SELF-HELP AND MUTUAL AID GROUPS AS FACTORS IN PREVENTION

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ABSTRACT

The public health model of prevention is used in examining the significance of mutual aid self-help groups as a resource in preventing physical/ mental-social disorders. The status of such groups in the United States and elsewhere is reviewed along with research data and theory that seeks to analyze and account for their effects. Examples of their possible utilization at critical stages of the life-cycle are presented and discussed, followed by implications for human service professionals and programs.

INTRODUCTION

This article takes a life-cycle approach in looking at the resources represented by mutual aid/self-help groups for the prevention of physical/mental/social pathology. The prevention model employed is the classical public health paradigm of primary, secondary, and tertiary prevention.

The purposes of the article are threefold: to review and illustrate stages in the life cycle in which clients' participation in mutual aid groups has been found to be useful in preventing physical/mental/social dysfunctions; to sketch some theoretical aspects bearing on the effectiveness of self-help; and to promote human service professionals' further understanding and use of such groups.

I. THE PUBLIC HEALTH CONCEPT OF PREVENTION

Prevention is and should be a basic element and goal of all human service remedial or meliorative programs. However, it continues to be strikingly neglected

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in the most influential of these, clinical medicine. As Colombotos has pointed out, "The practice of medicine in this country is oriented toward the diagnosis and treatment of disease rather than toward its prevention. This orientation is reflected in how the overall health care system is organized, and in its *incentives* (e.g., how practitioners are reimbursed for their services). On the level of the individual physician, it is reflected in the great professional satisfaction and stimulation he or she derives from curative activities, rather than from preventive endeavors and his or her perception of the greater medical value of the former" [1].

In contrast to the disease-centered orientation of clinicians, public health has developed a concept of prevention that guides its research and effectively underlies its programs. The notion of prevention emerged in public health sometime around the turn of the twentieth century, when there was special concern about the control of infectious diseases. A terminology and methods were developed to define the various steps necessary to mount programs which would control and subsequently eliminate communicable diseases. In less than a century, the following of these approaches has brought about notable achievements. Infectious diseases that have been largely or totally eliminated include tuberculosis, smallpox, cholera, malaria, and poliomyelitis. These successes were attributable not only to the scientific advances made in research laboratories, but also to the public health methodology that made it possible to apply this knowledge to the prevention and relief of human suffering.

The public health concept distinguishes three levels of prevention, usually referred to as primary, secondary, and tertiary prevention. *Primary prevention* means eliminating or blocking a known etiological agent. If a disease can be traced to a viral or bacterial source, or to an environmental toxin, then the effects of that organism or agent can be controlled through environmental measures, or by minimizing individual susceptibility through immunizations.

Secondary prevention in public health means finding and treating individuals with illnesses that can be terminated, arrested, or mitigated. This level thus involves a combination of early case-finding before an illness has become fully manifest, and the application of corrective or remedial measures to individuals. These interventions may not "cure" but will lessen, that is, in a weaker sense, "prevent" the further spread or worsening of the illness.

Tertiary prevention means limiting the disabilities an individual suffers once illness has become clearly manifest. An example from mental illness may be cited, the case of schizophrenia. At present, it is not known how to prevent the varieties of schizophrenia. However, at the secondary level of prevention, case finding methods can be used to bring people into early remedial or supportive treatment; and at the tertiary level, social resources provided to sufferers will limit or reduce their individual disabilities in functioning, and thus "prevent" their further physical and psycho-social deterioration.

To sum up the public health approach, primary prevention means eliminating or blocking disease before it occurs; secondary prevention means finding

unapparent or possibly untractable disease and treating it early; tertiary prevention means effectively treating apparent disease to prevent serious later complications.

II. SELF-HELP GROUPS

The last 20 years have witnessed a striking increase in the formation of various kinds of self-help groups in Western countries. Their growth has been so rapid and dynamic that they are difficult to count and classify. Data are fragmentary. The writer's 1976 estimate [2] that there were some half-million separate self-help groups in North America, embracing five to ten million member participants, was probably conservative at the time and is now certainly outmoded. That estimate was based on listings of more than 500 national organizations, each including local units; the latter ranging in number from a mere handful to some 27,000 chapters of Alcoholics Anonymous. The proliferation of self-help groups is not confined to those with national affiliations. The number of ad hoc local groups is immense. The 1976 estimate included the speculation that at least 50,000 unaffiliated local self-help organizations could be found, in addition to many state-wide and regional groups without national affiliations. Indeed, every community in the United States and Canada with a population of 20,000 or more probably has at least a few local or nationally affiliated self-help groups, and many are in process of organization, perhaps averaging a growth rate of 5 to 10 new groups daily. While less populous than the United States, and not having all the same pressures toward the creation of such groups, other Western countries have also experienced a rapid growth of self-help organizations in the past two decades. In the United Kingdom, Robinson and Henry have identified hundreds of self-help groups, both national and local [3].Van Harberden and Lafaille have published a similar account of the situation in Holland [4]. Israel, Australia, New Zealand, and countries in South East Asia and South America have extensive arrays of such groups and they are also found in some countries of Eastern Europe, such as Poland and Yugoslavia.

Contemporary manifestations of mutual aid principles and practices include: a) the natural and informal social networks of family, workmates, schoolmates, neighbors, friends, and peers, and b) a wide range of largely self-organized and self-directing healing, educational, economic and socially supporting groups. Self-help forms and practices are found in a variety of organizations that promote care in physical and mental health for the self or relatives, in housing cooperatives and other economic projects, in groups set-up to help so-called "deviants," e.g., homosexuals, ex-convicts, former mental patients, ex-prostitutes, and so on. Groups exist for single parents, for the parents of "run-away" children, the parents of gifted children, parents with actual or potential problems of child abuse and child neglect, parents of "gay" children, couples seeking to overcome infertility and so on. In the field of physical health there are groups for nearly all of the 200 major diseases listed by the World Health Organization from anorexia nervosa

to von Willibrandt's disease. Many self-help anti-drug organizations exist as well as several that combat conditions like compulsive gambling and chronic indebtedness. There are ex-prisoner organizations with differing ideologies and programs, but which have in common a mutual aid approach. In mental health there are a legion of groups for specified diagnostic categories—"neurosis," schizophrenia, "manic-depressive syndrome," as well as for more general mental problems. An exhaustive catalog of these proliferating groups in the broad health and welfare field cannot be made because they are growing and changing so rapidly as to outstrip the tempo of present resources for data collection.

III. DEFINITION OF SELF-HELP GROUPS

The half-million or more separate self-help organizations embody an extraordinary variety of types, purposes, structures, and ideological features, tap a variety of motives, and appeal to a vast range of members. To bring scientific order into this domain, through definitions and taxonomies, is a difficult task.

Approaches to definition have attempted first to define the nature and distinctive properties of the groups. A number of such definitions have been formulated since the mid-1970s, of which the most widely cited and used is that of Katz and Bender [2]:

> Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions. Self-help groups emphasize face-to-face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently "cause"-oriented, and promulgate any ideology or values through which members may attain an enhanced sense of personal identity [2].

To this definition, its authors appended a further list of defining attributes as follows: "(1) Self-help groups always involve face-to-face interactions. (2) The origin of self-help groups is spontaneous (they are not usually set-up by an outside group). (3) Personal participation is an extremely important ingredient; bureaucratization is antithetical to the self-help organization. (4) The members agree on and engage in some actions. (5) Typically, the groups start from a condition of powerlessness. (6) The groups fill needs for a reference group, a point of connection and identification with others, a base for activity and a source of ego-reinforcement" [2].

By these attributes, then, self-help groups may be distinguished from certain "mutual aid" groupings and agreements among those who exercise political or economical power—such as unions, cartels, corporation boards, "old boy"

networks, and friendship cliques. The groups are distinguished also from various voluntary membership organizations, such as "service organizations," oriented to traditional philanthropy (the Elks, Shriners) or to public education, (League of Women Voters). The definition also excludes such temporary or uncalculated natural associations as children playing together, the short-lived "emergency collectivism" of neighbors in times of natural disasters, and "encounter" groups.

The above definition of self-help groups emphasizes that the group, whatever its origin, belongs to and is run by its members. *Autonomy* is thus a key functional characteristic of the self-help group, that is, *self-direction from within* by members, rather than *direction by outsiders,* e.g., professionals.

IV. A THEORETICAL BACKGROUND FOR
SELF-HELP EFFECTIVENESS

It is pertinent to discuss some findings and theory regarding the actual and potential significance of self-help groups in the prevention of disease and the maintenance of health. It has been clear for some time that the chief problems affecting the health of populations in advanced countries are the chronic diseases, which account for some 75 or 80% of current morbidity and mortality. It is also clear that personal behavior, as summed up in the term "lifestyle," is highly involved, in interaction with the physical and social environment, in both the causation and management of such chronic long-term diseases or conditions. The examples of coronary artery disease, cancer, and hypertension are familiar in this respect. From many studies of ill populations, a further important general finding has emerged regarding vulnerability, namely, that persons who lack stable and satisfying social supports, i.e., those who are socially isolated, have the highest risk of morbidity.

According to these studies, to be discussed below, the rates of illness and death in a given population vary more with the degree and quality of social support and social interactions than with the presence or absence of any particular hazard or behavior, such as smoking or obesity. The studies also indicate that being vulnerable or at-risk correlates highly with the nature of the self-concept, which includes the individual's sense of being in control of his or her life and the factors that affect it. A positive self-image, embodying a sense of one's ability to master the environment and to cope with life pressures, seems to correlate with the tendency to resist illness and conversely, in its absence, to succumb to it. As a further corollary, epidemiologic studies have indicated that persons who are in relatively weaker, subordinate, or powerless positions in any population group stand at the greatest risk of falling ill and have the poorest prognosis for recovery and rehabilitation.

These views of the importance of social supports in health and disease were definitively presented in a classic paper by a leading social epidemiologist, John Cassel of the University of North Carolina School of Public Health.

Reviewing many studies, Cassel wrote: "A remarkably similar set of social circumstances characterizes people who develop tuberculosis and schizophrenia, become alcoholics, are victims of multiple accidents, or commit suicide. Common to all these people is a marginal status in society. They are individuals who for a variety of reasons (ethnic minorities rejected by the dominant majority in their neighborhood; high sustained rates of residential and occupational mobility; broken homes or isolated living circumstances) have been deprived of meaningful social contact" [5]. Cassel noted that, "The existing data have led me to believe that we should no longer treat psychosocial processes as unidimensional stressors or non-stressors, but rather as two-dimensional, one category being stressors, and another being protective or beneficial . . . the property common to these processes is the strength of the social supports provided by the primary groups of most importance to the individual."

Cassel concluded his review with recommendations that embody the use of self-help approaches: "With advancing knowledge, it is perhaps not too far-reaching to imagine a preventive health service in which professionals are involved largely in the diagnostic aspect—identifying families and groups at high risk by virtue of their lack of fit with their social milieu and determining the particular nature and form of the social supports that can and should be strengthened if such people are to be protected from disease outcomes. The intervention actions then could well be undertaken by nonprofessionals, provided that adequate guidance and specific direction were given."

V. HELPING NETWORKS AND PREVENTION

The research findings on which Cassel's views were based have been supplemented and reinforced by more recent work.

Researchers concerned with factors that help individuals cope with stress are increasingly focusing on social support. Individuals suffering from malignant disease, physical disability, the death of a close friend or family member, rape, and job loss have all been found to adjust better when they receive social support [6]. For example, Gore [7] found that unemployed men who felt unsupported had more symptoms of illness, and were more depressed than unemployed men who felt supported; high levels of depression were found for individuals with low levels of social support. In a prospective study, Berkman and Syme [8] found that people who lacked social ties had higher mortality rates than did those with social ties.

As Cassel suggested, these data offer clues to a concept of prevention that was not formerly available. In this view, prevention is not simply a matter of giving people didactic instruction on personal health habits, the right foods to eat, exercise, sleep, and so on, nor is it simply a matter of having periodic health examination by health professionals. As Cassel stated, ". . . disease, with rare exceptions, has not been prevented by finding and treating sick individuals, but by modifying those environmental factors which facilitate its occurrence . . ." [5].

In an important sense, the prevention of physical/mental illness and dysfunction is related to improving how people feel about themselves; and one route to such improvement is to enhance their social ties and connections as an alternative to structured professional counseling. In the mental health field, these ideas were clearly articulated in the Report of the President's Commission on Mental Health (1978):

> Naturally occurring helping networks exist independently of professional caregivers and formal caregiving institutions. Often they are invisible to professional scrutiny because the assistance given and received is qualitatively different from that offered within disciplinary frames of reference and is rendered outside the structure of the human services agencies within which most professionals work, i.e., within the family; in kin, kith, friendship and neighborhood social networks; religious denominations; common interest and mutual help groups. Professionals need to affirm the existence and worth of these natural helping networks. Linkages need to be developed between these social and community support systems, including mutual help groups, and the professional and formal institutional caregiving systems. They should be established on a basis of cooperation and collaboration, not cooptation and control, and without disturbing the potency of their very different helping processes. These linkages can provide people in need of help individual choice and freedom of movement between natural and formal systems of care. They can promote professionally responsive and consumer-accountable services [9, pp. 166-167].

Particularly, then, for persons suffering from chronic illness, unrelieved social tensions, sheer loneliness, and the absence of social connections, self-help and mutual aid groups supply vital elements of social support when these are otherwise lacking. As the experience of the last 25 years has also shown, they aid members to attain a more positive self-image through various means, such as redefining and reducing the stigmatizing effects of the problem, overcoming the individual's or family's sense of isolation, and conducting educational and therapeutic activities that patients and their families can engage in themselves without dependence on professionals.

VI. SELF-HELP GROUPS AND COMMON HUMAN TRANSITIONS AND CRISES

The role of self-help group participation in preventing common difficulties and disorders will now be discussed in relation to some critical stages in the life-history of individuals and families. Where available, data will be presented and examples given for each of these.

A. Perinatal Health Care

While self-help groups such as Alcoholics Anonymous, Recovery, and Make Today Count are highly publicized and familiar, not so well-known are groups that deal with perinatal issues—such as infertility, education for childbirth, caesarean deliveries, prematurity, neonatal death, breast-feeding, child-abuse, genetic and other handicapping and chronic illness in young children. There are self-help groups that specialize in helping parents meet each of these serious situations.

To quote from a paper on Self-Help resources for parents in the perinatal period:

> Parents Anonymous and Parents United have been helpful for parents involved in child abuse and neglect. Other parent groups have formed due to a child with a handicap; e.g., spina bifida, cleft palate, Down's Syndrome, autism, etc. Individuals facing infertility or couples considering adoption have also joined together to provide mutual support and assistance. Crisis events such as the death of an infant or a very young child have led to the development of groups such as Compassionate Friends, Candlelighters & AMEND (AID to Mothers Experiencing Neonatal Death).
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> In some instances, perinatal self-help approaches have expanded beyond group meetings to the development of hotlines, visitor programs and peer counseling or parent resource systems. Several Newborn Intensive Care Units (NB ICU's) utilize "graduate" parents to offer lay counseling to parents of critically ill infants. Groups like Parents of SIDS (Sudden Infant Death Syndrome) and Empty Cradle (fetal and newborn loss) provide hotlines and one-on-one resource parents to aid the newly-bereaved [10].

There is considerable and accumulating testimony from clinicians that these self-help groups for families experiencing a crisis around reproductive behavior or childbirth perform significant functions in prevention, both directly and indirectly.

Research has noted the importance of early bonding between the mother and the newborn as a key factor in the infant's emotional and cognitive development, and in the mother's parenting skills. With prematures, who may spend days, weeks or months in an Intensive Care Unit, normal bonding is delayed, and is much more difficult to achieve after the infant's discharge. A study by Minde et al. [11] showed that participants in a mother's self-help group visited their infants in the ICU more frequently, interacted with them more during visits, and felt more competent about their subsequent parenting role than did non-participants.

The incidence of caesarean delivery has shown a steady increase in recent years. A caesarean birth experience can have negative effects on the mother's mental health, and thus on her parenting abilities and the familial environment during the post-natal period and later. Caesarean support groups on the self-help model can provide "a safe atmosphere in which women can share their concern without fear of being misunderstood or belittled" [12].

Parents who experience the death of an infant through miscarriage, stillbirth, or other causes, need support, understanding, and information to assist them work through their grief. Such self-help groups as Empty Cradle, AMEND, The Compassionate Friends (loss of a child at any age) assist parents through group discussion, one-on-one peer counseling, overcoming feelings of isolation in their grief, and so on. That these resources can help prevent later pathology arising from lack of opportunity for working-through the grief process seems self-evident.

B. Children with a Handicap

When an infant with a physical/mental anomaly or illness has been born, there is usually need for parents to come to terms with such emotional reactions as grief, self-blame, and rejection of the child; to work-through an often profound family crisis, before healthy, supportive parenting styles and a nurturant family environment can be established. Even in the absence of prolonged parental emotional distress, the parenting of children with such special problems presents many difficulties. Material needs and psychological dilemmas abound— e.g., finances, medical care, schooling, housing adaptations, baby-sitting, and other respite care; uncertainty about developmental expectations, discipline, and handling—i.e., walking the narrow line between necessary physical cautions and over-protectiveness; avoidance of the inculcation of prolonged dependency and a negative self-image in the child. These and many related issues require strength, consistency, and sharing and agreement among the parents. Without these positive elements in the family setting, pathological psycho-social reactions can be expected in both the child and parents. Clinicians have recognized the dangers to the successful growth and social maturation of the child and to the integrity of the family unit if these elements of constructive behavior and attitude are not present or promoted. Most of the formulae for preventing patho- logical interactions and dysfunctions in these families and their children stress professional/clinical interventions.

However, parent self-help groups present an alternative, and sometimes more accessible resource. Some years ago, the writer's doctoral study, published in summary form as "Parents of the Handicapped," [13] cited evidence from parents of children suffering from cerebral palsy, mental retardation, muscular dystrophy, and schizophrenia, of the manifold benefits they derived from participation in self-help groups for these disorders. Since that time, a host of clinical and empirical studies of self-help group support activities in a wide array of child health problems have come into the literature, and provide confirmation of these early findings.

Parent participation in self-help groups cannot only be preventive of family dysfunctioning and its consequences, but significant also in the child's psycho- social development and the prevention of subsequent problems. In recent years, much clinical work and research has highlighted the importance of parent

stimulation of infants and young children who suffer from central nervous system disorders and developmental deficits. An example of such parent participation was reported by the Down's syndrome project at the University of Washington:

> The staff from the first encourage the parents to interact with the infant constantly during his waking hours: to cuddle, to talk to, to hold, and to play with the infant. And, at first, parents are often astounded as they watch the staff doing all of those things. But the staff have found that their enthusiasm about the baby is contagious—parents who had earlier been somehow frightened of this infant with his "differences" could begin to react to him as they might automatically have reacted to a normal infant . . .
>
> Parents are involved from the moment their child is seen by our staff and then throughout his school program. They are trained to use at home many of the exercised and instructional procedures used at school. When their children reach preschool age, they work in the classrooms—they are trained to be observers, data-takers, and teaching assistants. They use many of the data-taking procedures at home so that they and the staff can determine whether the child's behaviors at home and at school are complementing each other, and can then make informed decisions together about his behavioral objectives and program.
>
> Parents attend staff meetings on days they have worked in school; they have individual and group conferences with their children's teachers at frequent intervals—if necessary, by telephone . . .
>
> The parents' activities in the larger community are formidable. Some serve as counselors; they are on call at several Seattle hospitals to visit and talk to parents of newborn Down's syndrome infants almost as soon as the new parents have been told about their child's diagnosis. They lecture to students in various University of Washington departments—education, psychology, social work, and in the School of Medicine. Several have written articles for Sharing Our Caring, a nationally distributed journal specifically concerned with Down's syndrome. Finally, in what is surely one of the most appropriate testimonials to "parents' as partners," several young couples who have moved beyond commuting distance ". . . have been able, on the basis of their training here, to organize and maintain preschool programs for young handicapped children in communities where previously there had been no educational opportunities for this population" [14].

Parent participation in such stimulation programs is aided and reinforced when the parents join with other parents in a mutual aid group.

The learning of self-management skills by children suffering from some chronic diseases is also facilitated by child and parent involvement in group education activities targeted to the specific medical problem. Young hemophiliacs now routinely perform self-venipunctures, injecting prophylactic materials that prevent or minimize the occurrence of internal hemorrhages, and thus reduce the incidence of crippling arthropathies [15]. Child asthmatics learn to monitor their breathing

capacities, to recognize impending airway obstructions, and to take remedial actions [16]. Such programs, which involve the active cooperation of child and parents, have proliferated widely in chronic disorders, and are clearly pertinent to secondary and tertiary prevention. Self-help groups often organize this kind of program themselves; or in other instances support those organized under professional auspices.

C. Later Problems of Childhood-Adolescence

When it comes to problems that frequently arise in a child's later development, self-help groups also can play important educational/counseling roles in helping child and family coping. Common psycho-social problems in latency, puberty, and adolescence include difficulties in child/parent relationships, eating disorders, substance abuse, establishment of sexual identity, school alienation, and drop-out. In adolescence, problems of identity establishment, dependency-independence conflicts, vocational choice and preparation, and sexuality, come to the fore.

Teen-age "rap" groups organized on the self-help model embody the well-known peer communication preference of adolescents, and have demonstrated constructive effects on teen social values and functioning [17]. Programs for overcoming adolescent drug abuse and alcoholism have and continue to rely heavily on self-help approaches, which are demonstrably, the "treatment of choice" in such conditions [18].

Self-help groups have also been effective with respect to the employment situation of young people. Vocational choice, the development of a "working personality," including self-concept, attitudes toward supervision and authority, work habits, and so on, are fostered by participation in self-help group programs.

For young people who have a physical/mental disability or handicap, the Centers for Independent Living, provide job counseling and placement, skills in self-presentation to potential employers—and usually employ the self-help group discussion method [19].

D. Problems of Adult Life

These are of course protean, encompassing work, family, and other social relationships, migration and mobility, changes in values and life style, and so on. Space limitations preclude discussing the problems encountered and resources needed in all these areas, but, echoing Freud's well-known formula, two can be singled out: disruptions in the work situation, and in family relationships.

Economic changes of recent years have altered familiar concepts and expectations of full employment and job stability. Massive unemployment, the displacement of workers in industries previously thought secure components of the economy, the shifts toward automation, high-technology and service occupations, the geographic re-locations of industries from traditional to newer areas such as the Sunbelt states, have resulted and continue to result in major stresses

on the U.S. occupational force. There is documentation of the serious effects of these changes on the physical/mental health status of affected workers and their families [20].

Coping with the material and psychological effects of these stresses often transcends the abilities of individual workers and families, and poses a challenge in the prevention of physical/mental disorders in this at-risk population. Among various approaches to these problems, the use of self-help organization and methods for displaced workers has shown promise. In California, with the cooperation of the State Departments of Mental Health and Employment and Development, and the companies and unions involved, special re-training programs have been mounted to assist workers from automobile plants that have been closed or re-located to other States. In addition to vocational assessment and training for other occupations, these programs monitor the physical and mental health of displaced workers and their families, and provide both one-on-one and group counseling. Self-help groups of workers and their family members in these programs promote cooperation around material needs, and encourage the discussion of personal feelings and attitudes about the job loss, necessary adaptations in terms of personal and family attitudes and roles, support and reinforcement for necessary shifts in career expectations, job relocations, etc. Preliminary data from these demonstration projects reveal that participants in the self-help groups have fewer physical/mental problems, and have been able to accomplish occupational and family relationship changes more expeditiously and effectively than non-participants [20].

In 1981, the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) of the U.S. Department of Health & Human Services held a conference on Health Promotion/Prevention at the Worksite. This conference discussed various methods for employee stress reduction, including work environment modification and Employee Assistance Programs. Attention was called to a hitherto "untapped resource"—employee support groups on the self-help model. It was emphasized that such groups provide an effective opportunity to discuss not only work-site stresses, but other worker problems, such as family relationship, child-rearing, life-styles, etc. [21].

Within or outside the work setting, general problems of family relationships are one of the important areas around which self-help groups have come into being. Divorce, separation, single-parenthood, bereavement, child-rearing, the situation of adoptees and their adoptive and biological parents, child abuse/ neglect, and other kinds of family violence, are all important social traumas that create short or longer term crises and stresses for the individuals and family units experiencing them, who are thus at risk of depression and other undesirable sequelae. Self-help groups exist in increasing numbers and variety to assist individuals and family units in coping with and surmounting such traumas, and thus can play a significant role in the prevention of serious disorders.

E. Retirement and Problems of Elder Citizens

With demographic changes resulting from bio-medical and social advances that have brought about increases in life expectancy and reductions in mortality/ morbidity, the problems of elderly and aging citizens have come to the forefront of national attention.

In general, the elderly have an increased risk of incurring chronic disease and disability; they also stand at the greatest risk of social isolation and dependency through retirement, and the loss or absence of meaningful activities and connections with others.

In discussing this subject, it is important not to conform to common stereotypes by considering all persons over 65 (or 60) as a homogeneous population; but to differentiate various groups among them, for whom both distinctive problems and various possibilities of self-help may exist and be appropriate. Four groups should be distinguished: the well-aged, who are basically independent and as fully functional as any segment of the population; the aged who have one or more chronic health problems, but are not significantly limited or disabled in their functioning; the aged with chronic conditions that are severely limiting— e.g., those who are homebound; and, last, the so-called "frail elderly," many of whom are in nursing homes or other institutions. The mix of problems encountered, of possible activities, of useful knowledge and skills, of involvement of relatives, and of possible participation in self-help groups, is clearly different for each of the above groupings.

In a review of self-care and self-help programs for the elderly, Robert Butler, former Director of the National Institute on Aging, concludes with the following statement:

> Self-care and self-help, propelled by a variety of social forces, are moving to prominence on the health care scene. While their roles are not yet clearly defined, they show great promise. It seems only reasonable that this potential be tapped to benefit the elderly: the ailing, who must cope with disability and chronic disease; the isolated, who can join in shared experiences; the stultified, who can discover new ideas and pleasures; the impoverished, who can participate without paying; the bewildered, who can be guided by their peers; the grieving, who can better adjust to their losses; the retired, who have new leisure to learn about and take better care of their bodies [22].

In addition to self-help groups that organize around health problems of the elderly themselves, it is important to note the many self-help groups that have been formed by those—usually relatives—who are *care-takers* for elderly persons who suffer from debilitating diseases. Thus, as more has become known about Alzheimer's as a clinical entity, self-help groups for Alzheimer's disease have sprung up in a number of localities; the disease clearly poses severe problems to family members. In Huntington's disease, there are several national organizations of relatives and sufferers that should be included in an account of self-help

organizations to meet problems of the elderly. A rapidly growing self-help group has been the National Alliance of the Mentally Ill, a federation of local, state, and regional associations of mental patients, their relatives and friends, set up in 1979. (In the 80s) NAMI numbered some 40,000 members in 90 groups in 48 states, maintaining a legislative office in Washington, D.C. A major stimulus to its dynamic growth had been the deinstitutionalization of mental patients, which has obviously brought many "chronic" schizophrenics back to families and communities ill-equipped to take care of them. It seems evident that many of the returned "chronic" patients had spent years in mental hospitals, and were in older age groups. As a self-help consumer group, NAMI focuses on strengthening the family as a support system, with interest in "issues of stigma and misinformation," research, needed changes in treatment and service delivery, and with the maintenance of adequate funding for federal and state programs for the mentally ill. The importance of such activities to all levels of prevention, both for social policy and programs, and for individual patients and their families, seems clearly evident.

VI. COMMON UNDERLYING THEMES

Having briefly surveyed the pertinence to prevention of participation in social support, mutual aid and self-help groups for psycho-social problems encountered at various stages of the life-cycle, it is now necessary to briefly discuss the underlying common elements embodied in such participation, despite the greatly varying nature of both the human problems dealt with and of the support groups themselves.

The underlying common property of such groups is that they foster *empowerment*—that is, they facilitate the individual's sense of power or mastery over the predictable and unforeseen stresses and traumas of social living. The widow or widower, the adult who loses a job, the parents of a child who has died, may not break down directly, but these traumatic situations impose stresses that often exceed the lone individual or family's coping resources, and that, if prolonged and not resolved, can lead to pathological consequences. Empowerment means increasing the ability of individuals and families to cope with such stresses, and it correlates with the strength of the available social supports. Self-help groups may often function as substitute or "quasi"-families that not only give material aid and emotional sustenance, but also strengthen the individual's self-esteem and consequent feelings of power in being able to cope with disruptive events or environments.

Role modeling—the example of peers who have successfully met the same problems—is a powerful dynamic factor in the social learning arising from experience in mutual aid groups, and it is a factor not available from professional sources.

The analysis sketched above is closely akin to some recent conceptualizations of Antonovsky, a prominent medical sociologist. Antonovsky posits a "sense of

coherence" in patients and potential patients as the sum or result of what he terms the individual's "generalized resistance resources"; and he sees the sense of coherence as closely correlated with, even determinative of, the individual's health status. Generalized resistance resources are defined "as any characteristic of the person, the group or the environment that can facilitate tension management." Antonovsky identifies three kinds of GRRs—"adapt ability on the physiological, biochemical, psychological, cultural and social levels; profound ties to concrete immediate others and commitment of and institutionalized ties between the individual and the total community" [23, p. 99].

The totality of these GRRs make up the sense of coherence which Antonovsky conceives as "a global orientation that expresses the extent to which one has a pervasive enduring, though dynamic, feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can be reasonably expected" [23].

The concept of coherence relates closely to that of empowerment that has been discussed above. The sense of being able to control one's inner and outer environments is clearly a major component of an individual's self-concept and self-confidence. It embodies a positive outlook, which, as has been seen, correlates with "profound, concrete ties to immediate others" and leads to resistance or vulnerability to stressors, and thus to avoiding or overcoming pathological processes. Antonovsky's conceptualization may thus be applied to the role of self-help groups in facilitating prevention at all three levels of the public health paradigm.

The application of these concepts in the planning of preventive activities in the universe of human service programs has been rarely consciously attended to or attempted. The concepts highlight the importance of recognizing, fostering, and consciously using informal support groups of all types, including self-help groups, as indispensable resources in aiding troubled people cope with life pressures and crises. Such groups provide emotional and material sustenance, present peer models of successful coping, aid in the establishment of positive self-concepts, problem-solving and self-management skills, and give opportunities for the open sharing of problems in a non-threatening atmosphere. In all these aspects, and in major periods of the life-cycle, they present often-overlooked but potent resources for the prevention of human distress and disease.

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