social work, like medicine, be legally mandated to provide informed consent to its clients? Or would legally mandating informed Consent only serve to enforce the letter of the doctrine, ignoring its spirit and purpose in relation to autonomy? Perhaps social work would do well to include informed consent specifically in its Code of Ethics. This might prove to be insufficient by itself because practitioners would be left ignorant of the why and how of implementing informed consent. Since many clients of social work services are in some kind of crisis or pain, devising the most appropriate methods of providing informed consent will be a delicate process. This is in part the task of the academy as well as the profession, as is the transmission to the practitioner of the methods and reasons for implementing informed consent. It might be argued that the profession should include informed consent both in its Code of Ethics and as part of the professional education and socialization process so that the purpose of informed consent relative to autonomy will not be lost in a bureaucratic tangle of forms and duties. .

Social work has had a long standing commitment to self-determination as a primary value. This study has proposed that the profession refocus its commitment from self-determination to autonomy, and institute informed consent as the practical mechanism whereby the commitment to autonomy can be upheld.

A review of the literature has shown that the commitment to self-determination is problematic for the profession in that the meaning of the term is unclear and the term is used in the literature with diverse meanings; there is serious question as to whether self-determination should be viewed as a means to some other goal or as an end in itself; and there is no adequate test to demonstrate the existence of the profession's commitment to self-determination in practice.

For the purpose of resolving these problems, the chocept of self-determination has been clarified and confined to its literal meaning of self-caused behavior, and autonomy has been proposed to connote the broader meaning of self-government. An examination of the devalopmental and philosophical relationship of autonomy to personhood has provided the rationale for changing the focus of the profession from a commitment to self-determination to a commitment to keep the moral rule of not diminishing autonomy in the service to the moral ideal of safeguarding autonomy and the utilitarian ideal of promotion personhood.

An analysis of the prerequisites for autonomy and of the

consent has led to the emergence of the doctrine of informed consent as the practical mechanism whereby the profession can keep the moral rule intact and honour its commitment to autonomy.

The importance of keeping the moral rule intact has been emphasized by a consideration of the nature of the profession's client population, the interventions it uses and the knowledge on which these interventions are based, all of which make the client's autonomy very precarious.

This study has described the practitioner's task in implementing informed consent as that of monitoring the requirements of the doctrine and ensuring that they are kept in equilibrium with each other in order to counter-balance the intrusiveness of the intervention. The many implications for the client, the social worker, the adjucator and the profession that may follow upon this implementation have been briefly discussed. Further research will be required to devise specific ways of implementing informed consent in different settings, under diverse conditions and with various kinds of clients.

In conclusion, this study has shown that refocusing the efforts of the profession toward autonomy will have the effect of resolving the problems posed by the diverse meanings of self-determination and the means-end issue, and the application of the doptrine of informed consent will provide the needed test to ensure that the profession's commitment to autonomy is upheld.

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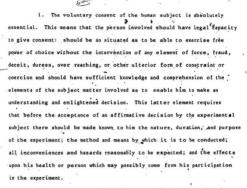
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THE NUREMBURG CODE



The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs, or engages in the experiment. It is a personal duty and reaponsibility which may not be delegated to another with impunity.

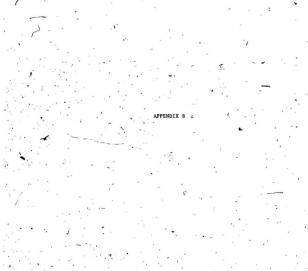
 The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.

The experiment should be so designed and based on the results

of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.

- 4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
- 5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except perhaps in those experiments where the experimental physicians also serve as subject.
- The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
- Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
- 8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct by engage in the experiment.
- 9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.
- 10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill, and careful judgement required of him, that a continuation of

the experiment is likely to result in injury, disability, or death to the experimental subject.



DECLARATION OF HELSINKI
RECOMMENDATIONS GUIDING DOCTORS IN CLINICAL RESEARCH

INTRODUCTION 😿

It is the mission of the doctor to safeguard the health of the people. His knowledge and conscience are dedicated to the fulfillment of this mission.

The Declaration of Geneva of The World Medical Association binds the doctor with the words: "The health of my patient will be my first, consideration" and the International Code of Medical Ethics which declares that "Any act or advice which could weaken physical or mental resistance of a human being may be used only in his interest."

Because it is essential that the results of laboratory experiments be applied to human beings to further scientific knowledge and to help suffering humanity, The World Medical Association has prepared the following recommendations as a guide to each doctor in clinical research. It must be stressed that the standards as drafted are only a guide to physicians all over the world. Doctors are not relieved from criminal, civil and ethical responsibilities under the laws of their countries.

In the field of clinical research a fundamental distinction must be recognized between clinical research in which the aim is essentially therapeutic for a patient, and the clinical research, the essential object

of which is purely scientific and without therapeutic value to the person subjected to the research.

- I. BASIC PRINCIPLES
- Clinical research must conform to the moral and scientific principles
 that justify medical research and should be based on laboratory
 and animal experiments or other scientifically established facts.
- Clinical research should be conducted only by scientifically qualified
 persons and under the supervision of a qualified medical man.
- Clinical research cannot legitimately be carried out unless the importance of the objective is in proportion to the inherent risk to the subject.
- Every clinical research project should be preceded by careful assessment of inherent risks in comparison to foreseeable benefits to subject.
- Special caution should be exercised by the doctor in performing clinical research in which the personality of the subject is liable to be altered by drugs or experimental procedure.
- II. CLINICAL RESEARCH COMBINED WITH PROFESSIONAL CARE.
 - In the treatment of the sick person, the doctor must be free to use a new therapeutic measure, if in his judgement it offers hope of saving life, reegtablishing health, or alleviating suffering.

If at all possible, consistent with patient psychology, the doctor should obtain the patient's freely given comsent after the patient has been given a full explanation. In case of legal in-

capacity, consent should also be procured from the legal guardian: in case of physical incapacity the permission of the legal guardian replaces that of the patient.

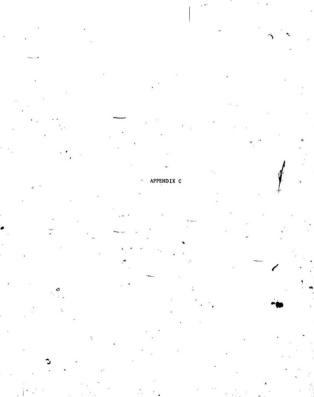
- The doctor can combine clinical research with professional care, the objective being the acquisition of new medical knowledge, only to the extent that clinical research is justified by its therapeutic value for the patient.
- III. NON-THERAPEUTIC CLINICAL RESEARCH .

2.

- 1. In the purely scientific application of clinical research carried out on a human being, it is the duty of the doctor to remain the protector of the life and health of that person on whom clinical research is being carried out.
- The nature, the purpose and the risk of clinical research must be explained to the subject by the doctor.
- 3a. Clinical research on a human being cannot be undertaken without his free consent after he has been informed; if he is legally incompetent, the consent of the legal guardian should be procured.
- The subject of clinical research should be in such a mental, physical and legal state as to be able to exercise fully his power of choice.
- Consent should, as a rule, be obtained in writing. However, the responsibility for clinical research always remains with the research worker; it never falls on the subject even after consent is obtained.

- 4a. The investigator must respect the right of each individual to safeguard his personal integrity, especially if the subject is in a dependent relationship with the investigator.
- 4b. At any time during the course of clinicial research the subject or his guardian should be free to withdraw permission for research to be continued.

The investigator or the investigating team should discontinue the research if in his or their judgement, it may, if continued, be harmful to the individual.



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