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60. By its very nature, science is a communal enterprise. I am deeply aware of the essential contributions to this work made by my many colleagues and friends throughout the last 15 years. This occasion recalls the daily life we have shared with warmth and affection as well as the personal debt of gratitude that I owe them. I am equally cognizant of the fact that the knowledge of antibody structure was developed by many laboratories and researchers throughout the world. Not all of this work has been cited, for specific recognition here runs the risk of an unintentional omission; reference may be made to the reviews cited. In addition to the fundamental support of the Rockefeller University, the work of my colleagues and myself was supported by grants from the National Institutes of Health and the National Science Foundation.

Science, Technology, and Some Dilemmas of Advocacy

Social implications of biological research in developmental disabilities are considered.

Margaret Adams

Advocacy is a time-honored concept that originated in the law, permeated medicine by way of the physician-advocate, and is now accepted as an explicit function of social work (*1*). Within social work, the terms "advocacy" and "advocate" ["one who pleads, intercedes, or speaks for another" (*2*)] are used to denote the actions and role that social workers are committed to when the human, moral, civil, and legal rights of their clients are transgressed by individuals, groups, or social institutions. This article presents some facets of advocacy that are now confronting social workers as a result of recent dramatic advances in the medical sciences and the impact these advances have upon the lives of individuals—in this instance, upon the mentally handicapped and their families. I attempt to explore major points at issue that can arise between social workers and research scientists, especially those working in the biological sciences. I also suggest areas of common concern that can be exploited to develop a constructive dialogue between the two professional groups instead of the mutual disparagement, suspicion, and even paranoia that sometimes color the thinking of both, to the detriment of cooperative effort and a more sophisticated understanding of the complex nature of the problems of mental handicap. To illustrate simply: the research scientist must keep in mind that an anomaly in, say, the chemical behavior of a neurone terminates in a badly damaged child who belongs to a distraught family; equally, the social worker, who is dealing with their immediate distress and future anxiety, must realize that this chemical misbehavior may derive from an aberrant gene, which could manifest itself in the tragedy of a second affected fetus unless there is scientific intervention in the shape of amniocentesis and genetic counseling (*3*).

Research and Social Priorities

The crucial areas in which science and social work are apt to overlap and work at cross-purposes are (i) future gains versus immediate relief, (ii) prevention versus supportive help, (iii) common good versus individual good, all of which impinge upon most of social work's cherished tenets and firmly entrenched methods of working. Consider, first, the different perspectives on the time factor—namely, reasonably certain, prompt relief as against predictable future gains. Social workers, with their orientation toward problem-solving, crisis intervention, and the pressing problems of the individual's adjustment to his social milieu, sometimes find it hard to accept the value of experiments that can do nothing for the damaged child and besieged family, even though they may save future families from the tragedy that their clients are experiencing. But if social workers are to keep pace with the march of crucial developments and retain the professional respect of their scientific colleagues, they must try to identify, at least in part, with these long-term goals, even though their primary allegiance is to the present client.

This area of concern is very closely tied in with another—public health versus individual treatment—which raises many issues. For example, given that it is desirable to reduce the incidence of defective children and that research technology has provided mechanisms for identifying at-risk parents, how should we react to a proposal for screening for Tay-Sachs disease the population known to be at high risk—namely, Jewish men and women of Ashkenazi origin? Although this is a physically harmless public health measure of unquestionably benign intent, it also contains a psychologically disruptive element: anxiety about ethnic discrimination. Because of their long history of persecution, all members of this group, particularly recent immigrants from Europe who carry inherited and firsthand memories of genocide, are potentially sensitive to discrimination. For people of African descent, screening for sickle cell anemia may have similar implications, which are reinforced by realistic fears of adverse discrimination in respect to employment, life insurance, and so forth (*4*).

The third issue, personal welfare versus the common good, presents a constant conflict to social workers,

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whose advocacy on behalf of socially vulnerable individuals rests on the vigorously defended principle of client self-determination. Calibrating this delicate balance between individual and societal claims is difficult in relation to the client of normal intelligence, but the complexity of the situation is magnified many times over when the client has obvious intellectual deficits that limit understanding. To deal with the normal clients first, is it socially practical to permit intellectually competent parents the option of producing several—or even one—defective offspring when the cause of the defect is known and reasonably safe preventive measures are available? Should the social worker, as advocate for self-determination, support such a desire, which may be integral to the family's personal aspirations and their cultural frame of reference, but which will increase the defective population and also result in a damaged human life? A great deal of rhetoric is uttered in antiabortion arguments about the rights of the fetus, but I would like to voice an appeal on behalf of the damaged fetus not to be born to a lifelong sentence of subnormal functioning and potential misery.

This sort of example leads to another hazard we must come to terms with—inconsistency and illogic. If we are in favor of intervening at the prenatal stage to prevent such a life, why are we so loath to terminate that life once it has begun, assuming the prognosis for any sort of satisfying existence is incontrovertibly bad? This idea cuts into one of the categorical imperatives of Western society, the inherent sacredness of human life, but with world overpopulation becoming a realistic threat, *is* life, per se, sacred anymore? Should we not at least stop to think about the long-range implications of keeping very damaged children alive by unrealistic, heroic means (*5*)? This issue is part of the much broader one concerning medicine's life-preserving function, and the quandary into which a highly advanced technology has thrown the profession (*6*).

Medical Exigencies versus Human Rights

The individual versus social benefit argument contains another twist, one that speaks even more cogently to the ethics and functions of social work—namely, when medical science requires the person of a retarded individual because it provides essential experimental material that will extend vital areas of knowledge. What line should the social worker adopt when research workers desperately need to perform some technological procedure on a living child, or a postmortem on a dead one, either of which will cause serious distress to a family who have probably been tested to the utmost of their emotional limits? Ideally, one would hope to be able to convert the prospect from a grisly scientific operation into an act of positive beneficence on their family's part, as well as a means of helping them to tolerate their immediate distress. This sort of psychological protection can, however, only be offered if there is a long-standing relationship of mutual trust with the client. Unless research scientists are aware of this crucial emotional component, social workers are often not brought into the situation in time to build up such trust. When the research scientist seems to be impervious to these emotional factors, is it the social worker's duty to protect the family from insensitive handling by advising them to withdraw, or to try to persuade them to give reluctant and fearful consent? I do not wish to imply that research scientists are so many voracious giants cheerfully humming "fe, fi, fo, fum" as they peer down their microscopes, but, with the tantalizing gleam of new knowledge just around the corner, there is an understandable temptation to subordinate the less obvious human claims to the immediate exigencies of research.

A much more difficult situation obtains when it is not parental cooperation that is in question, but that of the retarded individual himself—both those persons at the high and those at the low points on the scale of understanding and informed consent. With the severely retarded, there is the taxing problem of how to communicate research procedures in such a way that they are fully understood by the subject; how to gauge accurately his response, particularly distress and fear; plus the moral dilemma of how heavily these factors should be weighed against predicted scientific gains. If a retarded child or adult indicates a clear dislike of being part of a research project, even after every human precaution has been taken to minimize danger and anxiety, do social workers have an obligation to interfere on his behalf to prevent this involvement? How is the social worker's position affected if the parent or guardian (who may fulfill this role nominally and be much less familiar with the retarded person) is willing to give consent? Who, in fact, has the final right to determine whether or not the individual will participate—the scientist, who speaks for society's long-range goals; the parent, who presumably speaks for his offspring; the social worker, who speaks for an especially vulnerable client in need of protection; or the barely articulate client himself? If the client cannot comprehend the broader issue, that his participation may prevent someone like himself from suffering from his disability in perhaps 25 years time, who is to assume intellectual or moral power of attorney for him (*7*)?

This sort of ethical impasse is beautifully illustrated in a proposal, made a year or so ago, for transplanting the kidney of a severely retarded youth to his twin brother. The argument that the former was unable to give informed consent to this serious surgical hazard was countered by the normal brother's medical advocate, who deposed that it was unfair to deprive the retarded man, on account of his deficient understanding, of his right to save his brother's life and, in doing this, to make a contribution to the social weal by ensuring the survival of an especially gifted person. This situation opens up all sorts of philosophical issues about the social value of individuals, the morality of social contribution by proxy—that is, the retarded man's contribution is through the sacrifice of his physical integrity for the benefit of a more visibly productive person—and the extent to which our persons belong to corporate society rather than to ourselves.

Informed Consent and Intellectual Handicap

More subtle dilemmas occur when the mildly retarded are approached to participate in research. Often they do not understand the full implications of the request, but are unwilling to admit this ignorance, too overawed to ask questions, or overly anxious to have the financial reward or to please the staff. Psychological research that has revealed the intense need of mildly retarded, deprived, institutionalized boys for adult approval speaks very eloquently to this point (*8*). In addition, there is the danger that the involvement of such subjects in partially understood research projects may trigger unexpressed fears and fantasies of being innately different or inferior, and these will feed their already weak self-esteem and strong sense of stigma.

These are very subtle points to convey to scientists, whose training has not usually exposed them to the complexities of self-image and social relationships, particularly as they affect a disadvantaged group. In such a quandary, which counts more—another clue to a complex, damaging, genetic disease (which may be present only in a mild form, so that the patient in question does not benefit personally from the research findings) or the *relative* social and psychological well-being of an individual who will not be a particularly productive member of society, but whose chances in life have already been heavily penalized by poor endowment and adverse social experiences, including the deprivation of social opportunity through being institutionalized? The latter circumstance makes them a particularly vulnerable, easily accessible, captive group, a hazard they share with prisoners, who also belong to basically dehumanizing systems where social isolation and the pervasive undermining of human rights and dignity make it hard to exercise unbiased options about cooperating in establishment-supported projects (*9*).

Genetic Knowledge and Family Integrity

The controversial field of genetic counseling is presenting a number of dilemmas that press heavily upon the social worker and that may, on occasion, set him at odds with the scientist. An extreme illustration is the institutionalized child with a genetic disease whose existence has been concealed from the rest of the family or who is never discussed at home; the child's normal siblings are therefore in ignorance about his condition and have no inkling of its implications for themselves. As the normal children reach sexual maturity, how does the social worker (or any other concerned professional) handle the vital question of genetic counseling, when the parents flatly refuse to consider this an issue and deny professionals access to the siblings? Should the parents' authority over their normal children during their minority be respected, or does their refusal to warn them of their genetic hazard amount to indictable parental neglect? If society becomes an advocate for the normal children, and an outside agent—be it family physician, minister, teacher, or social worker—assumes responsibility for imparting this information, who picks up the emotional pieces after such a traumatic revelation? Here I submit a special plea for social work to be early involved in situations where there are heavily weighted scientific issues. In that way, the emotional, social, and cultural aspects of the medical diagnosis and prognosis can be dealt with from the start, and the seeds of subsequent counseling can be sowed. Social work intervention is not a guarantee against such denial as this hypothetical family exhibited, but there is a more than sporting chance that, if such intangibles are dealt with in a social as well as medical context at the time of diagnostic and placement crises, the family might not become entrenched in such a rigid denial system.

A final illustration that embraces researcher, family, and child in a particularly complex dilemma arises around chromosome testing, which, in one hospital, is done as a routine service procedure, along with tests for phenylketonuria, on all newborn boys. One objective of this procedure is to identify families and children at genetic risk in order that, where needed, help can be offered early. The other, broader public health goal is to plot the incidence and patterns of chromosome anomalies in the general population. The problem arises when this innocuously intended survey identifies a chromosome abnormality that may or may *not* have developmental relevance which would carry negative social implications—for example, mental retardation or conspicuous antisocial behavior in patients with errors in sex chromosome number. The advocacy issue here is severalfold. Should parents be given this disturbing information, which, by creating anxiety and biasing management, may prejudice the child's chances of a normal upbringing? Which is of greater social and ethical import, the parents' irrefutable legal, moral, and even functional right to knowledge about their child or the child's right to an unclouded childhood? In practice, the policy of the study under discussion is to share the information with the parents on a totally honest, cooperative basis and to provide them with ongoing support throughout the child's developmental years or until the feared situation has proved itself unfounded (*10*). But—taking an extreme line for argument's sake—how effective can this approach be with parents of very fragile emotional makeup, who could not, even with help, assimilate such information without detriment to their relationship with the child and their own marginal psychological health? A final question that might be posed is whether it would have been better for the family's integrity not to have had the tests done at all, so that no one would have been burdened with this unwelcome knowledge. In this case, what about the vital public health issues at stake—the importance of identifying both individual families at risk and trends in this disease pattern?

I have returned to one of the perennial dilemmas of social work—the individual good versus public welfare. Are social workers advocates for individuals or for society, of whom an individual is one fraction? Where should the profession's protective efforts be directed? I have no answer to this except that, from the beginning of time, the tree of knowledge has brought nothing but conflict, disruption, and change and that, in this era of spectacular intellectual fertility, the profession must rally its special skills to help harvest this bumper crop of apples. Such phenomena as changing societal situations, shifting roles and functions, and altered interpersonal relationships are the social worker's particular stock-in-trade, and effective communication of these intangibles should be his or her special charge. The research scientists have the new knowledge; social workers have skills in interpretation and communication. They must use these skills to make sure that scientific knowledge flows in their direction in a meaningful and comprehensible form, in order that the two sorts of minds meet and the two kinds of human social enterprise either march together or share territory.

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