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AUTHOR	Adelman, Howard S.; Taylor, Linda
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ABSTRACT

The paper discusses the ethical bases for practices in identifying learning disabilities (LD) in children. The state of the art in identification is briefly highlighted, as is the controversy over responsibility and abuse in the process. The author asserts that concerns over current practices do not change the underlying responsibility to provide LD persons with appropriate help. Current practices are reviewed in terms of their lack of efficacy and conceptual and methodological problems. Issues of ethical concern are discussed for three areas (sample subtopics in parentheses): utility and equity (cost vs. benefits); consent (autonomy and informed consent, competence and paternalism); and demystification about current limits of competence and knowledge. A final comment notes the social action nature of professional intervention. (CL)

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Ethical Concerns and Identification of Learning Disabilities

Howard S. Adelman and Linda Taylor
University of California, Los Angeles

Abstract

Currently procedures for identifying learning disabilities are much in demand, especially those for identifying problems at an early age. With the increasing demand has come widespread concern over potential abuses and misuses of identification and labeling procedures. Some critics have gone so far as to argue such procedures are unethical. The purpose of this paper is to discuss the ethical bases for identification practices and major ethical concerns, perspectives, and principles related to such practices. In particular, concerns are explored with reference to the differing perspectives of the various interested parties who may be affected and the concepts of utility, equity, consent, and demystification.

Howard S. Adelman is Associate Professor of Psychology at UCLA and Director of Fernald.*

Linda Taylor is Assistant Director of Fernald.

*Fernald is a clinical training and research facility of the Department of Psychology focusing on learning and related behavior problems.

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Ethical Concerns and Identification of Learning Disabilities*

Howard S. Adelman and Linda Taylor
University of California, Los Angeles

Awareness of the plight of those with psychoeducational problems leads to a desire to identify and help the individuals involved. In doing so, the intention always is to behave ethically--to respect individual rights, liberties, dignity, and worth. Unfortunately, these rather straightforward aims have proven easier to espouse in codes of professional ethics and statements of standards for practice than they have been to accomplish in daily actions.

Psychoeducational practices and research have been criticized by political conservatives, liberals, and civil libertarians. Ethical concerns have been raised regarding diagnostic testing, labeling individuals as learning disabled, and implementing various treatments based on specific diagnoses. Some critics have stressed the psychological, social, and possible physical negative effects on individuals; others have pointed out that subgroups may be unfairly discriminated against; and still other critics have raised the spectre that the society as a whole may suffer negatively from such activity.

In marked contrast to such critics are those professionals who have tried to underscore positive values of psychoeducational interventions. While acknowledging the potential for misues and abuse, they stress that it is a core ethical responsibility of professionals to advance knowledge

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and skills related to intervention activity and to use practices in ways which provide maximum benefits and minimal negative effects. To do otherwise is to ignore the responsibility to help those with learning problems and to deny the rights of those who want help.

The contrasting perspectives of those who stress concern over iatrogenic effects and those who stress the positive benefits of rights to psychoeducational intervention represent one set of ethical conflicts. Another major set of conflicts and dilemmas stems from the traditional tension between social control and individual freedom.

In this latter connection, critics have pointed to a tendency for individual rights and liberties not to be sufficiently considered and safe guarded during many psychoeducational interventions. The demand has been for greater concern for human dignity. Legally, this demand has been reflected in an emphasis on protection of rights and due process Ethically, the focus has been in improving consent procedures and clarifying the bases for mandatory intervention.

The purpose of this paper is to discuss the ethical responsibility for identifying problems, the ethical concerns which arise in doing so, and the ethical perspectives and principles involved in coping with these concerns. In the process, we briefly highlight the state of the art related to current identification procedures.

Ethical Bases for Identification

Identification or labeling is part of the general task confronting all practicitioners and researchers, namely, classification. Confronted with a problem, professionals attempt to organize and bring order to what otherwise might be confusing, overwhelming, and incomprehensible.

Classification is part of the process of understanding any phenomenon, and it is a prerequisite for most systematic practice and research.

Broadly, classification of learning problems and related phenomena may be conceived in terms of the need to categorize past, present, or future status as part of efforts to ameliorate, prevent, or study such problems. As used for scientific and practical purposes, classification is involved in meeting a variety of objectives of society, specific interest groups, and individuals. For example, in connection with learning disabilities, practitioners and researchers are interested in differentiating individuals with regard to the causes of their problems, current manifestations, prognosis, and treatment needs. More generally, rational communication with clients, colleagues, legislators and other policy makers, and the general public requires some way of differentiating among the many individuals who manifest learning problems (Adelman, 1979; Gough, 1971; Thorne, 1974, Zigler and Phillips, 1961). Obviously, there are a great many practical reasons for classifying learning problems.

Underlying the practical reasons are two major ethical justifications for identifying and labeling problems. From a scientific viewpoint, the philosophy of science stresses that investigation of phenomena is the essence of basic research, and to this end, classification is seen as an essential methodological component. From the perspective of the practitioner, there is the social philosophical principle which stresses that everyone is entitled to appropriate help in coping with problems for which they are not responsible. Again, identification is essential if practitioners are to provide such individuals with appropriate help.

While, in the abstract, identification is ethically justifiable and, indeed, desirable, prevailing practices raise many ethical concerns. It is important to understand, however, that the limitations of current practices do not alter the underlying responsibility to seek valid ways to classify in order to pursue important practical and research objectives. Ultimately, the value and justification for any classification scheme or particular label is judged, ethically and practically, by its sum-total contribution to research and practice. When the positive value is not found to outweigh the negative effects, the scheme or label is unlikely to be seen as ethically appropriate for practical or research purposes. This, of course, is not a criticism of the desirability of classification; it only reflects the inadequacies of current processes and the need for better ways to differentiate among those individuals manifesting learning problems.

Judgments about utility are strongly related to the needs of those making the judgments. Specific classification labels and identification procedures tend to be branded as useless and even as harmful and unethical by those who have no need for them, while those with a need for categorization tend to proclaim the value of the same labels and procedures with equal vigor. Even those who have a valid need for identifying learning problems, however, must ackowledge the limitations of prevailing practices.

State of the Art

Currently, procedures for identifying learning disabilities are much in demand. This is especially true of procedures which can be used to identify learning problems at an early age. Increased demand has made screening instruments a highly marketable commodity. This state of affairs has established a climate where both consumers and suppliers are less critical than they should be in evaluating the validity of proposed and prevailing procedures.

Indeed, there is a widespread and pervasive view among the general public that it is already, or shortly will be, feasible to make highly accurate predictions/identifications of learning disabilities. Large scale projects are being developed to implement mass screening in several states.

Efficacy

Because of the trend toward widespread application, it seems important to clarify that evidence does not support the efficacy of available predictive and identification procedures, especially those already being used for massive screening of preschoolers and kindergartners. Such widespread application provides another example of pressure and enthusiasm for new procedures leading to inappropriate extrapolations of research findings and premature application.

The fact is, few of the available procedures meet even the minimal standards set forth by the American Psychological Association and the American Educ. Research Association (see "Standards for Educational and Psychological Tests"). Earlier evaluations of research in this area remain true today. For example, Gallagher and Bradley stated in 1972: "It is important to note that the enthusiasm which generated these tests has not carried over to the technical development of the instruments" (p. 104). In 1975, Hobbs stated in the summary report of the project on classification of exceptional children:

> Every professionally competent report we have on early screening... strongly qualifies most assertions concerning the reliability, validity, or applicability of screening procedures..., especially for use in the early years of childhood. There are frequent references to the high level of clinical skill required to administer or interpret a test and to the need for sophisticated procedures or instrumentation... Tests are often described as "promising." Perhaps the most frequent recommendation of responsible reviewers is that more research is needed... Screening tests of sensory function (hearing, vision) are adequate for older children but difficult to use with younger children. Screening for retarded intellectual development in middle and late childhood is possible with a fair measure of confidence, although cultural backgrounds may render results problematic. Assessment of intellectual competence during infancy is highly unreliable. Early screening for affective or emotional development is extraordinarily difficult and perhaps impossible (except in extreme cases) with current knowledge (pp. 92-93).

In particular, we might add, the validity of first level screens is so low that they are expected to identify persons who don't even have signficant problems. At best, most screening procedures provide a preliminary indication that something may be wrong and that intervention may be needed. When the objective is to identify individuals with very specific problems and intervention needs, assessment procedures with greater validity are required. While warnings are made about the danger of blurring the distinction between first level screening and highly specific diagnostic-prescriptive activity (Meier, 1975), unfortunately, it is not uncommon for screening instruments to be misused. For example, some screens lead to the labeling of persons, and once this occurs, the label may be interpreted as a diagnosis, and the diagnosis may lead to a prescribed intervention (Adelman and Compas, 1977).

In addition to citing the technical inadequacies of available procedures, others have expressed a variety of concerns over child screening (Adelman, 1978; Adelman and Feshbach, 1971; Faust, 1970; Feshbach, Adelman, and Fuller, 1977; Hersch and Rojcewicz, 1974, Keogh and Becker, 1973, Meier, 1975). Perhaps, none have done so with greater fervor than Schrag and Divoky (1975) who go so far as to claim that "the prime function of all screening devices is mystification, a ritual conferring legitimacy on institutional decisions" (p. 129). This is a view which has been raised regarding comparable professional activity by such other sociopolitical critics as Laing (1970), Szasz (1961, 1970), Goffman (1973) and Illich (1976).

Conceptual and Methodolgical Problems

Essentially, three types of models underlie current identification procedures. The problem is that only one type of model has been used extensively (Adelman, in press). The three models can be conceptualized as (1) person oriented models, including both the disordered person (or "illness" model) and the developmental readiness model, (2) environmental models (also either pathologically or developmentally oriented), and (3) interactional models emphasizing the interplay between person and environment.

Research based on person oriented models has focused on assessment of early signs and symptoms of pathology (physiological and psychological) or on developmental deficits with reference to a delimited set of behaviors and learning correlates. Because of dissatisfaction with both the person model and findings on screening accuracy, environmental researchers recently have been assessing home and school variables in an effort to screen settings and with a view toward shifting the focus of intervention from persons to problem environments. Similarly, interactionally oriented investigators are interested in strengthening the predictive validity of screening procedures. They hope to do so by accounting for the portions of the variance of learning and behavior problems which stem from the transactions between the person's motivational states and response capabilities and such situational factors as individual differences among socializing agents (e.g., parents, teachers) and differing approaches to socialization (e.g., parenting, school instruction).

Most work focusing on identifying learning problems has been based on the person oriented paradigm. One very serious consequence of this which raises a number of ethical concerns is that the causes and corrections of learning problems are viewed primarily in terms of person variables. Some critics have suggested this is a classic instance of the fact that conceptual biases in psychology and education often result in a blaming of the victim (Ryan, 1971).

In addition to conceptual problems, there are critical methodological problems which should be highlighted briefly. In this connection, it is helpful first to understand the minimal requirements for developing satisfactory procedures for identifying learning problems at an early age on a large scale (Adelman and Feshbach, 1975; Muehl and Di Nello, 1976; Satz, Friel, and

Rudegeair, 1976). To maximize the likelihood of valid and practical identification, such procedures need to be validated longitudinally, using a multivariate design which incorporates a variety of measures of person and environment and a relatively large and homogenous sample. Such a design and sample is needed to allow for repeated measures, over time, of relevant variables and to control for such confounding factors as age, cultural and economic status and attrition. In addition, such samples need to be compared to a normative group, cross-validated on a similar sample and eventually on groups of different ages and cultural and economic backgrounds in different settings. Finally, if a procedure is to be used on a large scale (e.g., citywide in a large metropolis), there is a need to cross-validate under conditions of routine use, i.e., to do a "production-run."

It is well to recognize at this point that the best work in this area to date has not been able to come close to approximating these formidable methodological requirements. The relevant body of research suffers from the variety of traditional reliability and validity problems, such as rater/tester bias, fluctuations in children's performance due to motivation and the degree of assimilation of new behaviors and skills, and the limited range of behavior which can be sampled because of restrictions imposed by time and instrument availability.

These problems alone are sufficient to limit the usefulness of current approaches to identification. A related and particularly critical problem and one which has not been as widely discussed is the sparsity of standardized norms and standards which can be used as guidelines in making judgments about the behaviors and skills of children and the influence of environmental factors. Most commonly, this is a problem of the lack of specific criteria as to what constitutes "normal" and "abnormal" behavior and "success" or "failure" with reference to a youngster's performance or the performance of a socializing agent or program (e.g., parent, teacher, method, material). This is a problem for assessment efforts designed to identify contemporary problems and a compounded problem for efforts which attempt to assess antecedents in order to predict future performance. The lack of specificity regarding such criteria means that varying standards may be applied in indicating cut-off points for labeling a child as a problem. As a result, children with the same behaviors and level of skills could be seen as problems in one situation (e.g., one school) and not in another.

Because of the methodological problems cited above, whatever the approach to pinpointing psychoeducational problems, there will be a large number of false negative and false positive errors. Until such methodological problems are resolved, highly reliable and valid prediction or identification procedures which can be feasibly used on a large scale are not likely to appear.

In conclusion on this point, procedures currently used in identifying learning disabilities produce too many errors and appear most successful in detecting those who are readily identified informally. New approaches clearly are needed. In this connection, strategies guided by an interactional model and which recognize the importance of program improvement as a first step in screening are seen as particularly worth investigating.

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Ethical Concerns, Perspectives, and Principles

Table 1 lists 6 major areas of ethical concern which arise in relationship to processes used to identify individuals as learning disabled. Each area encompasses many specific dilemmas with which practicioners and researchers have to deal. Usually the dilemmas involve a need for and thus a responsibility to take systematic steps to minimize negative effects while maximizing positive objectives.

Unfortunately, the ethical responsibility to minimize negative effects related to the concerns outlined in Table 1 is easier to identify than it is to detail the specific standards and criteria for determining when this responsibility is being inappropriately ignored. Currently, ethical practice must rely on the perspectives and principles professionals adopt as the rationale underlying their work, especially the standards they choose to apply in judging positive and negative effects.

In this connection, Beauchamp and Childress (1979) suggest the principles of beneficence, nonmaleficence, justice, and autonomy provide a core foundation for understanding and handling major ethical dilemmas related to services, research, and public policy. In the following sections, we explore these principles and their application to learning problems with reference to three topics: utility and equity, consent, and demystification.

Utility and Equity

Traditionally, the most critical concern of interveners has been that

TABLE 1

Areas of Ethical Concern Related to Identifying Individuals as Learning Disabled

Outcome Concerns:

- Errors (e.g., false negatives and positives)
- Misprescriptions related to subsequent intervention procedures (including overidentifying individuals and subgroups as the object of change).

Process Concerns:

- Violations of rights (e.g., Failure to provide help; failure to get consent appropriately, invasion of privacy, denial of access to assessment reports and of the right to correct the record).
- Negative repercussions of assessment processes or products (e.g., increasing feelings of anxiety, incompetency, and lack of self-determination, increasing overreliance and dependency on professionals, initiating self-fulfilling prophecies and stigmatizing effects).
- Inappropriate financial costs and exclusion from services of those who can't afford services.

Field Concerns:

- Failure of professionals to take responsibility for improving standards of practice and advancing knowledge (including collusion with an inadequate status quo).

of ensuring that intervention benefits outweigh "costs". Recent legal emphasis on "rights to treatment" and "right of all children to an education" also have highlighted the moral obligation to ensure that interventions are allocated and implemented fairly. The directness with which such a statement of duties can be made tends to make implementation of these obligations sound less complex than it is.

¶ Costs vs. benefits. Those of us who work with learning problems confront the costs vs. benefits dilemma everyday. Should we proceed with an intervention? Will the special program help the child? If so, will the amount of help justify the pain, loss, and other potential negative effects the individual may experience on being labeled and differentiated?

It would be nice if professional training prepared us to deal with these concerns. Our particular training programs didn't and perhaps couldn't have done so. After grappling with the issues for many years on an ad hoc basis, we finally realized that perhaps it would be useful to go beyond our profession's ethical codebooks and attempt to assimilate the ethical principles underlying our concerns. With regard to cost-benefit dilemmas, this meant grasping the principles of beneficence, nonmaleficence, and their relationship to the principle of utility. Beneficence refers to one's duty to act positively in the interest of others. Nonmaleficence refers to one's duty to avoid acting negatively in relation to others. Utility refers to the obligation to produce the greatest possible balance of positive to negative effects for all persons affected.

When interveners talk of possible negative side effects, negative consequences, costs, risks, or harm, they recognize the possibility of maleficence. The emphasis is not only on intentional actions, but on unintended risks and harms, including acts of omission. What such phenomena make clear is that the ideal of nonmaleficence often must be compromised in efforts to help. In deciding whether to label a child as Learning Disabled, the principles of beneficence and nonmaleficence are in conflict. When such a conflict occurs, the decision to proceed can be made only by applying the principle of utility. Do possible benefits outweigh possible harm?

For example, in evaluating ethical concerns related to identification processes for learning disabilities, it often is suggested that the positive benefits accrue directly from the anticipated success of the intervention which follows or indirectly from research spinoffs. Unfortunately, there is a sparsity of reported evaluative research findings regarding the efficacy of most available intervention programs. Reviewers of the research on the efficacy of various psychoeducational interventions have found the external validity of reported studies to be quite limited and equivocal (e.g., Adelman and Compas, 1979; Bergin, 1971; Muehl and Forell, 1973; O'Leary and Drabman, 1971; Silverberg, Iverson and Goins, 1973; Sroufe, 1975). Thus, the perspective of positive benefits for identified children is a difficult view to support. And, even if there were proven benefits, they would have to offset any possible negative side effects on children resulting from identification and special intervention practices. In this connection, it has been hypothesized that persons who are labeled and treated as different may be stigmatized, isolated and excluded from important experiences, and this may negatively effect their motivation and further hinder their full and healthy development. The hypothesis of the self-fulfilling prophecy (Merton, 1948), suggests that attaching labels which connote disturbance and educational deficiency may just provide socializing agents with excuses for failure to relate to or teach a child. Moreover, it is hypothesized that such failure, then, eventually will determine the child's mobility, opportunity to associate with others, and opportunities for employment, marriage, and general social status. Just as there is a sparsity of efficacy data, there is a dearth of evidence regarding these potential negative side effects (Guskin, Bartel & MacMillan, 1975).

As the above illustrates, costs and benefits encompass more than financial considerations and often are not readily quantifiable. Besides finances, the costs and benefits most frequently discussed are psychological and physical effects on individuals. Unfortunately, the sparsity of data validating intervention efficacy and clarifying harmful effects makes it difficult to specify benefits and costs, nevermind determine net gains or losses. Thus, current efforts to resolve ethical dilemmas using a perspective which emphasizes cost-benefits for the individual must decide how heavily to weigh the potential--but unproven--positive and negative effects.

From a broader perspective, it has been suggested that cost-benefits also should be analyzed with reference to the societal "biases" perpetuated by intervention practices. For example, it has been contended that children whose backgrounds differ from the dominant culture will be classified and treated as deficient to the extent that their values and norms and, thus, their behaviors and performance are incompatible with those of the dominant culture. Whether intentional or not, in the process of providing benefits psychoeducational intervention practices can collude with biases against subgroups in society. Thus, the harmful effects on such subgroups must be considered in cost-benefit appraisals.

The point is that the focus can no longer remain simply one of cost-benefit to individuals. The concern over IQ testing related to minority students is a recent dramatic illustration of this point. Litigation arguing that minority populations have been inappropriately served by most IQ tests and resulting labeling (e.g., in California: Diana v. State Board of Education, 1970; Larry P. v. Riles, 1972) has led to the position that intelligence testing should be culture fair, including use of the individual's "home language," and that tests alone should not be used to classify students. Such litigation highlights the concern that the benefits of some school practices for any individual may be considerably less than the costs to a particular subgroup of the society, e.g., perpetuation of racial injustices in the form of additional discrimination, stigmatization, and restriction of educational opportunities.

Another level of ethical perspective, best articulated by Illich(1976), focuses on the iatrogenic effects of professional practices to the culture. He warns that the public's mystified reliance on professionals, who often are overstating their expertise, is growing. The negative effect of this trend for the entire culture is a general expropriation of people's coping ability so that society is manifesting an ever increasing, distressing and unnecessary overdependence on professionals.

This perspective suggests that professionals must judge the ethics of their activities not only in terms of the impact on an individual and the validity of their own and society's biases, but also with regard to the impact on the entire culture. From such a perspective, Illich would probably judge all mandated interventions as unethical. Obviously, few professionals are prepared to employ such a libertarian perspective in making ethical decisions regarding a given practice.

While balancing costs against benefits is important, the complexity of determining when and what costs outweigh what benfits makes the utility principle difficult to apply in many situations. Moreover, it must be remembered that even when the principle of utility can be used effectively in decisions regarding whether to pursue an intervention, it is still only one of the ethical principles to be considered. Overemphasis on the principle of utility at the expense of justice (fairness) in decision making, in particular, has been criticized. That is, there are times when costs, especially financial costs, of special programs for learning problems may well outweigh benefits; at the same time, application of the principle of justice may demand the programs be provided.

<u>Fairness</u>. It's not fair! is a classic complaint. On an intuitive basis, we often feel situations and people aren't being fair; and everyone believes in fairness. Students want privileges,

rules, and punishments administered fairly. One student must neither get more nor get away with more than another. We all want to see injustices corrected. The underdog should win at least some of the time. If someone is afflicted with a handicap or a learning problem, it seems only fair that they be helped. In providing help, interveners are expected to be just and fair. The problem is: How do we decide what is fair?

Beauchamp and Childress (1979) provide what they describe as a fairly standard list of nonmutually exclusive principles of distributive justice which have relevance for decisions about fairness.

- To each person an equal share;
- To each person according to individual need;
- To each person according to individual effort;
- To each person according to societal contribution;
- To each person according to merit.

All the principles are attractive. However, each may conflict with the others, and any one may be weighted more heavily than another depending on an individual's social philosophy.

As the above suggest, the matter of fairness involves such questions as: (1) Fair for whom? (2) Fair according to whom? and (3) Fair using what criteria and what procedures for applying the criteria? Obviously what is fair for the society may not be fair for a particular individual and what is fair for one person may cause an inequity for another. To provide special services for learning problems raises the taxes of all citizens. To deny such services is unfair and harmful to those who because of their problems need more help. Decisions regarding what is fair may be made paternalistically (unilaterally) or through informal or formal policy or by due process mechanisms. They may be made with regard to ethical or socio-political-economic criteria and priorities.

One basic principle formulated to guide decision making regarding what is fair and just is that similar cases should be treated alike and dissimilar cases should be treated differently. However, since we are all similar and dissimilar in so many ways, the characteristics which are to be considered in decisions of fairness must be relevant factors. Furthermore, it is regarded as unfair "to treat people differently in ways that profoundly affect their lives [particularly in negative ways] because of differences for which they have no responsibility" (Frankena, 1966, p. 10; as quoted in Beauchamp and Childress, 1979, p. 183).

Of more direct relevance to helping those with learning problems, there is the fair opportunity principle. This principle stresses that no one should be denied benefits on the basis of either "disadvantageous or advantageous properties," since they are not responsible for such properties. More affirmatively, fairness is seen as demanding that those with "disadvantageous properties" be given special aid. The duty to identify those who should be helped constitutes an ethical reason for classifying (labeling) individuals. However, this implies grouping individuals only with reference to relevant factors. At the same time, fairness requires that help and aid not become a basis for stigmatizing and isolating individuals and groups.

Psychoeducational intervention decisions based on the fairness principle often call for unequal allocation and affirmative action in distributing resources and applying rules. Thus, despite the fact they are intended to result in just and fair distinctions based on relevant differences, such decisions can be quite controversial, especially when resources are scarce.

There are always conflicting views as to which of many injustices should be assigned highest priorities in allocating limited resources. In a tight economy, controversies over fairness are likely to be extremely prevalent. Should school programs be cut back in favor of increasing welfare benefits? Should programs for the gifted be cut more than programs for students with learning problems? Should physical education and school athletic teams be cut more than orchestra and vocational programs? For the most part these are decisions made in the political arena with ethical concerns unfortunately playing a small role. However, even if they were made strictly on ethical criteria, the issues obviously are complex and only resolvable by giving more weight to one or a subset of the principles of distributive justice. In doing so, of course, there will not only be argument over the justification for giving extra weight to any particular principle but over the definition of such notions as "individual need" and "societal contribution."

On a more individual level, parents, teachers, psychologists, and other interveners consistently are confronted with the problem of applying rules differentially. Involved are matters such as whether different consequences (punishments) should be applied for the same offense when the students involved differ in terms of problems, age, levels of competence, and so forth. Again, the principles of distributive justice apply and again interpretations tend to vary and are debated. Furthermore, even when the adults involved agree on interpretations, one or more children may continue to perceive decisions as made unfairly. In such instances, adults may be seen to have the dual obligation of implementing justice in the full sense suggested above and of facilitating children's moral development toward understanding the complex nature of fairness.

Some persons try to simplify matters by avoiding making distinctions and treating everyone alike. From our personal experience, we recall many instances where teachers working with problem populations have insisted on establishing and enforcing rules without regard to the nature of a particular student's social and emotional problems. They usually argued that it was unfair to other students if the same rule was not applied in the same way to everyone. Years ago our main response to this argument was that to act so indiscriminately perpetuates the student's problem and undermined helping in the pursuit of social control and in the name of fairness. These days, we also try to expand teachers' awareness of the ethical complexities of fairness.

While making no exceptions represents a simple solution to resource allocation and rule application, it perpetuates injustices. We are painfully aware that an ethical commitment to fairness involves considerable effort to clarify how one understands the concept and how it can be implemented in the classroom and other intervention situtations.

Each principle of distributive justice has applications in such situations, and conflicts among the principles arise frequently. In the absence of simple prescriptions and great wisdom, only a very strong commitment to understanding and applying ethical principles can advance the cause of justice in such cases.

Consent

Currently, the concept of consent is a focal consideration in discussions of individual rights and professional ethics. To understand the importance of consent requires appreciation of the principle of autonomy. In a society which values fairness and personal liberty, the principle of autonomy and its relationship to consent is of paramount importance.

Autonomy and informed consent. As Beauchamp and Childress (1979) state:

> The autonomous person is one who not only deliberates about and chooses...plans but who is capable of acting on the basis of such deliberations...A person's autonomy is his or her independence, self-reliance, and self-contained ability to decide. A person of diminished autonomy, by contrast, is highly dependent on others and in at least some respect incapable of deliberating or acting on the basis of such deliberations. (pg. 56 &57).

Children and individuals with problems often are treated in ways that diminish their autonomy. This occurs because of assumptions about their relative lack of competence and wisdom. Even when they are treated autonomously, their decisions may not be respected.

> It is one thing to be autonomous and to apprehend that others are acting autonomously, but quite another to be <u>respected</u> as an autonomous agent and to respect the autonomy of others. To respect autonomous agents is to recognize with due appreciation their own considered value judgments and outlooks even when it is believed that their judgments are mistaken
>
> (Beauchamp and Childress, 1979, p. 58).

It is the idea that autonomy should be respected which has made consent not only a legal but a major moral concern. It is the fact that liberty is not absolute in any society and the problem that some indivudals are not able to act autonomously that has made consent a major socio-political issue. That is, society maintains the right to compel all its citizens at times (e.g., compulsory education), and when an individual is unable to act autonomously, others may be asked to assume the decision making role in consent proceedings.

Maintenance of autonomy in professional-client relationships depends on autonomous acceptance of authority by clients and ongoing respect for clients' autonomy by professionals. The legal and moral mechanism for maintenance of autonomy usually is designated as "informed consent."

Capron (1974) suggests six major functions served by the consent mechanism. These are:

- The promotion of individual autonomy;
- The protection of patients (clients, students) and subjects;

- The avoidance of fraud and duress;
- The promotion of rational decisions;
- The encouragement of self-scrutiny by professionals;
- The involvement of the public in promoting autonomy as a general social value and in controlling professional practices and research.

The desirability of such outcomes seems evident. The problems and issues involved in appropriately eliciting consent have to do with such matters as: When is consent needed? When is it justified for one person to consent for another? Who decides when consent is needed and when one person can represent another? What information must be given in eliciting consent? How can anyone be certain that consent has been voluntarily given? Each of these questions raises significant dilemmas for professionals, "consumers" of psychoeducational services, and for society.

With regard to the processes associated with the consent mechanism, Biklen (1978) stresses that the term <u>informed</u> consent probably somewhat misrepresents the nature of what is involved. As he states:

> It suggests that the key element of consent is the provision of information to people who are giving consent. Consent is a legal concept that has been referred to and implicitly defined in court cases and in legislation. It has three major aspects: <u>capacity</u>, <u>information</u>, and <u>voluntariness</u>. All three elements are equally relevant to any consent procedure or decision. Simply stated, one must have the ability

> to give consent in order to do so; one must have adequate information to do so in a knowledgeable way; and one must be free from coercion or any other threat to one's voluntariness (pg. 99).

In the following sections, we highlight major concerns associated with the concept of consent for psychoeducational interventions. Specifically, the focus is on (a) competence and paternalism as they affect decisions about when consent must be elicited and from whom and (b) the nature of relevant information and voluntary consent. The ethics of not obtaining informed and voluntary consent and thus coercing others is left for discussion elsewhere (Adelman and Taylor, in press).

The question of competence and the problem of paternalism. Capacity or competence in the context of consent essentially means the ability to understand (implying the ability to receive and process information) and to make decisions from among alternatives. Criteria for deciding about the adequacy of these abilities are difficult to specify. Therefore, global, undifferentiated criteria usually are established, such as age and mental status. Children and those diagnosed as mentally retarded, autistic, or insane are often seen as incompetent in a legal sense and in need of surrogates (parents, guardians, and courts) to give consent. Historically, but not that long ago, women and racial minorities also were seen as incompetent in a similar sense.

Decisions about incompetence and who shall act for those judged as incompetent continue to be primarily defined by legislation and court actions. While the bases for these actions can be found in social philosophy, they are also shaped by practical politics. As a result, current legal criteria which guide professional practice may be viewed as providing a rather conservative ethical perspective. Advocacy groups for the rights of those now seen as legally incompetent seek a much more liberal/radical ethical stance with regard to appropriate criteria and due process protections related to judging incompetence and allowing anyone to give consent for another.

Obviously there are times when intervention is necessary and those requiring help are not able to participate in the rational processes which are prerequisites for arriving at meaningful and valid consent. At such time, others must act. Beyond conservative legal criteria however, those who wish to adopt more liberal guidelines have difficulty agreeing on what constitutes competence and when others should act. The example of children's consent illustrates just how difficult the problem is.

Stated simply, the problem is: At what age should it be necessary to ask a child's consent before involving the child in a psychoeducational intervention (including testing)? With regard to mandatory school attendance, the legal answer is that no individual consent is needed from either parents or child during the age period when attendance is compelled by the State. With regard to specialized interventions such as psychological testing, special class placement, and therapeutic treatments, the common answer is that only the parents' consent is needed and in some cases not even their consent is sought.

Until recently a similar stance prevailed with regard to the participation of school children in research projects. In the USA, Federal guidelines now indicate that valid consent for participation in research is to be solicited not only from parents, but from all children 12 years of age or older. Moreover, there is discussion about the possibility of lowering the age for consent for research participation to 7. The pros and cons of this matter are debated heatedly. In the process, of course, the question of what constitutes competence is raised, but so are important questions about society's prerogatives, responsibilities, and needs.

It should be noted that the question of competence is strongly related to the problem of paternalism. It comes as no surprise that professionals, parents, governmental agents, and many others in society have opinions as to what is good for various groups and individuals. When the opinions are backed up by the power to impose them on others, the decision as to whether to do so raises the problem of paternalism. The teacher or parent who must decide whether to intervene in order to help or protect others from the consequences of their autonomous choices is confronted with this problem. For example, it is a paternalistic action to stop a child from pursuing a chosen activity such as reading comic books, eating candy, being exuberant and noisy, etc., or to punish a child for misbehavior because it will be in her or his "best interests." When such actions are taken, the child's autonomy is seen as less important than (a) the possible, harm, nuisance, or offensiveness (to the child or others) of the child's chosen activity, (b) the possible benefits to be gained if the child were allowed to pursue the autonomous course of action, or (c) the benefits to be gained from pursuing the newly prescribed actions.

When a paternalistic intervention can be accomplished with relatively little complaint and reaction from the child or when major health and safety considerations are at stake, paternalism is unlikely to be much of an issue. However, there are times when the only way for the paternalistic intervention to prevail is by the exercise of major physical or psychological force and times when a significant segment of society thinks the intervention is not in the best interest of the child (such as in the case of special class and institutional placements, corporal punishment, etc.) In such instances, paternalism becomes an extremely controversial consent issue, separable but usually quite related to the problems and issues regarding competence.

Obviously, paternalism is not so great an issue when persons are viewed as incompetent. Thus, those who wish to act in a paternalistic way may well be tempted to believe that persons who resist the judgments of those in authority are incompetent (e.g., immature, ignorant, incapacitated) or are unduely influenced by others (e.g., under the influence of bad values and models). As long as there is a lack of objective criteria in so many areas as to what constitutes competence in making and acting upon one's decisions without undue interference, the problems and issues associated with paternalism and decisions about who is incompetent will continue to be major ethical concerns.[1]

Relevant information and voluntary consent. However the problems of competence and paternalism are resolved, whenever consent is to be elicited relevant information must be provided and decisions must be made voluntarily. Basic to the notion of relevant information is that the information be provided in an understandable manner. The more complex and unspecifiable key intervention procedures and outcomes, the more difficult it is to meet this requirement. Cultural and language differences may also be barriers in this connection.

Levine (1975) enumerates 11 elements of information which should be communicated and understood. These are:

(1) statement of overall purpose; (2) defining the role of the subject; (3) informing the prospective subject why he/she has been selected; (4) a fair explanation of the procedures, including the setting, the time involved, with whom the subject will interact; (5) description of discomforts and risks; (6) description of benefits; (7) disclosure of alternatives; (8) offer to answer questions; (9) offer of consultation; (10) noncoercive disclaimer; (11) consent to incomplete disclosure.

To facilitate communication and understanding, such information may need to be presented in a variety of ways. Certainly, more than one time oral or written communication may be required. Language translations, media presentations, question and answer follow ups to evaluate whether information was understood, feedback from other consumers, all may be relevant at various times.

While a critical element, provision of relevant information does not guarantee that consent is given voluntarily. In many situations, consent is given because people feel they have no meaningful alternative choice. For example, parents and children in special school programs may consent to additional assessment, therapy, medication, and so forth because they fear refusal will result in exclusion from the rest of the program. In some cases, the fear is a correct perception. That is, legally, and thus from a conservative perspective ethically, participation in many types of additional activities can be made requirements for remaining in a program even though they were not specified on admission. Additional psychological testing is one example. In other instances, the fear of revocation of services is unfounded and might have been dispelled if appropriate information is conveyed. To counteract covert, and often unintended, coercion to consent, advocacy groups have sought to increase awareness about the problem and to liberalize ethical standards beyond legal guidelines. It has been suggested that, ultimately, persons should be able to withhold consent in any situation without prejudice and that consent procedures would be expected to clearly communicate this ethical commitment.

Given procedures for obtaining valid consent, there remains the ethical concern regarding when voluntary consent is needed.

A related question is: When may consent be waived (as contrasted to witholding of consent)? The answer to this question seems clearest to most people when a problem is seen as extremely threatening or an activity is seen as extremely unthreatening. Thus, persons who are seen as imminently dangerous to others or as incapable of protecting or caring for themselves generally are accepted as likely candidates for waivers of consent.

In contrast, activities which are common facets of everyday living such as much of the assessment and evaluation activity which permeates all of our lives usually are not understood or discussed in these terms. They are, however, instances of de facto waived consent. While ethical concerns related to waived consent are most likely to be raised in connection with extreme problems and dramatic interventions, consent which is waived in a de facto manner perhaps ought to be of equal concern. Many not very dramatic activities, such as routine achievement, intelligence, and interest testing in schools, can have life shaping impact and are likely to have an effect on a large segment of the population. In any instance where consent is ignored, in effect coercion is involved.

Demystification: Beyond Informed Consent

In discussing autonomy, utility, and equity, we have underscored that ethical practices involve concerns beyond those related to individuals directly involved in a particular intervention. However because of the common tendency to ignore ethical responsibilities to the society and culture, we want especially to highlight the responsibility of interveners to demystify clients and the public regarding current limits of competence and knowledge.

The concerns over providing adequate information to the public goes well beyond the matter of information related to consent. Interveners have a comprehensive duty to honesty. This involves not only providing information as part of eliciting consent but taking steps to avoid mystifying others as part of an affirmative, ethical commitment.

The general public appears mystified by what can and cannot be accomplished by formal psychoeducational interventions. Thus, there is an ethical need for all interveners to accept greater responsibility for clarifying appropriate uses and limitations of such practices and to warn against misuses, abuses, and premature applications.

It is risky to be truthful, and yet it is well to be aware of the risks of not being honest. Such consequences include (a) oppressing others by mystifying them (b) being oppressed in return by the backlash which inevitably occurs when the public becomes aware of information, and (c) holding back systematic inquiry by encouraging premature closure on complex questions. In the Learning Disabilities' field, in education in general, in medicine, and so forth, the failure to demystify the public probably is accountable, in part, for

- perpetuation of fads and panaceas,
- movement toward naive accountability measures,
- increased numbers of malpractice suits,
- widespread use of relatively unvalidated practices, such as preschool and kindergarten screening for learning problems and stimulant drugs for treating children labeled as Hyperactive.

The duty to honesty raises questions about non-disclosure and deception in practice and research. At times, both have been justified when the duty to honesty has come into conflict with ethical commitment to beneficence, nonmaleficence, and respect for autonomy. Usually, the argument takes the form that to clarify the facts would interfere with helping the individual or would cause them discomfort. ("What they don't know can't hurt them".) Sometimes it is argued that clients don't have the ability to understand the complexities involved or that they don't really want to know.

In fact, some clients are annoyed when professionals ask that they become more involved in making decisions. There are, indeed, instances when other ethical principles should prevail. However, the likelihood is that these instances are comparatively few. Therefore, the apparent proclivity of professionals to use and justify nondisclosure and deception on a broad scale is seen as a political act involving intentional mystification to maintain a power imbalance (e.g., Halleck, 1971; Laing, 1967; Rogers, 1977, Szasz, 1970).

Studies of the nature and scope of intentional mystification by professionals are not readily available. However, it may be noted that in a review of complaints about practices of psychologists, Sanders (1979) states that violations of one or more sections of the "Principle on Public Statements" are the most frequent ones received by the APA's Committee on Scientific and Professional Ethics and Conduct. (The Public Statement Principle stresses, among other matters, the responsibility to clarify the limits and uncertainties of present psychological knowledge and techniques.)

A major way in which interveners mystify others is by the use of jargon and special professional language. Professional jargon not only mystifies but perhaps makes interveners feel superior and clients feel inferior in the same way that a paternalistic stance often does. In turn, this perpetuates tendencies toward paternalism and away from demystification. As Wasserstrom (1975) states:

> If there is, in fact, an area in which one does know things that the client doesn't know, it is extremely easy to believe that one knows generally what is best for the client... In addition there is the fact...the client has a serious problem or concern which has rendered the client weak and vulnerable. This, too, surely increases the disposition to respond toward the client in a patronizing, paternalistic fashion. The client of necessity confers substantial power over his or her wellbeing...Invested with all of this power both by the individual and the society, the...professional responds to the client as though the client were an individual who needed to be looked after and controlled, and to have decisions made for him or her... with as little interference from the client as possible (pp. 21-22).

It is in meeting the duty to demystification that many professionals come full face with their vested interests in being perceived as an expert and in maintaining their guild's power, e.g., institutionalized special credentials, roles, privileges, and rewards. In effect, social justice and morality come face to face with political and economic interests in a classic confrontation which unfortunately seems to be no contest in the majority of cases.

Ironically, not only is there a tendency for professionals to mystify the public, the public seems more than ready to be mystified by "experts". In this connection, one writer states:

> Some academic disciplines breed obscurity. Much of American behavioral psychology, for instance, has achieved the rather dumbfounding condition of being at the same time trite and inaccessible... These disciplines presently enjoy a certain deferential reverence-from-a-distance, an uncritical acceptance from outsiders. This deference comes not so much of understanding as it does from a willingness to praise those who make us feel ignorant. Confronted with one expert or another who proceeds to confound us... we blame ourselves for not understanding...and assume (it was) right because an expert said it (Nyberg, 1971, pp. 67, 69-70).

In turn:

> Overconfidence in "better knowledge" becomes a self-fulfilling prophecy. People first cease to trust their own judgment and then want to be told the truth about what they know. Overconfidence in "better decision making" first hampers people's ability to decide for themselves and then undermines their belief that they can decide (Illich, 1973, p. 93).

The need for demystification highlights once again that psychoeducational interventions raise not only moral but broad socio-political-economic concerns. Interveners daily are confronted with problems related to conflicts between the interests of society and the individual and their own professional and personal interests as well. Like it or not, when such conflicts are present, the basic ethical question often amounts to: "Whose interests should be allowed to prevail?"

Concluding Comments

Figure 1 outlines the major perspectives and ethical principles discussed in this paper. Understanding ethical concepts and concerns, however, is no guarantee they will be adhered to. Indeed, ethical considerations often appear to be honored more in discussion than in practice.

While most professional organizations have committees to deal with reports of ethical lapses, no one claims that such committees create ethical interveners. Ultimately, ethical practice is a matter of individual understanding, conscience, and action.

As we have stressed throughout this paper, however, ethical considerations extend well beyond individuals and professional fields. Learning problems are a societal concern. Programs designed to deal with such problems require the support of the general public and their elected representatives. The impact of the programs and the professionals who staff them is not only on individuals, but on major subgroups of the society and on cultural thought and attitudes. A significant part of the foundation of future societal

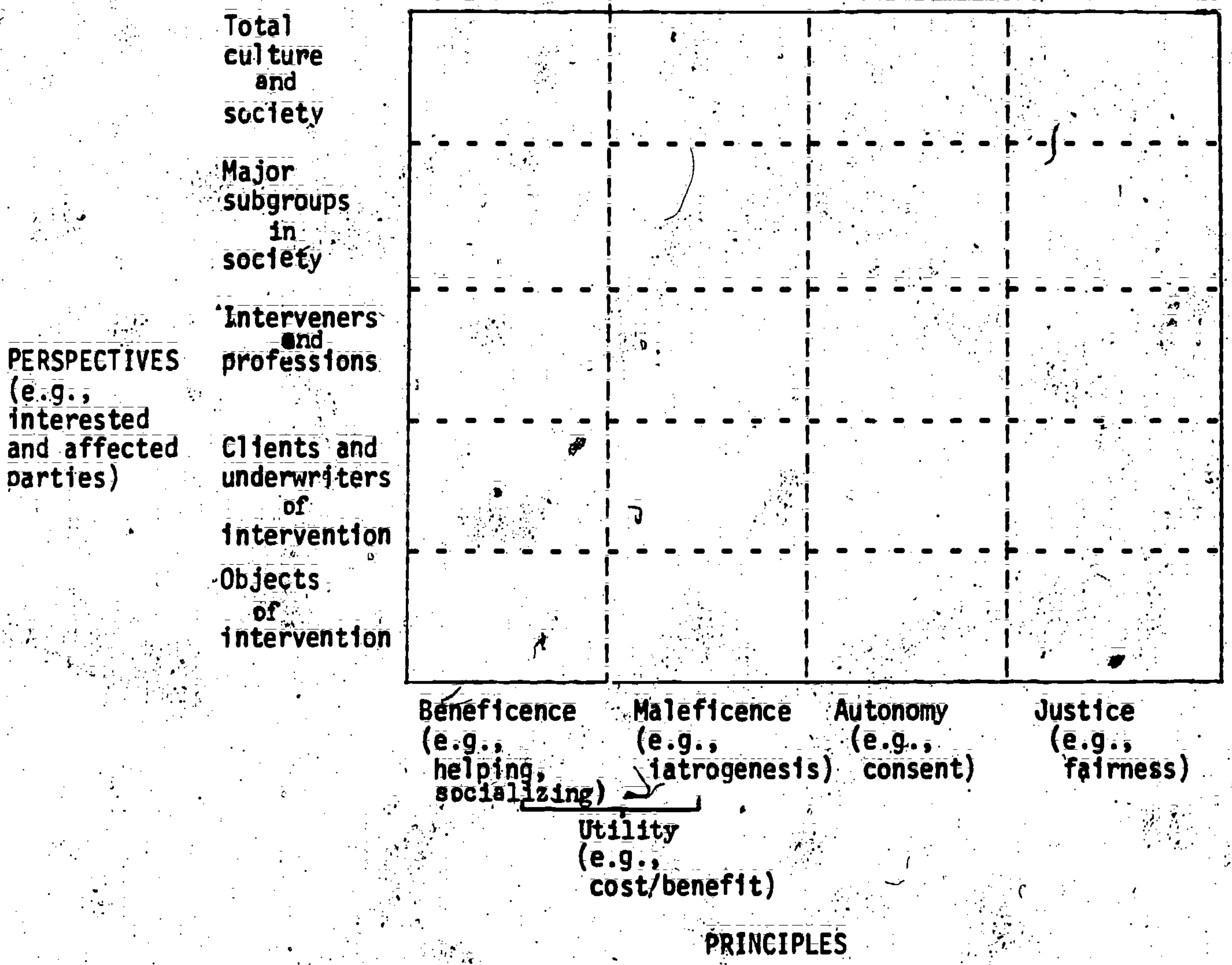

Figure 1. Ethical principles and perspectives involved in psychoeducational interventions.

priorities and policies is being laid by current psychoeducational interventions. Consequently, from both an ethical and a pragmatic perspective, such interventions can be seen to be socio-political-economic acts.

Recognition of the social action nature of professional intervention increasingly is being recognized and indeed advocated. As Hobbs (1965) states:

> A mature profession does not simply respond to the needs of society but [illegible] in determining what society should need and how social institutions as well as individual professional careers can be shaped to the services of an emerging social order... the responsible professional person becomes the architect of social change.

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Footnote

[1] Some writers have distinguished between strong and weak paternalism. Feinberg (1973) sees the former as the decision to intervene even when an individual's choices are informed and voluntary. Weak paternalism involves intervening only when the indivudal's conduct is substantially nonvoluntary or when the intervention is a brief one designed to determine whether the conduct is or is not voluntary.