

*Chapter 1*

**A BRIEF DESCRIPTION OF THE LIMITATIONS OF THE  
CURRENT HEALTH CARE SYSTEM IN THE UNITED  
STATES, AND A PROGRAM RESPONSE TO THE  
COMPLEX ISSUES OF MANY INDIVIDUALS  
WHO ARE CONFRONTED WITH MULTIPLE,  
CHRONIC CONDITIONS**

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**ABSTRACT**

This article describes an innovative, theory-driven, multidisciplinary intervention program designed to a) improve the health and health care of individuals who are dealing with multiple chronic health conditions, and b) help these individuals learn to manage their health care by means of an empowerment process through modeling, education, and decision support by a collaborative, multidisciplinary team (a nurse, a physician, and a psychosocial specialist). The focus of the intervention is to empower participants to be responsible for their health care through a gradual process of increasing personal involvement in the health care decision-making process. The program addresses the physical, social, psychological, spiritual, financial and vocational well-being of an individual, and was designed to eliminate the traditional "departmental-like" walls that impact patients with chronic care needs, as well as their providers. The on-going team process involves: a comprehensive assessment of all available previous health care records; collaborative on-going meetings with their Advocacy Team, the participant, his/her providers, and other significant individuals (e.g., family members, friends, etc.) to determine, and revise when appropriate, plans for treatment; assisting the participant's primary provider by providing a comprehensive summary of previous health care issues,

tests and treatments; and providing avenues for communication between providers regarding an individual's treatment goals. The Advocacy Team's goal to remove the traditional barriers that have interfered with the participant's achievement of best possible health (e.g., restrictions on mental health care appointments, prohibitive co-payments on prescriptions, transportation to appointments, etc.) is described. The team process of identifying the participant's current social network, the process of helping the individual to develop other relationships to address spiritual, employment, physical, mental, and other issues are clarified. Another goal of the program is the effective use of health care dollars. The literature review explains the reasoning behind the goals of this program. A description of information learned through the research data collection process is described, and conclusions are presented.

## INTRODUCTION

Health professionals and researchers indicate that costs related to chronic diseases, such as heart disease, arthritis, diabetes, and cancer, are causing an alarming escalation in health care costs in the United States (Anderson and Horvath, 2004). Chronic health conditions often necessitate expensive, long-term care, which may involve a number of medical specialties. Over 125 million Americans have at least one chronic health condition, and this number is expected to increase steadily in the future (Anderson and Horvath, 2004). Unfortunately, the current health care system is not equipped to address the numerous needs of these individuals with chronic conditions (Ostbye et al., 2005). In response to these expensive developments, a number of researchers have focused on finding ways to help prevent chronic diseases, as well as finding ways to improve the health status of individuals who are suffering from chronic diseases (i.e., disease management education programs).

The purpose of this article is to explain the inadequacies of the current health care situation in regard to the management of chronic conditions, and to introduce the Integrative Health Advocacy Program<sup>SM</sup> (IHAP<sup>®</sup>), a unique and innovative intervention designed to address the numerous issues of individuals who are dealing with multiple chronic diseases. This intervention process involves a comprehensive assessment of the physical and psychosocial issues of patients, the development of appropriate treatment plans, monthly meetings of patients and their advocacy team, and tailored patient education sessions. The goals of the program are to build a true collaboration process between health care providers and their patients, to improve the quality of life, health, and health care of patients, to gradually empower patients to successfully manage their chronic diseases, and to use health care dollars more effectively. This paper will explain in greater detail the impact that care for individuals with chronic diseases has on our current health care system, as well as the inefficiencies of the health care system in terms of its impact on the wellbeing of individuals who are dealing with chronic diseases. Also, a brief overview of existing interventions will be provided, and then a response to the current state of health care will be provided by means of describing the Integrated Health Advocacy Program. Finally, we will describe the theoretical concepts that form the basis of IHAP, the key components of the intervention, the research methodology and a brief description of the information learned through the research data.

## LITERATURE REVIEW

Chronic conditions are defined as long-term conditions (at least a year) that require continuous medical care and that may lead to disabilities/limitations of activities of daily living (ADL) (Anderson and Horvath, 2004). Cardiovascular diseases (e.g., coronary artery disease [CAD], and hypertension), diabetes, behavioral health disorders (e.g. depression, anxiety, posttraumatic stress disorder, and substance abuse disorders), osteoporosis, chronic obstructive pulmonary disease (COPD), cancers, asthma, and arthritis are some of the most prevalent chronic conditions that affect people's everyday lives (Center for Prevention and Health Services, 2005; Ostbye et al., 2005). Chronic disease management is currently the most urgent health issue, with an estimated \$277 billion being spent on chronic disease treatment (Committee for the Study of the Future of Public Health, 1988, as cited by Center for Prevention and Health Services, 2005). A large part of health care spending, over 75%, is the consequence of approximately 125 million individuals who suffer from at least one chronic disease and more than 60 million individuals who suffer from two or more chronic conditions (Anderson and Horvath, 2004). The Center for Disease Control and Prevention (2005) found that the costs of cardiovascular diseases and arthritis in 2001 reached \$429 billion and almost \$82 billion, respectively, due to treatment costs and loss of productivity. Furthermore, behavioral health disorders, such as depression, anxiety, and substance abuse, cost employers approximately \$17 billion every year due to a loss of workdays and a decline in productivity; these disorders are a major cause of long- and short-term disability in the United States and worldwide (Center for Prevention and Health Services, 2005).

Understandably, the escalating costs of health care are distressing employers and their employees as this country is experiencing a tremendous pressure "to reduce, ration and delay health services to contain health costs" (Bandura, 2004, p. 144). According to results of the 2001 Employee Benefits Study conducted by the U.S. Chamber of Commerce, "benefits cost an average of 37.5% of payroll [expenses] in 2000, or an average of \$16,617 per employee" (as cited in Parmenter, 2003, p.60). Over 35% of benefit expenses are a result of insurance premiums. Furthermore, health care costs have increased dramatically since the publication of this report (Parmenter, 2003), and thus health insurance coverage has become even more expensive for employers and employees.

To restate an alarming prediction, experts agree that we should expect a considerable increase in the number of patients with chronic illnesses and their associated health care costs over the next several decades (Anderson and Horvath, 2004). Although this upward trend will be found in all age groups, there seems to be a worrisome rise in the prevalence of children and adolescents dealing with conditions such as asthma, and other conditions found historically in the adult population, such as type-2 diabetes, obesity, and high blood pressure. The development of chronic conditions at younger ages will no doubt impact future chronic disease costs. At the other end of the spectrum, Americans are also living longer and, as they age, they become more susceptible to developing chronic conditions (Bandura, 2004). In fact, approximately 85% of individuals 65 years or older have at least one chronic disease, and over 60% have two or more chronic diseases (Anderson and Horvath, 2004). Furthermore, we are on the verge of a population shift; that is, many "baby boomers" are reaching retirement age, and this population is at an increasing risk of developing multiple chronic illnesses.

Some researchers predict that almost 50% of Americans will have at least one chronic illness in less than 20 years (Anderson and Horvath, 2004). As Albert Bandura clearly stated, "Demand is overwhelming supply." (2004, p. 144).

Compounding these issues is the fact that, unlike acute illnesses, chronic diseases are rarely ever curable and often progressive. However, our current health care system is based on an acute care model (Holman and Lorig, 2004). Under our acute care model, illnesses or injuries, even those known to be chronic or those that may eventually lead to chronic conditions, are treated as acute conditions. Furthermore, typically, the physician is the primary decision-maker, and the patient is expected to adhere to a previously established course of treatment without having much input (Anderson and Horvath, 2004; Bodenheimer, Lorig, Holman, and Grumbach, 2002; Holman and Lorig, 2004). For example, bacterial infections are treated with antibiotics and a broken bone is set and put in a cast while the injury heals. This model was effective in past centuries, when acute illnesses were very common and most people did not live long enough to develop chronic diseases. However, advances in medical treatments have made, and are continuing to make, diseases that were once considered fatal, survivable, and surviving a chronic disease over an extended period of time is far more likely today than it was even 20 years ago.

It is clear that chronic diseases require different types of treatment protocols than acute conditions. The treatment of chronic conditions is not only long-term, but also incredibly complex, as patients often require continuous, comprehensive and integrated care by a number of medical and behavioral health specialists (Schneiderman, Antoni, Saab, and Ironson, 2001). There is no "quick fix," and people with chronic conditions tend to experience a decline in physical health and mental health over time. These individuals often have to deal with "pain, functional impairment, social and emotional dysfunction, and premature loss of wage earnings" (Marks, Allegrante, and Lorig, 2005b, p. 148). Even though it is apparent that it would be helpful to attend to medical and psychosocial problems as part of routine health care to improve a patient's health, these issues are often not addressed in the current health care environment. One reason for not addressing these issues is that there is continuing pressure in primary care to limit visits and "there is a reported 18 to 21 minutes for office visits for most patients" (Ostbye et al., 2005, p. 210). Furthermore, patients with comorbidities have more medications that need reviewing for potential side effects, have more compliance issues, and "these patients have been found to require more primary care physician visits and time than patients with fewer co-morbid conditions" (Schellevis et al., 1994, Starfield et al., 2003, and Westert et al., 2001, as cited in Ostbye et al., 2005, p. 211).

Another serious issue in today's current care environment is that a number of health care services that are necessary or helpful to an individual's recovery are not covered by some insurance providers (Holicky, 2008). For example, mental health coverage was separated from physical health coverage with the development of managed care, even though individuals with chronic conditions have been found to frequently develop one or more comorbid psychosocial issues (Center for Prevention and Health Services, 2005). Furthermore, some health care policies provide limited coverage of services related to hearing, vision, and speech problems; these limitations essentially interfere with an individual's ability to recover, or maintain, sensory and cognitive functioning, and limit an individual's recovery from a stroke, spinal cord injury, or traumatic brain injury.

Furthermore, there are social issues that appear to be associated with chronic diseases, such as social isolation, patients' and families' actual, or perceived, lack of emotional support,

and the lack of support for informal caregivers (Krause and Kuhn, 2007) that physicians seldom address during regular appointments. The absence of these support structures may result in an individual developing long-term dependency on medical treatment.

Another concern that is very much related to the issues of individuals with chronic conditions, that further complicates chronic disease care and management, is the fragmentation of the U.S. health care system. For example, when an individual who is dealing with multiple chronic conditions is treated by different physicians, as is often the case, the lack of communication among the patient's health care providers may result in a failure to coordinate treatments and medication usage (Blendon et al., 2003). Blendon and colleagues (2003) found that Americans with chronic health conditions reported having appointments with three or more physicians during a two-year period. Berenson and Horvath (2003, as cited in Anderson and Horvath, 2004) found that Medicare beneficiaries with more than four chronic diseases see more than 10 different physicians, visit their physicians' offices almost 40 times a year, and fill up to 50 prescriptions a year. In their study Blendon and colleagues (2003) found that 20% of U.S. respondents who were suffering from chronic conditions indicated that they were prescribed duplicate medical tests or procedures by different health professionals, resulting in unnecessary health care expenditures. Consequently, medical resources are being wasted, and these unnecessary expenses add to the burden of the U.S. health care system. Furthermore, there is an increase in the risk of harm to individuals who see multiple health care providers. For example, Blendon and colleagues (2003) found that many American respondents reported receiving conflicting information regarding their health issues and medication usage from their health care providers. Additionally, although medications may cause serious side effects or interactions if taken with other medications, "30% of U.S. respondents indicated that their physicians had not taken the time to reevaluate their current medications within the last two years" (Blendon et al., 2003, p. 107). For individuals with multiple chronic illnesses, this failure to review medication usage may result in unnecessary and expensive emergency room visits, hospitalizations and/or nursing home stays.

Clearly, the current health care system in the United States is not prepared to manage the increasing numbers of individuals living with chronic conditions (Holman and Lorig, 2004), as it has not found a way to coordinate the extensive health care services that these individuals require (Blendon et al., 2003). In response to the current health care crisis, health professionals and health behavior experts have developed interventions that focus on providing education to promote healthy behaviors (e.g., public health campaigns to reduce drug, alcohol, and tobacco use and to promote healthy eating and exercise). Additionally, other interventions have focused on the management of a specific chronic disease, such as osteoarthritis (Groessl and Cronan, 2003; Osborne, Wilson, Lorig, and McColl, 2007), breast cancer (Lev, 2000), dementia (Fitzsimmons and Buettner, 2003), renal disease (Oppenheimer et al., 2003), pulmonary disease (Arnold et al., 2006), asthma, and diabetes (Newman, Steed, and Mulligan, 2004). The next paragraph will describe the specific goals of a few of these disease-specific interventions.

In a review of existing intervention programs for asthma patients, Newman, Steed, and Mulligan (2004) found that the interventions tend to focus on educating these patients to avoid the triggers that may lead to an attack and on making adjustments to medications as a preventative measure, and that little time is spent on psychosocial issues related to the disease. Also, researchers reviewing diabetes interventions found that most focused on

promoting health behaviors and lifestyle changes (Newman et al., 2004). An intervention for heart disease, however, focused on improving communication skills with physicians and found improvements in psychosocial functioning, but not physical functioning (Clark et al., 1992). Each of these interventions had different measures of success; however, each of the interventions focused on treating individuals with only one specific disease. .

Today, there are many different types of chronic diseases, and it would be very difficult to have a specific intervention for each chronic disease. However, Lorig and colleagues (1999) recognized the need for a broader chronic disease intervention program. They developed an intervention for patients with different types of chronic diseases, with the goal of educating these individuals regarding disease self-management skills (e.g., cognitive symptom management skills, effective communication skills, and coping skills to manage emotional reactions). The intervention also had the goal of increasing the patients' self-efficacy to improve their level of confidence in dealing with their conditions (Lorig et al., 1999, 2001; Lorig, Ritter, and Jacquez, 2005). Specifically, in a 6-month randomized study over 900 self-selected patients over the age of 40, who had lung disease, heart disease, stroke or arthritis, were asked to provide self-evaluations of their health status, health behaviors, and health care utilization (Lorig et al., 1999). A follow-up study two years later (Lorig et al., 2001) on these patients indicated that even though the patients' disabilities had worsened, their emergency room visits had decreased, and their health behaviors and level of self-efficacy had improved. As stated by Lorig and colleagues (1999), "These results indicate that it is possible to educate patients with different chronic diseases successfully in the same intervention at the same time." (p. 13).

Additionally, many intervention programs educate patients about the effective use of community resources. It is important to note that having patients rely on peers to support and educate them is not as effective, and does not result in changes in health-related behaviors, as having professionals facilitate educational sessions (Lorig et al., 1999). Thus, it is imperative that intervention programs for individuals with chronic diseases have professionals presiding at educational sessions.

To summarize, the key component of many intervention programs for individuals with chronic disease is teaching self-management skills, with a focus on positive changes in health-enhancing behaviors to improve patients' mental and physical status and to maintain those health-enhancing changes. In order for an intervention to be effective, skills, such as cognitive symptom management skills, effective communication skills, and coping skills to manage fear, anger, depression and fatigue, need to be taught (Lorig et al., 1999). Additionally, individuals with chronic diseases need to be taught the skills necessary to manage their conditions on a regular basis (e.g., to take medications as prescribed, to recognize and correctly evaluate the severity of new symptoms, to manage stress levels, etc.).

Although many intervention programs have focused on providing patients with educational sessions, numerous current self-management intervention programs, including Lorig and colleagues' programs (1999; 2001; 2003) are based on Bandura's Social Cognitive Theory (1977), and its key concept of self-efficacy. Self-efficacy is generally defined as a person's belief in his/her ability to display behaviors to successfully achieve goals. Furthermore, a person's self-efficacy beliefs influence whether he or she will initiate behavior changes and researchers have found that individuals' self-efficacy scores predict the outcome of their behavioral changes. Specifically, high self-efficacy levels are related to a greater likelihood that patients will initiate a behavior change and maintain it; lower scores have been

found to be associated with a smaller chance of successful behavior change. According to Bandura (2004) and others (Lorig and Holman, 2003), changing health behaviors requires a person to self-monitor his/her behavior, recognize the social and cognitive conditions under which he/she does self-monitor, set achievable, short term goals, and recognize motivating incentives and social supports that cause him or her to continue to practice health-enhancing behaviors. Self-efficacy scores have not only been found to be a consistent predictor of health outcomes (higher levels of self-efficacy are related to better outcomes), but are also related to better social functioning and psychological functioning (Arnold et al., 2006). Additionally, researchers have found that increased levels of self-efficacy are related to lower utilization of health care services, providing more evidence that health care costs may be impacted by intervention programs that focus on enhancing patients' level of self-efficacy (Holman and Lorig, 2004). Furthermore, researchers (Osborne, Wilson, Lorig, and McColl, 2007) found that "increased self-efficacy was a significant predictor of positive change in health status" (p.112), indicating that increasing self-efficacy is an important step in helping individuals with chronic diseases enjoy a healthier view of themselves.

Another important objective of some health intervention programs is to encourage a patient to create a partnership relationship with their health care providers in order to be active participants in deciding their health and treatment goals. This process involves having professionals propose different treatment options and then having the patient choose one of those options (Rodin, 1986). This process is suitable in that the physician is the expert regarding the various treatments that are appropriate and available for medical conditions, and the patient is empowered by being able to choose the best option. By having the physician provide both information and treatment options, the patient is able to make an informed decision regarding his or her care (Bodenheimer, Lorig, Holman, and Grumbach, 2002). This exercise of personal control by patients may increase their self-efficacy levels. Increasing self-efficacy levels can influence individuals' level of confidence in their ability to produce behaviors that lead to desired outcomes, and motivate them to continue practicing health-enhancing behaviors (Marks, Allegrante, and Lorig, 2005a). Practicing health-enhancing behaviors, in turn, may have a positive effect on performance levels (Perlmutter, Monty and Chan, 1986), lead to a reduction in harmful psychological reactions, such as a reduction in stress levels and in cortico-steroid levels, and slow down disease progression (Rodin, 1986). Cortico-steroid hormones are released in stressful situations to help the body deal with the situation; however, long-term exposure to these hormones is known to wreak havoc on all body systems, especially the immune system (Wiedenfield et al., 1990). Additionally, patients' improvement in health, and reduction in stress, would result in a reduction of health care expenditures (Kaplan, 1991).

There have been many different approaches taken to help individuals who are dealing with one specific chronic disease, and there are a few interventions that have been created for individuals with different chronic conditions. However, over 60 million Americans suffer from more than one chronic disease (Anderson and Horvath, 2004) and there is a serious need for an intervention program that is specifically tailored to their needs. This program needs to coordinate physical and psychosocial health care services for these patients. This program could prevent the unnecessary duplication of medical tests, oversee medication utilization, and could periodically re-evaluate participants' compliance with their treatment plans (Blendon et al., 2003). As Anderson and Horvath (2004) state so well:

We need information systems that allow clinicians to communicate with each other on a timely basis. Finally, and perhaps most importantly, we need to align financial incentives within health care systems and among medical, psychological, and supportive care systems. Ultimately, care coordination for people with multiple chronic conditions must become a standard of quality care, against which health plans and providers are measured. (p. 270)

It is in response to the current health care climate that the designers of the Integrated Health Advocacy Program began to envision an intervention that would significantly change the health care system, a program that would gradually empower individuals to manage their health care, and that would seriously address the fragmentation issues of the current, acute health care system. The designers of IHAP recognized the importance of Bandura's research findings regarding the positive effects of increasing a patient's level of self-efficacy, and recognized the economic situation of many individuals with chronic conditions, whose access to comprehensive health care and medications was limited by their insurance plans and their co-payments (Joyce, Kuhn, Curtin, and Murphy, 2003).

## **THE INTERGRATED HEALTH ADVOCACY PROGRAM**

The Integrated Health Advocacy (IHAP) program is an innovative, theory-driven, multidisciplinary intervention program designed to improve the quality of life, and the health and health care of individuals with multiple, chronic conditions, while decreasing the long-term financial impact of the health care costs of these individuals (Krause et al., 2006). The initial goals were to improve the health and wellbeing of a heterogeneous group of patients with multiple, chronic conditions, to tear down the "departmental-like" walls that patients and providers experience, and to decrease the long-term health care costs associated with these individuals. These goals would be realized through an empowerment process that would invite, encourage, and support participants as they gradually learn to be accountable and responsible for their conditions, health risks, and health care.

This program is a response to a fragmented, acute care system; in this program medical and treatment information is shared among three advocacy team professionals, the participant, and with his or her various health care providers. This advocacy team of professionals includes a primary advocate (nurse, case manager), medical advocate (M.D. or O.D.), and a psychosocial advocate (psychologist, counselor or social worker) (Joyce, Kuhn, Curtin & Murphy, 2003). These advocates do not provide health care services; they work together in collaboration to: a) define problems, b) set priorities, c) establish realistic goals, d) create treatment plans that include traditional and alternative health care options, and e) address problems related to physical and psychosocial issues. The advocacy team was created with the goal to work towards consensus, ignoring the popular hierarchical realities in the health care professions (e.g., the physician being responsible for all clinical decisions) and to set up a procedure to work together with each participant to achieve his or her best possible state of physical and psychological wellbeing.

In this intervention program, the three professionals work together with the participant to determine realistic goals based on the participant's medical issues, psychological issues, his or her current support system, and a comprehensive life review process. Ordinarily, a health team of this configuration would have the medical advocate as the clinical leader of the team;

however, the IHAP advocacy team members use a collaborative process and it is through that process that consensus decisions are made that allow for a clinical depth and detail that is unique. The advocacy team members also provide support and model effective communication skills, review medications on a regular basis, encourage the participant to prepare questions for health care appointments, discuss the participant's understanding of the health care professionals' responses to questions after appointments, work with the participant to establish realistic short-term goals, and meet monthly with the participant to plan and revise treatment goals.

It is important to make sure that the participants understand that short-term goals must be realistic and are considered to be small steps toward a greater goal, that of a healthier lifestyle. Goals that are set too high may result in failure. However, when individuals achieve their goals, they increase their self-efficacy; an increase in self-efficacy also motivates the individuals to sustain health-enhancing behaviors, and to develop other goals (Bandura, 1977).

The IHAP is not a short term intervention that lasts a few weeks to several months. The IHAP program is different in that it is a long-term disease management program that may last for several years. Other differences occur in that monthly meetings are held with each participant and all of the advocates: the primary advocate, the behavioral advocate, and the medical advocate. Also, the advocacy team meets face to face with the participant as it is the most effective method to address the participants' multiple and complex needs. This face-to-face approach is in contrast to other interventions that had quarterly meetings without the patient or physician (Oppenheimer et al., 2003). Another difference is that the primary care physicians and other health care providers, as well as significant partners and formal or informal caregivers, are invited to attend these meetings with the advocacy team and the participant. Furthermore, communication is initiated by the team to all care providers regarding treatment goals, outcomes or medication changes. Finally, primary care physicians and all other health care providers also receive a copy of the comprehensive treatment plan (the transition plan summary). These differences are all important to meet the complex goal of helping these individuals reach their best possible state of health.

The IHAP program is also unique from other intervention programs because it has both an individual and a group format (Schneiderman, Antoni, Saab, and Ironson, 2001). Each participant's program goals are different and tailored to meet his/her unique physical, psychological, financial, spiritual, social, and health care needs given his/her multiple chronic conditions, and the planning process acknowledges and respects his/her unique abilities and limitations, as well as the work and care-giving responsibilities of each participant. Additionally, the participant is empowered to be responsible for his/her health and wellbeing through a gradual process of increasing his/her personal involvement in planning and prioritizing realistic short- and long-term personal health and wellbeing goals. This gradual process is to allow the participant time to increase his/her level of self-efficacy. In addition to the individual format, a group format is utilized in monthly educational sessions (which address topics such as the wise use of the health care system, medication issues, the use of complementary self-care, stress reduction techniques, etc.). These educational sessions provide participants the opportunity to obtain social support from professionals, as well as from other participants in the program. Also, given the research findings that peer educational or support sessions are not as effective as professional sessions (Lorig et al., 1999), group

health education sessions are led by either team advocates or by a local professional in collaboration with a team advocate.

Each member of the advocacy team does an extensive, whole-person assessment of each participant which involves reviewing all the obtainable health care records and documents, medical as well as psychological over the individual's lifetime. The assessment process also involves reviewing all previous and current prescribed and over-the-counter medications, herbal supplements, the person's life history and lifestyle, and examining historical and current social, financial, spiritual and vocational issues. The advocacy team members perform a utilization review of all treatment records, and write comprehensive medical, psychological and social reports regarding the history of the individual (Joyce et al., 2003). The assessment process, therefore, involves examining the life pattern of issues for individuals to determine the issues that need to be resolved in order to treat the whole person.

### **The Primary Advocate**

The participant is encouraged to develop a relationship with each of the advocacy team members, the first of which is the primary advocate. The participant is instructed to contact the primary advocate with any concerns that might interfere with his or her ability to work towards the transition plan goals (e.g., financial difficulty regarding obtaining medications, loss of resources such as phone or electricity, unexpected injury or illness, etc.). The primary advocate serves as a resource to the participant regarding the effective utilization of the health care system. The primary advocate directs and facilitates communication with all ancillary health care providers.

### **The Psychosocial Advocate**

Unlike most intervention programs, behavioral health issues are aggressively addressed in this intervention program, and they are tailored to each individual's needs. This process is a crucial part of IHAP as participants frequently identify symptoms consistent with Axis I diagnoses (e.g., depression, stress, anxiety, trauma, addictions, etc.) (American Psychiatric Association, 1994). The psychosocial advocate works within the existing benefit plan to identify and educate psychosocial professionals who have the clinical expertise to work with this unique population. The psychosocial advocate links each participant to a clinician, oversees the utilization of services, performs clinical reviews of progress, and facilitates communication between the providers and the advocacy team.

### **The Medical Advocate**

The medical advocate reviews and analyzes all health care records and conducts a comprehensive physical on the participant, then synthesizes all of the information into a comprehensive report with an extensive biometrics section, a review of body systems, and the identification of all major diagnoses. The medical advocate is a critical resource who provides information regarding available medical procedures and treatments. This advocate also periodically reviews all medical tests, consultation reports, and pharmacy changes to insure the wellbeing of the participant and the wise use of the health care system. Through dialogue and education (e.g., disease prevention guidelines, benefit plan promotion) this advocate

serves as a valuable resource to the participants, the participants' health care providers and the advocacy team.

### **The Advocacy Team**

The advocacy team is viewed as a repository of clinical information, but these advocates also serve as role models, or change agents, as the participants go through the program. The advocacy team models and teaches problem-solving skills, cognitive symptom management, and communication skills; these skills are also beneficial in that they increase participants' self-efficacy, which has been shown to result in "higher motivation, greater persistence, more effective performance, and ultimately greater success." (Bandura, 2004, p. 199).

During monthly meetings with each individual participant, casual conversation is exchanged and positive feedback is given to the participant for reaching transition plan goals. This process is to acknowledge the successes of the participant, and to provide encouragement. When appropriate, the advocacy team also asks questions regarding the events or situations that may have interfered with the participant's goals that were agreed upon and set in the individual's transition plan. The participants also report on their compliance with treatment goals by bringing their calendars that contain information regarding their behaviors involved in achieving their treatment goals. The other expectation of each participant is to be an active, productive, and willing participant in all components of the collaborative process, but the expected level of participation is determined by his/her functional level. Participants are also expected to have regular communication with their primary advocate and advocacy team members, and to show a genuine desire to enhance their level of functioning and wellbeing.

The processes of gradually empowering the participant through a self-monitoring process (i.e., use of a calendar), increasing his/her level of self-efficacy, and increasing perceptions of personal control is imperative in the IHAP program. Previously, researchers have found that having patients involved in the management process of their health care improves their health status and decreases health care costs (Kaplan, 1991; Kaplan and Greenfield, 1994; Barry et al, 1994, as cited in Groessl and Cronan, 2003). However, 50% of patients reported that their physicians did not consult with them regarding their treatment options (Blendon et al., 2003). In response to these research findings, the advocacy team encourages participants to become more and more active in the process of setting realistic goals, and this gradual process of empowering participants is made possible through the use of phases. Each person moves through three phases at his or her own rate. Movement is determined by the individual's ability to meet transition plan goals and the individual's level of self-efficacy, including his/her level of confidence in being able to manage his/her health conditions. Participants move through phases that are hierarchically arranged and require the participants to develop self-management and effective communication skills.

After the team completes the whole person review of all available health records, the team develops the first summary transition plan. This plan is then reviewed with the participant and when agreement is reached, Phase I begins. In this phase the goal is to increase self-efficacy through gradually addressing all the areas in the plan, which involves working towards short-term, realistic treatment goals. In phase II the participant is required to be more actively involved in the transition plan process. The participant works with the Primary Advocate to set realistic health-related goals and then presents the new transition

plan to the entire advocacy team for discussion and collaborative input. In this phase the participant is expected to be more active in communicating his or her progress with the team by identifying issues that interfered with new or revised transition plan goals, by taking the initiative to self-monitor his/her behaviors, and by demonstrating self-efficacy over health issues. In phase III the participant plans his or her health goals, and then presents the transition plan to the entire advocacy team for feedback. In this phase of self-actualization, the focus for the participant is on maintaining his/her whole person well-being. The individual is asked to anticipate issues, to respond to challenges, to accept ongoing life changes, and to maintain his or her best possible level of wellbeing (Joyce et al., 2003)

At any time in any of these phases, transition plan goals may be modified with the advocacy team at meetings, either when the realistic goals are reached or when the goals are unrealistic for the individual at that point in time. Also, participants may move back into a previous phase, if they become overwhelmed by health or life issues.

### **The IHAP Participants**

Initially, the majority of IHAP participants in this program were hospital employees or their family members. This intervention program was initiated in hospital settings as hospital employees were viewed as a group of individuals who would provide unique feedback on the program design, given their involvement with the health care system. Additionally, most hospitals are self-insured and have flexibility regarding program design in their benefit plan. At this time, however, the program has been utilized at city municipalities, manufacturing companies, small businesses, a school district, a bank and at numerous hospitals in both urban and rural settings, with the number of employees at these hospitals varying from 110 to 35,000.

The procedure used to identify participants was based on previous findings that 20% of individuals account for 80% of health care costs (Parmenter, 2003). Participants who were spending the most health care dollars were identified through claims data (Joyce et al., 2003). Specifically, individuals eligible for this program were identified through a process of examining the utilization history of health care costs. During this process, health care records were reviewed with the purpose of finding individuals who have diagnoses that are frequently consistent with multiple, chronic conditions. The individuals who were identified through this process were sent an invitation to set up a meeting with the primary advocate to obtain information about the program. As a means to encourage voluntary participation, health care benefits were amended to allow increase usage of regular, behavioral and alternative care treatments, treatments not usually covered in health care plans. According to Oppenheimer and colleagues (2003), expanding benefits is an effective way to encourage volunteer participation in intervention programs. It is important to recognize that when an intervention program is effective there is a temptation to require mandatory participation; however, this mandated approach may negatively impact the self-efficacy of the participants, and ultimately impact the outcomes.

### **Materials**

Surveys are used to measure participants' physical and psychological well-being. Each participant completes these surveys every six months that they are participating in the program. The SF-36 Health Survey (Ware, Snow, Kosinski and Gandek, 1993) is used to measure participants' level of physical functioning, actual health, as well as perceived physical health. The Perceptions of Personal Control Questionnaire (Krause and Saarnio, 1996) is utilized to measure participants' level of health, and to measure their personal perceptions of control over numerous domains in their lives (e.g., stress, family relationships, spirituality, physical health, mental health, job, etc.). The Self-efficacy to Manage Disease (Lorig et al., 1996) measures participants' level of self-efficacy in managing their health care, in continuing activities, and in being able to decrease their use of emergency care. The Client Satisfaction Questionnaire (Attkisson and Greenfield, 1999) was modified for this study to determine the participants' level of satisfaction with their health care services in IHAP, in contrast to their services before the intervention process.

## DESCRIPTIVE AND STATISTICAL RESULTS

### Descriptives

The data have been examined at various times and presentations made at various conferences. At this time, over 500 participants have been through the process, 69% of these participants are females. Sixty-four percent of the participants are married, 13% divorced, and 13% single, the other 10% are either widowed, or have a significant partner after being divorced. Over 70% of the individuals are employed, 10% are disabled, 15% are unemployed (dependents of an employee). The average age of the participants is 52 years, with the most common age (the mode) of 53 years. The average years of education is 14 years, with 13% of the participants reporting between 16 and 23 years of education.

When joining the program the individuals reported in their screening forms an average 4.66 current health problems (10% reported 10 or more current health problems), the average number of current medications as 7 medications (5% reported taking 15 or more medications at the current time). These individuals also reported taking an average 1.7 over-the-counter medications (5% reported 4 or more over-the-counter medications), and an average of 2 vitamin supplements (5% reported taking 5 or more vitamins, with 1% reporting 10 or more vitamins). Fifty percent of these individuals reported having more than 7 previous health conditions (with 10% reporting 13 or more previous health conditions), and 50% reported having had 5 or more hospital stays in their lives (10% reported 12 or more hospital stays). Fifty percent had 4 or more operations (10% reported 9 or more operations).

Twenty four percent of the individuals reported that they did not exercise, not even once a week. Forty percent reported that they slept less than 7 hours a night. Furthermore 5% of the individuals reported that they had more than 8 cups of caffeinated beverages per day. On average, these individuals were employed at their current site for an average of 13 years, with 10% employed at their current site for 30 or more years.

Twenty-five percent of the participants reported that they smoked cigarettes, at least occasionally; 20% of these individuals reported smoking more than 10 cigarettes a week, 10%

reported smoking more than 20 cigarettes a week, 1% smoked more than 70 cigarettes a week. One percent of this group reported that they chewed tobacco at least once a day.

## Statistical Results

An analysis of participants' physical functioning from the time they entered the program to a year later (on the SF-36 and Perceptions of Personal Control) indicates that the participants perceive an improvement in their overall physical health. Additionally, level of self-efficacy was examined by means of the Self-efficacy to Manage Disease Survey, which presents a series of six questions about the participants' beliefs in being able to manage their conditions. This questionnaire uses a Likert scale of 1(*not at all confident*) to 10 (*totally confident*). Three examples of these questions are: "How confident are you that you can keep the tiredness caused by your health condition(s) from interfering with activities that you want to do?", "How confident are you that you can perform the tasks and activities necessary to control your health condition(s) in order to decrease your use of emergency care?", and "How confident are you that you can keep the emotional distress caused by your health condition(s) from interfering with activities that you want to do?" (Lorig et al., 1996). Participants significantly increased their level of self-efficacy in being able to keep their conditions from interfering with desired activities, being able to manage their conditions, and being able to avoid emergency care in each of the six areas examined from time 1 to time 3, all  $t_s > 3.060$ ,  $p_s < .01$ .

Finally, participants rated their level of satisfaction with the IHAP intervention program using a scale of 1(*quite dissatisfied*) to 4 (*very satisfied*). The results indicate that participants rate their health care services with the IHAP program as significantly more effective in helping them deal with their conditions, and they report being more satisfied with their health care services, as compared to their previous health care services,  $t_s > 2.70$   $p_s < .01$ .

To summarize the findings, the participants report an improvement in their physical health, an increase in their level of self-efficacy in being able to manage their health issues, they report being more satisfied with their health care services, and also indicate that the IHAP services are more effective in helping them deal with their conditions, as compared to previous health care services.

## CONCLUSION

The IHAP program was created in response to the current crisis in our health care system. The number of Americans with chronic conditions is over 125 million, the number of Americans with multiple, chronic conditions is over 60 million, and the number of individuals with multiple chronic conditions is expected to escalate rapidly in the future. The current health care system is not equipped to handle the millions of individuals who have numerous and complex needs. This IHAP program is a response to the issue of fragmentation in U.S. health care; it is a collaborative and comprehensive intervention that attempts to meet the whole person and health needs of individuals with multiple, chronic conditions: their physical, psychological and social needs. The goal of the program is to increase the participants' level of self-efficacy by helping them set realistic, short-term goals regarding

their health and well-being, and to set up a system of collaboration with their health care providers. This gradual and empowering process provides the participants with an advocacy team, who act as mentors, who helps the participants learn to communicate effectively and self-manage their health and health care.

The IHAP program provides an effective information system for health care providers and their patients to communicate with each other in a timely fashion. Even through the participants are receiving services that were not covered previously by insurance, the program is effective in controlling health care costs, in that the advocacy team's ongoing utilization review process prevents the duplication of services and unnecessary treatments, and oversees effective medication and treatment compliance. This intervention is innovative in its uncompromising process of integrating medical, psychological, and social care into one comprehensive whole person treatment plan. This whole person approach is required because chronic conditions have negative effects on individuals' psychological and social functioning.

The designers of this program responded to an invitation to create a program that addressed the complex needs of this unique population for it was understood that these individuals were most at risk in the current health care climate. Additionally, this group of individuals has been utilizing the healthcare dollars at an increasing rate. It would be gratifying to the designers, those involved in implementing this program, and the numerous healthcare systems who committed to this whole person, integrated and collaborative process, if this intervention process became "the standard of quality of care, against which health plans and providers are measured" (Anderson and Horvath, 2004, p. 270). This process offers a serious solution to the fragmentation issue in the current American healthcare system.

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