



**CAREGIVING: EMPOWERMENT FOR COMMUNITY PROBLEM SOLVING**

by

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## **ABSTRACT**

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Latino populations are characterized by high poverty and low educational levels, underemployment and unemployment and high school drop out rates. While the median age of Latinos is only 23 years, the numbers of those who are 65 years and over are rapidly growing; this group grew 61 percent in the last two decades compared to 40 percent for all elderly persons. Unless there are changes in their overall socioeconomic condition, the elderly simply will be the poor young Latinos who have become old. They will face all of the problems of aging complicated by conditions which are the result of their socioeconomic condition.

Despite their vulnerability, Latinos do not use community services nor have access to public programs designed to improve their well being. Lack of information, lack of skills to negotiate large help giving systems, cultural and language insensitivity of service providers, and a small pool of bilingual bicultural personnel combine to limit access to available services that have improved the overall life of most elderly in this country. In addition to these barriers, policies and procedures combine to prevent Latinos to break the cycle of poverty. Most U.S. policies that deal with economic distress have not only emphasized income support but promote the disconnectedness of family members that result in the breakdown of bonds of mutual help. Policies that support independence and access to the work place through empowerment and self reliance must be supported if this population of elderly is to reach old age with dignity and self respect.

Development of a national policy that will support and strengthen the family has not been possible due to the variety of vested interest that result in fragmentation of

policies and programs along age lines and defined in terms of specific but narrow problem areas. A life span perspective in the context of cultural diversity and equal distribution of resources should assist in framing a comprehensive family policy and/or policies. This perspective has the potential to support the cultural patterns of Latino populations that value family regardless of country of origin, socioeconomic status, religious preference and racial/ethnicity identification. While there is discussion that the Latino family is deteriorating as a result of the process of modernization, available research findings indicate that there are other factors that determine changes in the structure and function of the family. These include an ideology that values familism as well as new roles identified according to specific time, situation and place. Findings from available research support the notion that the extended family continues to be a vital support system that reserves a special role for its most vulnerable members such as the young and the elderly. For Latinos, the family as an institution has been a mediating force between the individual and society, negotiates with other community systems and brokers resources for its immediate members. In these types of transactions, help giving and help receiving are the key characteristics that enable family members to manage the stress of daily living.

Empowerment, as an strategy for social change, address the themes of competence and equity in a manner that promotes problem solving and self determination. Empowerment, or the act of gaining control over one's life, requires acceptance of the responsibility to act on one's behalf. In reality no one can empower someone else; rather one can strengthen the capacity for self and mutual help that can mobilize internal and external resources, initiating, supporting and joining groups of people that address issues of justice and equity.

This strategy is of particular value as the Latino population ages, the need for

caregiving increases and resources decrease. The family will emerge as the key mechanism for caregiving in which the ability for mutual help and support is crucial.

Research findings provide overwhelming evidence that families and other informal support networks furnish the bulk of the assistance that the elderly need to maintain their independence, and remain in their homes and communities.

Different conceptualizations underscore the variation in the caregiving role and point out to the need for an accurate understanding of a variety of factors that enter into the definition of this role. Generation and gender, socioeconomic factors, early parent-child relationships, differences in caregiving patterns and expectations, as well as the prevalence of care needed are more often recognized as playing a role in caregiving. There is growing recognition that cultural factors as well determine patterns of care. Just as there is greater acceptance of the impact of these different factors on different configurations of the caregiving role, there is greater need to examine the family as a premier help giving and help receiving network and thus the key vehicle for empowering populations at risk such as Latino elderly.

Empowerment to be meaningful and lasting must be firmly grounded in self determination the right to choose for oneself, and to be in control of one's life. This translates into the ability to define reality, mobilize resources, and design alternative help giving and help receiving models and life styles that are more in line with cultural traditions and values.

# **CAREGIVING: EMPOWERMENT FOR COMMUNITY PROBLEM SOLVING**

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## **ICUS XIX**

### **Introduction:**

Latinos do not compete well in today's society, a fact that is reflected in the high rates of poverty experienced throughout their lives. According to the Center on Budget and Policy Priorities (Washington, D.C. 1989), about one in four Latino workers paid by the hour now earn wages so low that full-time work would not lift a family of three out of poverty. A report released in October of 1980 by the Bureau of the Census indicates that while per capita income rose for Whites and Blacks in 1988, it did not change for Hispanics. Only 58 percent of those who are 25 years of age and over complete 4 years of school while 78 percent of the total population do so. The levels of economic dependence of future generations will at best remain the same if present conditions such as high school drop-out rates, lack of job training, and limited skills to compete successfully in the market place, remain constant.

While the current median age of Latinos is 23 years, it is expected to increase to 28 years by the year 2000. Those who are 65 years and over represent the fastest growing group among this population group. Since 1970, this age cohort has grown by 61 percent compared to 40 percent for all elderly persons. Their numbers are expected to quadruple by the year 2020 (U.S. Bureau of the Census, 1989). Unless there are changes in their overall economic condition, the elderly simply will be the poor young Latinos who have become old. This population group will face problems related to the normal process of aging complicated by conditions caused by

their severe economic disadvantaged to include poor health, poverty and hunger, lack of access to established community services, and lack of resources to purchase them in the market place. The identification of their inner strengths and support systems, such as the family, and their mobilization for empowerment is crucial for their future well being.

### **Empowerment vs. Dependency Policies:**

Despite their vulnerability, Latinos do not use community services designed to meet similar needs. Their low utilization rates of community support services, such as social services and health care, have been well documented (U.S.Civil Rights Commission, 1984; Select Committee on Aging, 1991). Lack of information about availability of such services and skills to negotiate large helping systems have been identified as deterrents to service utilization. But, discrimination, insensitivity of service providers to cultural and linguistic differences, a small pool of well trained personnel who understands culture and language and interprets programs within such context, and public policies that undermine basic informal support systems are also key factors that influence low service utilization rates.

Most self help efforts to improve their condition have focused on creating change in the way resources are allocated and services organized. Low service utilization rates are seen as a reflection of the powerlessness of this vulnerable population group to access the many types and levels of the service and health care infrastructure. Social change efforts have been based on the conviction that access to such services is a basic human right just as their establishment is a responsibility of government to protect and maintain the welfare of its citizens. While participation in the resource allocation process is definitely a power issue, discussion of alternatives by Latinos themselves for help giving and help receiving that focus on

self sufficiency and independence by-and-large has assumed a secondary role. On the other hand, self determination is recognized as a cornerstone for change by the helping professions. Yet, at the implementation levels most governmental policies neglect the desire of participants for self sufficiency and independence. For example, programs such as unemployment insurance, Aid for Dependent Children (AFDC), Social Security, Supplemental Security Income (SSI), Food Stamps, and subsidized housing are cash support programs that pay individuals who are neither working nor in training and in most cases penalized by reducing and/or eliminating their already poverty level benefits if attempts are made to increase their income of their own. Some of the same programs, such as the housing for the elderly (Section 202) supported by the Department of Housing and Urban Development (HUD), only allow the construction of one bedroom housing that prevents family members to provide care for the frail elderly in their own home, a strategy that has been proven to be cost effective in terms of money and quality of life, and rather promote and support the costly phenomena of "elderly living alone" that is characterizing the aging of America. SSI benefits, as limited as they are, are reduced if the recipient receives assistance from any source; recipients of AFDC remain trapped into a system that offers no incentives for work and independence. Instead, other countries have supported policies that include a range of approaches to deal with poverty such as employment programs that include continuing training and upgrading of skills to maintain the competitiveness of employees in the work place, restricting job dismissals, short-time compensation programs for shared employment, and relocation assistance.

The fact of the matter is that most present U.S. policies that deal with economic distress have not only emphasized income support but promote the disconnectedness of families that result in the breakdown of bonds of mutual help



among its members. The poor always experience joblessness, in times of a recession and in a healthy economy and arguments that the poor do not want to work have been dismissed with demonstration project after project. A most noted one was the large-scale experiment during the 1970's that refuted the contention that high youth unemployment is voluntary. When youth aged 16 to 19 years of age who had not completed high school were offered a guaranteed job, they responded in mass. This one program raised the overall employment/population ratio of poor teenage African Americans and Latinos above that of poor Whites (Farkas, 1982).

There is a sense of urgency to create changes early in the life of economically disadvantaged Hispanics in order to prevent undue dependence on public programs that perpetuate continued poverty into old age. Training, education, and employment policies should address this population group early in life in order to allow entry into the market place with utmost expediency. Recognition and support should be given to the roles that the intergenerational family and informal exchange networks, as part of their cultural heritage, play on promoting reciprocal help, and thus empowerment, among its members.

#### **Development of a National Family Policy:**

While discussion of instituting a national family policy has been discussed on and off for the last 20 years, movement in that direction has been extremely slow simply because different interest groups advocate for their individual agendas resulting in complex and burdensome policies, fragmented along age lines, defined in terms of specific problems. The controversy regarding different definitions of family has added fuel to the discussion. A life span perspective in the context of cultural diversity and available resources as viable tools for framing a comprehensive family policy have received little attention.

The truth of the matter is that the need remains to establish not one but several

family policies that recognize strengths and resources of our communities in which the elderly play such a key role and function. Focus should be on examining and mobilizing all strengths and resources available to families that will enable powerless populations, such as Latinos, to be in control of their lives and age with dignity. Arguments for disarray and disintegration of the Latino family have not been supported either in the literature regarding Latinos specifically or in the literature on changes in family structure in general.

According to most social change theoreticians (Moore, 1965; Smelser, 1964; Goode, 1968), the belief that all cultures, through modernization, will converge towards a common culture overlooks the prior diversity of societies, the historical period in which modernization takes place, the resistance of values to change, as well as the possibility of ideological changes and inter-changes between cultures. The possibility also exists that certain dimensions and functions ascribed to prior family patterns were already in the process of dysfunctionality and thus more susceptible to changes brought about by modernization, particularly if additional alternatives were made available under a radical societal change process. For example, the value of social responsibility to kinship beyond the nuclear family becomes weakened as a result of a value structure that recognizes achievement rather than prior kinship obligations. Thus kinship relationships become permissive rather than obligatory. The essential reciprocity and submission through rewards typical of traditional structures are substantially diminished. Conversely, the individual is more likely to make it on his/her own reducing the necessity of consulting with kin on important decisions. Reciprocal helping patterns are diminished since members of the extended kinship, through recognition of achievement, are reluctant to ask for help. Conflict and tensions associated with these changes in behaviors can only be resolved through value changes. A new system of specialized social structures,

proliferation of interest groups and associations develop to meet the needs previously met by large, kinship groupings. The result is undermining or loss of prior informal social control functions of some, or all, of the kinship units. Family disintegration, often defined as loss of control through a certain set of key events necessary through modernization, takes place. Prior patterns associated with traditional family structures are modified. For example, tensions between the generations occur as children receive significant training from others not necessarily their parents or grandparents. The social position of women begins to change as the family ceases to be a self-contained economically productive unit. This should apply particularly to urban settings where the possibilities of female employment are better and greater freedom of movement for women as well as a greater amount of free time is available.

It is not quite clear how modernization alone has created changes in family life. It has been suggested that too little attention has been given to ideological variables existing at a particular time in a particular culture. It is possible that there are other family variables that have considerable impact upon the social structure, and that these variables may facilitate or retard the acceptance of any type of societal change. It is at this point that the ideology of the family could play an important role by opening the way to new family behavior as well as to the expected market place role patterns.

The weakening of social integration by modernization is underscored by Rosow(1967). He defines social integration within two referents. One states that social integration is related to the network of linkages, reciprocal relationships, and functional connections between structures. The other integral part of social integration is the individual's web of beliefs, significant groups, and the position with accompanying actions, that he/she occupies in the social structures. Similarly,

social integration was defined by Axelrod back in 1956 as the social participation and/or interaction between the self and others which manifests its expression through the institutional form of informal and formal social activities. The institutional informal activities are construed here to include family and kin, while institutional forms such as social activities, groups of friends and communal peers. It is important to note that the literature points out that certain Hispanic groups such as Mexican Americans and Puerto Ricans are more closely involved with local kin groups than is the majority society; emotional and financial support received from their families is perceived as the main factor than influence their well-being. According to Valle and Martinez (1982) the aid that Mexican American families provide to members is critical to their survival. Sobogal and Marin (1987) studied the effects of acculturation on family attitudes and found that despite differences in national origin, family support appeared to be the most essential dimension of Hispanics, with the bulk of their sample being of Mexican descent. The authors noted that the perception that family support would be available when needed did not diminish with the level of acculturation. The protective function of family support in prevention stress or in mitigating its impact was also examined by Vega and Kolodny (1985). The findings from data collected by Keefe, Padilla, and Carlos (1979) and others support that family support systems provide a buffer against the development of stress in Mexican Americans. The research on other Latino subgroups is minuscule to generalize, however, there are indications that such strong family bonds appear in most Latino American families regardless of country of origin, religious preference, economic status, race and/or ethnicity. The findings from the above studies also support the notion that the extended family is a vital social support system that reserves a special role for certain family members such as women, the young and the elderly. While Torres-Gil and Negm

(1980) suggested that the socioeconomic barriers encountered by the Mexican American elderly may make them more dependent on their natural support networks than their white counterparts, nevertheless economic support was seen as one of the key factors in a relationship of reciprocity. According to Sotomayor (1973), Miranda (1981), and Maldonado (1979), the reciprocal supportive relationship that exists between older Mexican American and their families serves as a source of mutual support and/or protection especially during times of crisis. Valle and Martinez (1980), Valle and Mendoza (1979), Keefe, et al. (1979) and Sena-Rivera (1980) also found that helping interaction is essential to the well-being of all family members. These authors suggest that for Mexican American populations, the family as an institution has been a mediating force between the individual and society; it negotiates with other community systems and brokers resources of its individual members and for itself as a unit not necessarily diminished with years of living in this country, levels and degrees of interaction, and/or immersion in the majority society. It is in the emotional proximity and in the commitment to these relationships that support and intradependence is defined. In these types of relations, help giving and help receiving are the key characteristics that enables the family members to manage the general stresses of daily living. It is difficult to perceive a change process that will ignore the value given to family, in whatever form it may appear, by most Latino populations and within the family the process of help giving and receiving among its members.

#### **Empowerment as an Agent for Change:**

Empowerment is an approach to creating social and economic change that values self help and thus has the potential to mobilize Latinos and other minorities with a history of poverty, exploitation, discrimination, and disfranchisement towards a better quality of life. The theme of competence, as it relates to ameliorating the stress

resulting from socioeconomic and political factors, is repeatedly mentioned in the literature that deals with the empowerment of minority neighborhoods (Biegel, 1984). Empowerment is dealt in terms of two main components: "capacity and equity". Capacity is defined as the ability of a community to use power to solve problems; power is seen to promote equity and a fair share of the distribution of resources. In essence, empowerment becomes the process by which individuals and communities gain mastery over their lives (Rappaport, 1984). Ossofsky (1985) expanded the concept of empowerment to mean the creation of community based affordable services; empowering means giving those in need an opportunity to choose from an array of services that meet their perception of need.

The process of empowerment, or mastery in community, touches the issues of power and authority at every turn challenging their traditional and accepted meaning. Power and authority are converted into the ability to accomplish desired ends specifically by influencing the behavior of another individual or group so as to improve the standard of living for oneself and others. This definition of power and authority is totally different from that experienced by most Latino immigrants in their country of origin where power is oppressive, exploitative, and abused at every turn. In this new definition, legitimate power requires the assent of the respondents, evoking and promoting a sense of control and mastery over one's life; first and foremost this is done through the conviction that self and mutual help are inherent in that process. To gain control over one's life requires, above all, acceptance of the responsibility to act on one's behalf.

Empowerment, to be meaningful, profound, and lasting must be initiated and experienced by those who see themselves as powerless. In reality one cannot empower someone else. What someone else can do is to strengthen the capacity of those who see themselves as powerless to deal with life as subjects rather than

objects. And this can be done by enhancing strengths, enabling the development of the skills necessary to mobilize internal and external resources on their own behalf, initiating, supporting and joining other groups of people that address issues of justice and equity so as to lead productive lives.

The basic values and conceptual principles inherent in the process of empowerment have been applied successfully in many instances dealing with different age, ethnic, racial and linguistic groups. In fact, the literature on organizational history of Latinos in this country, specifically that of Mexican American, reveals self-help and mutual-help as critical elements in the daily process of coping with the environment.

Mutual aid societies, or **sociedades mutualistas** flourished in the Hispanic Southwest at the turn of the century serving as indigenous vehicles for community self help and social support. Unity, work, education, faith and brotherhood (**hermandad**), were seen as the guiding values of the function of protection that was carried out through a variety of mutual aid societies established by a population group that suddenly found itself dispossessed upon entry of U.S.A. forces into their territories. Most of these organizations had disability, burial, and widow's benefits as well as "protective" components, a function utilized to confront the Anglo in situations of discrimination.

Rivera (1984) examined the case histories of four self and mutual help societies that have survived to date: the **Alianza Hispano Americana** in Arizona, the **Sociedad Progresista Mexicana** in California, the **Sociedad Protección Mutua de Trabajadores Unidos** in Colorado, Utah and New Mexico and the **Unión Protectora de Santa Fe** in New Mexico. The findings of his study highlight at least five of their characteristics: (1) their organizational continuity or staying power over time, (2) their flexibility and capacity to perform a variety of functions and meet the needs of

its members, (3) their capacity to reflect and express the sociopolitical climate and concerns of the time, (4) their effectiveness in developing community and organizational linkages and networking, (5) their tremendous potential for becoming alternative resources for self help and channeling resources to others in the community. This study points out the total lack of knowledge of these networks by providers of services, thus neglect of a most viable resource to improve the well being of members of this population group.

A recent study (Sotomayor, 1989) that sought to obtain information on some of the factors that impact negatively on the Latino elderly's utilization of services revealed that all of the twenty-five (25) Latino community based organizations selected at random for the study were originally organized as self-help groups during the Civil Rights Movement of the 1960's. Three characteristics of these organizations merit emphasis; they deal with the type of organizational model and style of leadership. (1) The organizational model was primarily horizontal rather than hierarchical with a strong dedication to social justice, equity and capacity building. Their approach to problem solving was comprehensive. While they sought to meet immediate needs, they focused on the effects of an unbalanced power relationship between the majority and Latino communities. Change was sought primarily through advocacy and institution building. Their leaders, all Latinos, were particularly effective in performing this function because they understood the meaning of empowerment and the role that self help and mutual help play in this process. (2) Their leadership style reflected the cultural and sociopolitical political dilemmas of the population they sought to serve. But, it also reflected the demands of the dominant culture on these new institutions and the stress that such demands create on Latino leadership seeking to develop different power relationships based on partnerships between service providers and consumers. Their effectiveness was also related to their



ability to operate in multiple cultural and linguistic worlds at the appropriate time and place on behalf of their constituencies and communities; all changed easily from English to Spanish and vice versa with the behaviors appropriate to each linguistic/cultural world view. (3) These organizations sought to mobilize internal community strengths so that the participants felt the sense of ownership as they themselves guided community problem solving.

An integral component of the process of empowerment, the mobilization of internal strengths has led to focus on the viability of informal support networks to create change and community problem solving. For purposes of this paper, informal supports are non-bureaucratic and derive from caring and a sense of personal obligation; formal supports are the result of law, public policy or agency mandates.

#### **The Aging of America:**

The increase in the older population of the country as a whole, particularly the old old, will bring about societal challenges that raise additional questions about the country's future capacity to meet them given the present structuring of the helping industry. For example, it is anticipated that the increase in the numbers of elderly will require the provision of medical care over the long run that inevitably will tax national, state and local resources. This situation is juxtaposed to increasing poverty, escalating health care costs, the growing competition for resources to confront the devastating effects of AIDS, substance abuse, and growing rates of childhood mortality that increase federal, state and local budget deficits resulting in diminishing public resources. Thus, as demands increase, services provided by the formal health and social services systems decrease. Inflexible vested interests will posit one age group against another for diminishing federal, state and local resources. The well being of minorities will be at the center of these dilemmas.

It seems not only appropriate but necessary to systematically address the various functions and interrelationships of a variety of help giving approaches as options and/or alternatives to increase the local community's potential to take care of vulnerable and at risk populations, such as the elderly. The family surfaces as the key institution that embodies a set of activities and expectations based on the value of mutual help and support; their empowerment becomes a crucial issue.

### **The Family as the Main Support Network:**

As the U.S. population ages there is growing recognition that immediate family members are the main care providers of those in need and/or in crisis. This is so because of each family members' emotional commitment to one another; indeed, caring for one another in a personalized and voluntary way is expected in the normal process of daily living and assumes greater proportions as the need increases. Family, for the majority society as for Latinos, is the paradigm for other informal supports such as friends and neighbors; although the sense of personal or social obligation will vary from one type of informal support to another (Shanas, 1979). Since the late seventies, policy makers, researchers, and administrators in the field of aging have shown increasing recognition and interest in the role families play in caring for their elders. In the last two decades, the Federal government alone sponsored over one hundred research and demonstration projects on family support systems. The results and findings of these projects provide overwhelming evidence that families and other informal support networks furnish the bulk of the assistance the elderly need to maintain their independence, remain in their homes and communities (Hoffer, 1990). Family members, specifically women in their mid lives have become the primary caregivers of the growing older population the majority of whom are also women.

### **The Caregiving Role:**

The caregiving role has been described in many different ways. From the specific topology of daily activities (Matthews and Rosner, 1988), to the responsibilities and tasks that change as the elder's needs and situation change (Montgomery and Hatch 1986). As the elderly person becomes more impaired, carrying out the caregiving role can entail providing or arranging direct assistance with household chores. The need for placement in a nursing home, with focus on the management role, increases as the need for physical assistance grows. The burden of care is also multidimensional depending on the degree of care needed, availability of resources, and family's wherewithal to cope with the emotional and moral challenges posed by the demands of providing care for extended periods of time.

Different conceptualizations underscore the variation in the caregiving role and points out the need for an accurate understanding of a variety of factors that enter into the definition of this role. Generation and gender, socioeconomic factors, early parent-child relationships, differences in caregiving patterns, as well as prevalence of care are more often recognized as playing a role in caregiving. There is growing recognition that cultural factors as well determine patterns of care. A broader conceptualization of eldercare has the potential to increase understanding of interrelationships between formal and informal support networks within different cultural contexts, particularly as it pertains to several family functions and values such as the division of labor, allocation of resources, decision making, conflict resolution, problem solving, and transmission of values and traditions. Just as there is greater acceptance of the impact of these different factors on different configurations of the caregiving role, there is greater need to examine the family as a premier help giving and help receiving network and thus empowerment for populations at risk such as Latinos and other peoples of color.

### **The Impact of Informal Networks on Long Term Care:**

The high cost of health care, lack of access to health insurance and preventive health will inevitably result in large numbers of people in need of long term care. As the Latino population ages and their socioeconomic condition remains, the need for long term care, costing exorbitant amounts of money, will be out of reach for them. The cost of caring for patients with dementia illustrates the magnitude of these issues. It affects 5 to 10 percent of the older population (Zarit et al., 1980); approximately 1.5 million Americans suffer from a severe condition and another one to five million have mild to moderate levels of dementia. This is tenfold the number that were affected in 1900, and by the year 2000 that number is expected to increase by another 60 percent. By the year 2040, an estimated 7.4 million Americans will be affected if no means of cure or prevention has been found in the interim. Alzheimer's Disease accounts for 66 percent of the over 70 conditions that can cause senile dementia. The Centers for Disease Control (CDC) reports that Alzheimer's disease was listed as the underlying cause of death for 46,202 Americans in the period from 1970 to 1987. In California, the death rate increased from 0.5 per 100,000 people in 1970 to 3.9 per 100,000 in 1987. While there are no specific figures regarding the incidence of Alzheimer's Disease among Latinos, it is clear that it will appear in the same proportion as it does in other population groups. Their increased longevity rates and awareness about the dementias will increase the actual number of those in need of medical care and the numbers who will actually die of the disease. Since the clinical markers of this condition consists of severe physical and psychological changes that progressively deteriorate over a period from 5 to 20 years, care will be required for a considerable long time. Rather than loss of social skills, the most prominent clinical criterion for the disease is a substantial loss of cognitive skills, which in many ways may be a less critical

variable in determining whether a patient can be maintained in the community (Anderson, 1981). Yet, loss of social skills, unlike loss of cognitive skills, is not a variable which has been well-documented in the literature. Nevertheless, if this observation is correct, loss of social skills may impose more burden on the family than loss of cognitive skills. The implication here is that at low levels of cognitive impairment, cognitive and social skills may be the key variables in dealing with the caregiving burden of families with Alzheimer's patients.

Research on the effect of dementia on the family has examined feelings of burden experienced by caregivers (see specially Zarit et al., 1980). The researchers hypothesized that the amount of burden on the caregiver would be proportional to the occurrence of behavior and cognitive impairment of the patient. Contrary to expectations, none of the behavior or cognitive variables were correlated with the level of burden experienced by the caregiver; nor was duration of the illness. Only the frequency of visits to the home by other members of the family was significantly related to family burden. These researchers conclude that enhancing the informal support network of the patient may also prevent overwhelming burden on the primary caregiver and the breakdown of the family system.

As far back as 1968, Barber described the process of adaptation which families of retardates go through in coping with the problem. Likewise, Perucci and Targ (1982) describe the process by which members of immediate social networks react to mental patients and ultimately hospitalize them. Each of these models suggests that the nature of the relationship with the family and/or informal support networks is a most important variable in determining the response of the family to the disease. Farber, Perucci and Targ address the process of progressive social isolation on the part of the patient and that of the family from its network of social supports. For Farber and Perucci and Targ, the outcome of this progressive isolation is the

expulsion of a role player from the family, most often the institutionalization of the patient. This notion of social isolation becomes more interesting in the light of Ernst et al.'s (1978) suggestion that social isolation leads to sensory deprivation and that this in turn produces changes characteristic of chronic brain syndrome.

Ernst hypothesis remains intriguing, i.e. that there is a circular dynamic of social isolation leading to change in behavior which leads to further social isolation. This model of interaction of social contacts and disease processes is made all the more interesting by the work of Berkman and Syme (1979). Their study reveals a consistent pattern of increased rates of mortality and morbidity associated with decreases in social connectedness.

The implications of these findings are important in that it allows the postulation that people who have high levels of social connectedness seem better able to cope with the presence of a demented patient in their lives (Zarit et al., 1980; Cantor, 1983 and 1991, Hanson et al., 1983; Rundall and Evashwick, 1980), particularly if they are connected with others, such as family members, in a close and supportive relationship. People who are socially isolated seem to decline into chronic brain syndrome (Berkman and Syme, 1979).

We can then assume that if there is enough support available for the family from its wider sources of contacts, particularly from close and meaningful support and exchange networks, the family will be able to manage the patient for long periods of time. However, if there is not a large pool of support, a number of things may occur: the patient might be institutionalized, caregivers may become ill, certain key family members may be forced to leave. Further, if Ernest et al. are correct, changes in patterns of interaction with the patient may occur which could lead to rapid degeneration of function and more dependence on society, particularly on health and social service systems.

In summary, while Alzheimer's and other dementia patients suffering a debilitating illness that may require institutionalization cannot be cured medically, strengthening the family's support network on their behalf may improve significantly in areas that are more crucial for social functioning but also ease the caregiving burden. The meaningful involvement of the family network and other help giving supports will assist ease the physical exhaustion that is characteristic of the caregiving role. But most importantly, it will assist in coping with frustration, anger, guilt and stress that are characteristics of the caregiving role. This understanding may well result in further development of intervention strategies designed to strengthen the family and other informal support networks' ability to function on a day-to-day basis and utilize its energy in more cost effective ways. This understanding is even more important as we work with new immigrant groups, such as Latinos, whose family support networks have been valued as cultural traditions, in many ways reinforced by the very lack of community supports and/or lack of access to the a formal help giving system in this country as well as theirs. The family continues to be the primary vehicle for empowerment for it is here that self esteem, sense of identity and responsibility for others are learned and nurtured. Support for empowerment strategies that focus on self sufficiency, independence and dignity will continue to grow as we seek to accept the notion of cultural and language diversity as a societal value.

#### **The New Immigrant Populations:**

The "pull" and "push" forces that accompany migration are complex and dynamic. Most people leave their country or origin in order to improve their socioeconomic condition. For most Central Americans, migration more-often-than-not is the outcome of political upheaval in which established governmental and formal institutions play a predominant but a negative role. The fact remains that the

waves of immigrants that have changed the total ethnic/racial demography of this country and will inevitably change our perception of the helping process. The vast majority of newcomer families no longer come from Europe, but from Asia, Latin America and the predominantly Black populations of the Caribbean. During the 1980's, 89 percent immigrants came from Latin America, with those of Mexican origin being by far the largest number with 54.9 percent. This group alone account for more than half of all Latin American arrivals in the last ten years and constitute approximately two-thirds, or the majority of the total Mexican American population in the U.S.

According to the Bureau of the Census (1989) new immigrants from Latin America and those who have been in this country for several generations account for the fastest growing population group in the U.S. It increased by 61 percent since 1970 and it is expected to number at least 47 million by the year 2000; it increased almost five times as fast as the non-Hispanic population, 34 percent between the years 1980 and 1988. In one year alone, from 1986 to 1987, there were about 700,000 more Latinos in the civilian population in this country, an increase of 30 percent compared to 6 percent for the non-Hispanic population. From 1982 to 1987, the Central and South American population in the nation experienced a 40 percent growth.

The result of this great population shift is a new infusion of ethnic diversity into American society that cannot be overlooked. Planning and implementation of services within the context of empowerment will require the consideration of several unique characteristics that distinguishes this new group of immigrants from others. The following are most salient ones:

(1) New migrants from Latin America have arrived in family groups and oftentimes in entire communities. Key informal support and exchange networks,



although somewhat fractured because of the political situation from whence they come, can be easily identified and strengthened.

(2) A significant number of elderly individuals have migrated as part of these family and community units increasing the number of the overall elderly in the Latino population. Economic survival consumes the largest part of the new immigrants' daily experience oftentimes requiring holding two or three jobs at the same time. The elderly assume the main responsibility for childcare and homemaking functions performing the caregiving role within new dimensions and configurations.

(3) There is a "revolving door" effect, or a constant travel back and forth between their country of origin and their new country, therefore culture and language is reinforced time and time again maintaining culture and language across the generations.

(4) The recent wave of immigrants have little or no knowledge of the formal help giving systems as they exist in this country and less of the goals, structures and functions of the aging network. Most have relied on traditional family and other informal supports for help giving and help receiving of which eldercare has assumed a significant and accepted value and tradition.

(5) Most Central American immigrants have arrived with a rural orientation, low formal education levels, often illiterate, and little knowledge of the English language.

While these characteristics have been defined as barriers for coping in 20th century U.S.A. they are used solely to describe these population groups. There is little interest in identifying other strengths to include values and traditions that have allowed them to survive and cope despite the very difficult political and economic conditions encountered in their own and in their adopted country.

## Case Study

Estimates indicate that there are more than 500,000 immigrants from Central America in the Washington, D.C. Metropolitan Area, the bulk of whom are from El Salvador who have arrived to escape the long civil war that has afflicted that country for approximately 20 years. Most come to be reunited with their families and escape the ravages of war. This population group can be characterized by the economic and emotional impact of the trauma experienced in their lifetime but also by a strong work ethic, sense of community and family in which the elderly and children are highly valued. Women seem to play key roles in performing the nurturing and economic functions of these family configurations. Because lack of legal status, lack of employment history in this country, and poverty, the bulk of this elderly cohort's lack access to entitlement programs of Social Security, SSI, Food Stamps, etc. One would think that their dependence on younger family members is the rule rather than the exception, yet all participated in one way or another in contributing to the economic survival of their respective families.

This project was primarily one of information gathering, it was designed with a deep acknowledgment that research and/or simply information gathering for no other purpose than getting information is also a form of exploitation. Those who collect data are seldom in the position of giving something in return other than paying a few dollars per interview or paying their bus fare. The rationale used is that such information will help someone else in the long run; this can be interpreted to be too abstract and difficult to justify.

The following information was obtained from participants of a project entitled **Circuitos de Familia** sponsored by the National Hispanic Council on Aging (NHCoA) headquartered in Washington, D.C. and illustrate the value of family and informal networks in coping with their very difficult and painful lives. The project

illustrates how the value system of the *circulos* (circles) and the structure itself became an empowering experience for the elderly participants and the intergenerational (ages 22-31) data collectors.

The groups met once per week for a period of six weeks. An agreement was made to share information regarding their experiences in meeting with day-to-day living but with particular focus on identifying their strengths for coping with life. In turn we were to provide information, support, referrals if appropriate, to community services. No written questionnaires to complete were given because most were functionally illiterate both in Spanish and English. Rather, the participants selected their own themes for discussion through a variety of group exercises and activities that were selected for their potential to evoke difficult as well as pleasant life experiences. Themes discussed during each session and the dynamics of participant interaction were analyzed through briefing sessions with three young group leaders after the meetings and through cataloging of the main themes discussed during the meetings.

There were approximately 35 elderly participants in this project ranging from ages of 55 to 92 years of age; only two were men. All of the participants were referred to the program by an elderly community developer. There was no attempt to select specific individuals to participate; invitations were made to the total group at a local Hispanic Senior Nutrition Center. Participants were self-selected. The women identified themselves as being unattached and there seemed to be little concern about their marital status; in fact, all stated that they were better off without men and the dilemmas of associated with personal commitments of this type even though all, with the exception of one, had all been in a relationship simulating marriage. All recalled a life long of hard work in their country of origin and in this country and all wished they had employment at this time despite their age so they

could help their children and/or sent money home to El Salvador to different members of their extended network.

Without exception, the themes more often discussed were (1) family as the main vehicle for survival and the main reason for coming to this country, (2) the *barrio* (neighborhood), neighbors and friends as extensions of the family for support, help giving and help receiving, (3) *Fe viva* (living faith) in God who provides strength to cope with tremendous suffering and is ones' companion in the struggle to survive, and motivation to help others, (4) all expressed great pride on their children and grandchildren who were seen as the center of their activities and meaning in life, (5) while God was placed first in the hierarchy of reciprocal love and support, mothers were ranked second and grandmothers third.

The information shared by the participants supported other reports regarding the importance of the family and informal supports to cope with everyday life. Equally as important, the participants were able to share, compare, explore and identify how family and other informal networks assisted them in coping with life. All expressed the value received from the group sessions for in the process of sharing they found a "connectedness" with one another and their own cultural roots that they knew had been fractured in the process of migration. All felt an incredible strength from their faith and caring they received from their own networks that energized them and encouraged them to continue living and to give to others as well beside their own immediate families.

As they developed their own *arbol de la vida* (genealogical tree/tree of life), the grandmother was inevitably placed at the root of their trees that symbolized life giving and strength. They were able to identify the linkages, connections and relationships between each family member that evoked a story of reciprocal help. Problem solving and conflict resolution strategies were recalled with new insights as

to how they could have been resolved with less pain for those involved. Very often they were able to laugh at their own mistakes and insensitivity to others. Music played a key role in the group dynamics for the songs were selected to express a particular experience, emotion, and response. This was particularly important for two or three participants who seemed particularly unhappy and isolated. The participants utilized a number of **dichos** (sayings), again to illustrate a meaningful experience or merely words of wisdom and/or warning of difficult outcomes. It was in the remembrance of giving and receiving from members of extended family network, both blood related kin and non-blood related, that each participant acknowledged receiving strength to go on, continue giving and receiving. By the completion of the four week of meetings, the participants had developed friends, confidants, and allies and acknowledged their need to get home and continue helping family.

#### **Summary:**

In summary, the Latino population is increasing at a most rapid rate and it is also growing old. And while their numbers continue to grow, their socioeconomic condition do not seem to improve proportionally. As this population ages, their health condition will deteriorate due to their concentration in the types of occupations that expose them to physically harsh labor and lack of adequate preventive and on-going health care. Lack of resources and high rates of unemployment and underemployment, lack of medical insurance, and other income generating options meant that as this population ages their dependence on publicly funded programs has a real potential for increasing.

As this population ages, different types of problems will appear superimposed on the already existing ones requiring different types of skills, resources, and coping strategies. Incidence of physical or mental limitations such as those created by

strokes, falls, fractures, osteoporosis, and osteoarthritis and others that create mobility limitations will increase with age. Conditions, such as Alzheimer's and other dementias will undoubtedly increase.

As one ages and vulnerability increases, supportive networks and resource exchange networks become even more important than in younger years. Mutual exchange, collective and collaborative efforts, egalitarian relationships and resource distribution are functions of support and resource exchange networks that play key roles in time of need (Cox, 1989; Goodstein, 1983). There are common characteristics among these two types of support groupings the most important being that they tend to be not-for-profit, with emphasis on informal arrangements, designed to facilitate the exchange of various goods and/or services particularly in times of scarce resources (Sarason, 1979). The primary goal of such informal groups is to assist its members to move toward greater competency so that they can cope and even improve their day-to-day life. Equally as important, participation in such groups can also mean participation in the restructuring of society in general (Cox, 1989).

Goodstein (1983) states that human service networks perform some of the functions of resource exchange networks. But in addition, they have to be concerned with a different set of functions the most important being the establishment of linkages between human service agencies, facilitating communication among the various sectors in any given community, reducing interagency boundaries, assessing community resources and targeting them to assist the most vulnerable in any given community. Thus, human service networks can play a key role in moving the community in the direction of greater competence, for in the performance of their functions they can prevent at least two of the most formidable barriers to their utilization, that is, their complexity and fragmentation.

It is the family unit and other informal support networks that may pose the strongest ally in amelioration of health conditions that accompany the process of aging and increase the understanding of bonding among the generations. Its potential to do so underscore the importance of family and kin interaction and interface with formal helping networks. Family members, informal support networks and formal service provider systems, together, should pool their capacity to to maintain them in their homes and communities at a time when this group will be significantly larger and community supports diminish.

Empowerment has become a popular theme at local and national levels. Oftentimes its definition varies to suit a particular cause or group; those who mean well want to "empower" those who are less fortunate usually planning and designing programs and/or strategies "for the powerless" that fit their own definition of reality. Empowerment to be meaningful and lasting must be firmly grounded in self determination, the right to choose for oneself, to be in control of one's life. This translates into the ability to define reality, mobilize resources, and design alternative help giving and help receiving models and life styles that are more in line with traditions and values.

For new immigrants, most of whom are Latinos of color, the term empowerment in itself often has little meaning. Its context and outcome are vague and oftentimes illusive despite the fact that liberation movements in Latin America, particularly Central America, has surfaced a set of values that form the foundation for this process. Empowerment will have to be a process implemented in a variety of ways and settings, most importantly, it must be value focused.

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