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### A Formative Evaluation of Select Evidence-Based, Healthy Aging Programs for Seniors in East Central Illinois

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A Formative Evaluation of Select Evidence-Based,  
Healthy Aging Programs for Seniors in  
East Central Illinois

Kathleen M. Raynor

A Capstone Project Submitted in Partial Fulfillment of the  
Requirements for the Degree of  
MASTER OF SCIENCE  
Department of Sociology

ILLINOIS STATE UNIVERSITY

2015

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## **Abstract**

This study serves as a formative evaluation of two evidence-based, healthy aging programs that are funded by the East Central Illinois Area Agency on Aging (ECIAAA). The first, the Chronic Disease Self-Management Program, is a six-session course designed to alleviate symptoms of chronic health issues in older adults and encourage participants to act as self-advocates in regard to their health. The second program, A Matter of Balance, attempts to reduce fear and risk factors related to falls in older adults over the course of eight sessions. The methodology of this study involves focus groups with former participants of these programs as well as key informant interviews with program teachers and trainers to better understand the advantages, challenges, and implications of administering such programs; the roles and relationships of the practitioners and consumers of these services; and in what ways program involvement affects said practitioners and consumers, with attention to the programs' anticipated outcomes as well as other, secondary outcomes. This study aims to offer recommendations to ECIAAA and its contracted service providers for strengthening and scaling up their evidence-based, healthy aging programs in the future.

## **Acknowledgements**

I would like to extend my deepest appreciation to the following individuals and entities that have supported this capstone project, in the hopes of empowering our nation's older adults to live longer and stronger. Your guidance and encouragement during this project have been critical, and you have each made significant contributions to the project. Thank you.

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## **I. INTRODUCTION**

As a Planning and Programming Fellow for the East Central Illinois Area Agency on Aging (ECIAAA) from 2014-15, I developed an interest in the concept of “aging in place.” Aging in place is simple in aim—to enable seniors to live independently in their own homes and communities for as long as possible—but can be quite difficult to execute. A wide array of variables, including health status, socioeconomic status, environmental factors, and presence of close friends and family may influence where and in what condition an elderly person will spend their later years. One strategy for empowering older adults to stay active and healthy, and thereby prevent costly stays in hospitals and nursing homes, is to encourage them to enroll in evidence-based, healthy aging programs. In line with ECIAAA’s mission statement—“Age Strong, Live Strong”—evidence-based, healthy aging programs are educational classes that employ scientifically proven interventions to promote self-management of physical and mental health concerns for older adults.

The issue of developing low-cost, reliable healthcare strategies for aging persons is quite timely. An estimated four in five Americans over the age of 50 live with one or more chronic health conditions (AARP Public Policy Institute 2009). Roughly one-third of the senior population falls each year, which often results in injuries, hospital stays, and fatalities (Centers for Disease Control and Prevention 2006). These and other health burdens may be aggravated by financial insecurity and uncertainty surrounding how to get help. Unfortunately, healthcare concerns are likely to continue to intensify into the coming years given the projected rise in the US senior population as the baby boomer generation ages. Estimates show that nearly 20 percent of the population will be over the age of 65 by 2030 (n4a 2011).

Health and social service professionals therefore seek low-cost methods of treatment that can be disseminated to an older audience on a large scale. One promising contender is evidence-

based practice, which has been steadily gaining momentum in medicine and the social sciences for more than two decades. Evidence-based practice is an approach to treating clients that emphasizes the mindful usage of the best scientific evidence available. In the field of aging, evidence-based programs aim to empower older adults to manage the symptoms of mental and physical health concerns, ideally resulting in older adults that are stronger, more informed, and more capable of handling their own health issues in order to continue to live in their homes for as long as possible.

The East Central Illinois Area Agency on Aging (ECIAAA) is a funding source and an advocate for several exemplary evidence-based programs. The Agency's mission is to provide support and services, primarily for adults over the age of 60, to assist with daily living. Although the Agency provides only limited direct service, it is responsible for establishing continuity in services throughout the region by determining service priorities and acting as a pass-through agency in distributing federal and state funding to local contracted organizations. Spurred by guidelines on funding allocations at the federal level implemented in federal fiscal year 2012, ECIAAA and other Area Agencies on Aging across the nation are now required to incorporate high-quality evidence-based programs into their selection of service options (Administration on Aging 2014).

In accordance with my professional practice at ECIAAA, this capstone project serves as a formative evaluation of two of the Agency's evidence-based, healthy aging programs. Using focus groups and key informant interviews, this formative evaluation offers answers to several vital questions for ECIAAA and partners, including:

- What are the advantages, challenges, and unintended implications of administering the evidence-based programs of interest?

- What perceived social and health benefits do participants gain from attending classes?
- To what extent do participants continue to utilize learned skills after the completion of their time in classes?
- How can ECIAAA and its contracted service providers use findings from this study to scale up in the future?

As a Planning and Programming Fellow with ECIAAA I was in the unique position to serve both as insider and outsider for this project, which was instrumental for the purpose of conducting a formative evaluation. I was able to build relationships with key administrators of evidence-based programs in our region, as ECIAAA acts as a funding source for community-based organizations throughout our region to conduct the programs. Yet, as I have no direct practice with attending or administering the programs, I was able to more objectively identify strengths and weaknesses of the programs without my judgment being biased by personal experience.

This project solicits the views of students, teachers, and administrative trainers of two evidence-based, healthy aging programs of interest. The first program, the Chronic Disease Self-Management Program, teaches seniors how to effectively manage an array of chronic health concerns. The second, A Matter of Balance, aims to reduce fear of falling and risk factors that lead to falls in seniors. This evaluation strives to address the dearth of research related to these programs' long-term social and health effects on participants within a regional context. The project offers practical recommendations for ECIAAA and its partners to improve awareness, attendance and effectiveness of the programs.



## **II. Literature Review**

### **ECIAAA BACKGROUND**

The East Central Illinois Area Agency on Aging (ECIAAA) was founded in 1972 in accordance with the federal Older Americans Act of 1965, which was a major piece of legislation designed to improve social services for the elderly population. The Older Americans Act prompted more research, training, and opportunities devoted to adults aged 60 and older. Early efforts included the creation of multipurpose senior centers and giving more assistance to disadvantaged and minority groups, including older Native Americans. The Act also built a hierarchical infrastructure of aging-related organizations at the federal, state, and local levels: the Administration on Aging, State Units on Aging, and Area Agencies on Aging, respectively.

Today, there are over 600 Area Agencies on Aging operating across the United States. These agencies enforce the requirements of the Older Americans Act at the regional level by promoting a connected, collaborative network of community organizations wherein older adults can access information, apply for benefits, and be assessed for eligibility for a variety of programs. Area Agencies on Aging act as intermediaries in distributing federally and state allocated funds to local organizations. In contrast to the direct service that local organizations provide, the bulk of Area Agencies' responsibilities involve administrative support, which includes monitoring and evaluating grants and programmatic efforts.

ECIAAA is tasked with coordinating services for the 160,000 older adults who live in the 16 counties that comprise east central Illinois: Champaign, Clark, Coles, Cumberland, DeWitt, Douglas, Edgar, Ford, Iroquois, Livingston, Macon, McLean, Moultrie, Piatt, Shelby, and Vermillion. Clients are predominantly adults over the age of 60 and their family caregivers. However, a recent merge between the aging and disability sectors at the federal level mandates that services must also be made available to individuals between the ages of 18 and 59 with

cognitive, behavioral, developmental, and physical disabilities. In alignment with Older Americans Act goals, the Agency promotes targeting of services to disadvantaged groups including poor and rural older adults.

## EVIDENCE-BASED PRACTICE IN AGING SERVICES

Evidence-based practice (EBP) as seen today in the field of aging evolved from evidence-based medicine, which initially gained traction during the 1990s (Rahman and Applebaum 2010). As EBP began to show positive effects in the medical field, professionals from other disciplines including social work, psychology, youth education, and gerontology began to translate its principles to their own work. The primary goal of EBP is to develop highly effective interventions to solve problems, based on the best available evidence. This evidence should blend with clinicians' own knowledge and patients' individual preferences to arrive upon an agreeable course of treatment.

Initial funding to support evidence-based programs in aging services was provided by Title IIID of the Older Americans Act. Since 1987, Title IIID has promoted educational activities designed to increase healthy aging in older adults. Beginning in fiscal year 2012, a new amendment denoted that Title IIID funding would henceforth be used solely for the support of healthy aging programs that are highest-tier, evidence-based programs. Highest-tier programs are those which have demonstrated statistically significant results in an experimental or quasi-experimental study, have made program materials available to the public, and have been successfully adopted at one or more community-based organization(s) (Administration on Aging 2014).

Evidence-based, healthy aging programs typically target a specific facet of physical or mental health and work to educate older adults on how to relieve symptoms; programs exist, for example, to reduce the negative effects of diabetes, strengthen balance and prevent falls, reduce feelings of depression, alleviate arthritis, care for family members with Alzheimer's disease, and much more. The programs typically, but not always, take place in group settings and thereby encourage physical activity and socialization. Class sessions also focus strongly on teaching older adults techniques to manage their medication and act as self-advocates when communicating with family, friends, and doctors.

### *Choosing an Appropriate Evidence-Based Program*

Though certain evidence-based, healthy aging programs have come to gain more prominence than others, there are dozens of highest-tier programs recognized by the National Council on Aging (2014). As such, it may be an overwhelming task to select one program that will demonstrate the greatest health effects for the target population. To this end, Levkoff, Chen, Fisher, and McIntyre (2006) provide a comprehensive background on how to choose an appropriate evidence-based program to meet an organization's specific needs. The first step discussed is to identify the target population. This entails determining the ethnicity, age, and most pressing health concerns for participants, as well as any necessary language or cultural accommodations. Bass and Judge (2010) also recommend ensuring that funding opportunities align with interest among the target population. In some cases, funding may come from a third-party, such as private insurance, Medicaid, or Medicare reimbursements. In other cases, though, the costs of the program are left for clients to pay out of pocket. In the latter scenario it is important to predetermine that participants are financially capable of paying, and also that they

find the program advantageous enough to enroll. Additionally, there must be a large enough pool of interested individuals to make the program sustainable.

Next, the organization turns to the literature to uncover what evidence exists (Bass and Judge 2010). This may include searching online academic databases, attending conferences, or discussing with colleagues in the field. After thorough research has been completed, the organization selects an evidence-based program to implement. The organization should choose a program that will translate well given contextual factors such as setting, training requirements, and budget. If there is not presently an evidence-based program suitable for the targeted population or condition, the organization may elect to turn to an emerging practice or a service informed practice (SIP). In these cases, though, organizations must heed caution because the reported evidence is simply not yet fully supported.

### *Advantages of EBP*

The support for evidence-based programs in the field of aging is clearly observable at the national level. According to the National Council on Aging (NCOA), roughly 40 percent of organizations report minimal difficulty with administering their evidence-based programs (Whitelaw 2010). In their most recent Strategic Plan, the Administration for Community Living (2013) identified the need to expand upon the availability of evidence-based, healthy aging programs over the course of the next five years. The Administration on Aging (2014) plainly states, “evidence-based health promotion programs reduce the need for more costly medical interventions.” Evidence-based programs are advantageous for a variety of reasons, including a low cost for participants and organizations when compared to most other healthcare

interventions, scientific credibility, ability to be disseminated on a large scale even in the absence of trained medical professionals, and adaptability to a variety of settings and populations.

A major draw of evidenced-based programs is their capacity to offer aging service providers a preexisting, reliable method of treating common health occurrences. Evidence-based programs are generally developed by research institutions, undergo randomized, controlled trials to measure effectiveness, and are then disseminated to the public. In this light, evidence-based programs essentially serve as a mold for agencies to utilize. As such, Kerz, Teufel, and Dinman (2013) note that one prominent advantage to EBP is a lower development cost for agencies. Agencies spend less time researching and instituting their own interventions, and the inclusion of pre-established training materials contributes to less time expended to educate supporting staff. Additionally, the rigorous research that goes into establishing an evidence-based program establishes credibility. Many interventions have statistics and scholarly journal articles published so that aging agencies can feel confident in offering the programs at their sites.

The NCOA, a nonprofit organization that advocates for older adults and coordinates services on a national scale, is one of the pioneers of supporting and implementing EBP in aging. Nancy Whitelaw (2010) writes on behalf of NCOA and pushes for a renewed devotion to expanding the evidence base among aging organizations, which entails conducting ongoing research. Whitelaw also recommends that regions and states form organized coalitions for their advocacy efforts, which conveys a sense of unity and provides strength in numbers in the effort to disseminate programs. For instance, an agency in Florida, the Healthy Aging Regional Collaborative (HARC), is a paradigm in successfully implementing evidence-based initiatives in over 140 locations in its founding year. Whitelaw (2010) attributes HARC's success to partnering with a number of public, private, and government organizations of varying sizes

devoted to maintaining the health of older adults. From this commitment to collaboration emerged a strong social network with much greater reach than any one organization alone would be able to assemble.

The US Administration on Aging (AoA) has been yet another steadfast supporter of evidence-based practice. Kerz, Teufel, and Dinman (2013) describe an organization established over three decades ago by the AoA, known as OASIS, that aims to allow adults 50 and over to age healthily by lowering their chances for disease and disability, keeping them physically and emotionally fit, and encouraging civic engagement. The organization reports that “evidence-based programs have improved OASIS’ reach and social impact” (Kerz, Teufel, and Dinman 2013, p. 134). OASIS tends to collaborate with federal agencies and leading research institutions to develop their curricula and set outcomes for their health and technology programs.

At present, ECIAAA supports evidence-based programs almost exclusively for their 60+ clientele. However, researchers have also developed programs for caregivers—another of the ECIAAA’s target populations. Informal caregivers tend to be family members who aid aging loved ones in a home-based setting. Carbone and Gugliucci (2014) note, for example, that family caregivers to older adults experiencing delirium would benefit from a greater foundation of evidence, as more education and coping strategies are needed. While there is a healthy amount of literature surrounding individuals with delirium and how to treat them, very little of it focuses specifically on successful techniques for the family caregiver. Alarming, delirium is considered a preventable condition, yet many caregivers and medical professionals do not have proper training or experience, leading to uncertainty in handling delirium onsets and even incorrect diagnoses and treatments. Estimates show that medical personnel and family members may be able to lower delirium episodes that occur in hospitals by 40% if they were given the proper

training (Carbone and Gugliucci 2014). Interviews with caregivers show that caregivers often feel distressed and unconfident in managing delirium, and that there is not a solid consensus on how best to educate them. An evidence-based program designed specifically for caregivers of those with delirium could provide positive results in terms of improved mental and physical well-being for both caregivers and their loved ones, as well as a decline in hospital visits.

Another incentive to offering evidence-based, healthy aging programs is that the sessions are often conducted by volunteer community members with little or no history of working in the medical profession, known as lay-leaders. Lay-led models allow for lower operational costs, the ability to reach a larger audience, and in some cases, increased trust because participants have preexisting relationships with their class leaders. In one case, Krukowski et al. (2012) describe an evidence-based program designed to reduce weight amongst rural older adults. This program recruited a large cohort of 20 lay health educators, dubbed “coaches,” to run a 12-week lifestyle intervention program at senior centers. This allowed the program to expand its scale so that a greater number of participants gained access to evidence-based opportunities in more communities. Coaches were either volunteers from the local community or senior center staff members. After four months, participants showed an average 3.8% decrease in weight which was statistically significant when compared to a control group.

The aforementioned program documented successful and innovative strategies for training, recruiting, and retaining personnel, which is often a struggle in start-up locations. Senior center directors were first asked to identify community members with strong leadership potential to serve as coaches. These individuals did not need prior experience in healthcare. Rather, directors looked for people who would be comfortable instructing groups and who demonstrated high levels of organization and dedication. The lay-led method is valuable for rural

areas including east central Illinois in that, by recruiting community leaders as opposed to external health experts, participants may feel more at ease. Additionally, local residents are better able to understand contextual factors and community resources that may be available in their location. With lay-led models, it is fairly common to recruit instructors who have the health concern of interest, as this may encourage and empower participants to follow their coaches' model (Lorig et al., 1999). In this case however, coaches were not required to be overweight, which may have resulted in a greater number of potential leaders. After initial contact and an interview to secure each coach's position, they received instruction on how to recruit older adults. Coaches perceived recruitment to be among the more difficult components of running the program, yet each center managed to enroll approximately 15 participants, underscoring the effectiveness of their involvement in the process.

### *Challenges with EBP*

Evidence-based practice in the social sciences, despite its merits, raises several concerns from a sociological perspective related to access and equity for community-based stakeholders (Wellin 2014). For instance, evidence-based programs typically mandate a high degree of fidelity to program curricula in order to ensure likeness amongst diverse settings. This may imply, though, a power hierarchy in which those at the top—the researchers and physicians, for example, involved with a program's development—are perceived as inflexible or insensitive to participants' and practitioners' individual and cultural preferences. Similarly, EBP policies may restrict experienced practitioners from tailoring presented information and activities that would otherwise address a specific, unaddressed need or otherwise benefit participants. This thwarts the ability for practitioners to provide individualized, person-centered care to clients.



Additionally, in an era in which social service agencies are relentlessly tasked with reporting the efficacy and impact of their programs and must endure competitive processes to receive limited funding, clients who access agencies that achieve positive outcomes may benefit disproportionately, and vice versa for those in resource-deprived regions.

Though evidence-based programs often come equipped with material to guide practitioners, agencies may also experience difficulties with the implementation process. Organizations tend to have logistical concerns such as finding the space and time to train and recruit staff (Kerz, Teufel, and Dinman 2013; Whitelaw 2010). Older adults often struggle to attend program offerings in the community because of lack of reliable transportation (Kerz, Teufel, and Dinman 2013). Also, agencies must carefully inspect the “evidence-based” label prior to implementing a program (Bass and Judge 2010); while many programs are of very high quality, the evidence-based designation does not necessarily guarantee that the evidence is strong or relevant enough to show results in every organizational context, and agencies should consider potential obstacles in any case. For example, if a pilot study shows a high attrition rate, then the concluding evidence may be unreliable and many organizations would likely have similar trouble with retaining participants. Careful consideration of an agency’s cultural context wards against results that are not generalizable. Further, there sometimes is simply not enough existing evidence to guide a practitioner’s decisions. Areán and Gum (2006) note that when there is not sufficient evidence available for treating of a target population, practitioners may choose to use evidence from a closely related population or rely on evolving practices from other agencies’ recommendations.

### *Formative Evaluations of Evidence-Based Programs*

Published formative evaluations of evidence-based programs for older adults are sparse, and as such, this project makes a valuable contribution to an existing gap. One effective model by Primetica et al. (2013) delineates the process of implementing an evidence-based program known as the Reducing Disability for Alzheimer's Disease (RDAD) intervention in a new community setting. The RDAD intervention, developed originally at the University of Washington, encourages individuals with Alzheimer's Disease to exercise to mitigate their symptoms, and offers management tips for family caregivers.

The evaluation by Primetica et al. relays a sort of timeline of the RDAD replication process in Ohio which considers the multiple components that, collectively, compose the program's infrastructure. In the beginning, the implementation team was tasked with deciding which community agencies would be involved in dissemination, and also where sessions would be held for participants. Program interventionists and administrators had to be selected and trained, and participants had to be screened and selected. A method for recording participants' progress was created. Agencies needed to determine whether or not they would attempt to alter any of the structure or contents of the original RDAD intervention, as produced by the University of Washington. The intervention's developers provided community agencies with a Replication Manual to ensure program fidelity. Then, a model was selected for evaluating the outcomes of the program's replication. In addition, fidelity monitoring was conducted to ensure that the translated program adhered very similarly to the components and outcomes of the original RDAD randomized, controlled trial.

Primetica et al. attribute the success of the RDAD implementation in Ohio, firstly, to effective collaboration and communication. Involved agencies frequently coordinated their efforts before and while RDAD was fully implemented, which resulted in reaching a greater

breadth of participants and streamlining processes. Additionally, buy-in on the part of community organizations and potential participants, as well as secure funds, are essential to establish before entertaining the idea of introducing a new evidence-based program to a community. This evaluation serves as a comprehensive guide for any agency wishing not only to replicate a new evidence-based program, but also for those who aim to assess the status of existing programs.

In the spirit of Primetica et al. (2013), the goal of my capstone project is to describe the circumstances that have culminated in the implementation of the two evidence-based, healthy aging programs of interest, and later to depict how and why the programs are administered today at the East Central Illinois Area Agency on Aging. This formative evaluation will center on the advantages and struggles involved with the implementation process of the targeted evidence-based programs in several communities in east central Illinois; the roles and relationships of the practitioners and consumers of these services; and in what ways program involvement affects said practitioners and consumers, with attention to the programs' anticipated outcomes as well as other, secondary outcomes.

## EVIDENCE-BASED PROGRAMS AT ECIAAA

ECIAAA strongly supports evidence-based programs as instrumental tools for empowering adults to live strongly in their later years. Several contracted service providers have committed to offering evidence-based programs in various counties in the region, supported financially in part by ECIAAA's distribution of Older Americans Act dollars. Though ECIAAA may assist operationally when asked, service providers are the primary parties responsible for training staff members, recruiting participants, and establishing locations to hold sessions.

Programs are frequently hosted via partnerships with churches, community centers, and senior living facilities.

There are currently five evidence-based healthy aging programs offered by ECIAAA service providers. The Chronic Disease Self-Management Program (CDSMP) and the Diabetes Self-Management Program (DSMP) are sister programs which educate participants on proper diet, exercise, and management of their conditions. A Matter of Balance is an educational falls prevention program. Strong for Life is an exercise-based program that uses rubber therapy bands to build strength. Finally, PEARLS (the Program to Encourage Active, Rewarding Lives for Seniors) is designed primarily to lessen the symptoms of depression. ECIAAA offers only five of dozens of highest-tier, evidence-based programs for seniors that are recognized nation-wide, but these five programs are all fairly prestigious choices with well-documented effects on participants. In the coming year, ECIAAA also plans to introduce an evidence-based program known as Savvy Caregiver, for family caregivers who care for a loved one with Alzheimer's disease. Two programs in specific—A Matter of Balance and the Chronic Disease Self-Management Program—are the focus of this formative evaluation.

### *The Chronic Disease Self-Management Program*

The development of the Chronic Disease Self-Management Program (CDSMP) began at Stanford University in 1991. The program's goal is to develop students' abilities to confidently manage their health concerns by adopting healthy nutrition and exercise habits, reducing stress, managing medications, and discussing health matters with their caregivers and doctors in an assertive way. Students facing a range of chronic diseases, including heart disease, stroke, lung disease, arthritis, chronic pain, and diabetes coexist in group-based classes. Students are typically

60 years old and older, though individuals with chronic diseases in their 40s and 50s occasionally attend as well. Participants attend six weekly group classes which are 2.5 hours each. Classes are taught by a pair of Class Leaders who often have one or more chronic diseases themselves.

CDSMP was introduced to the ECIAAA service area six years ago, and is currently conducted in Champaign, Macon, and McLean Counties. In fiscal year 2014, CDSMP was administered or conducted by 10 of the 13 Area Agencies on Aging in Illinois, and over 300 participants completed the course throughout the state.

A six-month, randomized, controlled trial examined the effects of CDSMP on three main variables—health behaviors, health status, and health service utilization — for individuals who participated in the program against a control group that was on the waitlist (Lorig et al., 1999). The study showed significant, positive results for all three variables. In the category of health behaviors, participants spent more time exercising, had greater cognitive symptom management, and communicated better with their doctors. In the category of health status, participants reported better self-rated health, a lower occurrence of limiting their activities, more energy, and less health distress. In the final category of health service utilization, medical records showed a decrease in participants' number of hospital stays as well as numbers of nights in the hospital. Further, the study estimated cost savings from hospital visits, after subtracting the cost of operating the program, to be approximately \$750 per person. A longitudinal follow-up to this study with measurements at one year and two years after baseline showed that participants had greater self-efficacy surrounding their health and had fewer self-reported ER and outpatient trips to the hospital (Lorig et al., 2001). A subsequent meta-analysis of 13 studies on CSDMP showed that “the program consistently results in greater energy/reduced fatigue, more exercise, fewer social role limitations, better psychological well-being, enhanced partnerships with physicians,

improved health status, and greater self-efficacy” (National Council on Aging 2008). This analysis also expresses confidence that CSDMP results in savings on healthcare expenditures, though a more uniform instrument is needed to accurately determine the exact amount.

### *A Matter of Balance*

In 2010, 32.1% of adults 65 and older reported that they had fallen (Centers for Disease Control and Prevention 2013). Of these, many are serious falls that result in emergency room trips, lengthier hospital visits, or stays in nursing homes for rehabilitation. Disseminated from Boston University in 2004, A Matter of Balance (MOB) seeks to combat the danger of falls among the elderly population. The program is designed to reduce factors that contribute to falls and fear of falling amongst the elderly in eight, 2-hour group sessions. MOB is the most recent addition to the selection of evidence-based programs at ECIAAA. The program is funded or conducted by 6 of the 13 Area Agencies on Aging in Illinois, with an estimated 600 seniors completing the workshop statewide in federal fiscal year 2014. In FY2014, ECIAAA welcomed MOB to McLean and Macon Counties and in FY2015, the program was introduced to Champaign County.

Funding from the Administration on Aging in 2003 allowed for a volunteer lay-led model of MOB to be developed. The adapted program showed similar results to the original, clinician-led model, and has since spread to over 30 states across the US. A Matter of Balance is thought to save an estimated \$938 in total medical costs annually (Centers for Medicare and Medicaid Services 2010).

A preliminary study reported that individuals who participate in MOB show a decreased fear of falling, though not necessarily a decline in number of falls (Tennstedt et al., 1998). A lay-

led version of the program in Texas, however, showed more positive results; the A Matter of Balance/ Volunteer Lay Leader Model (AMOB/VLL) was introduced in Texas via the Texas Falls Prevention Coalition, which enlisted Area Agencies on Aging to deliver the program throughout the state (Ory, Smith, and Parrish 2010). Results showed that, similar to initial trials with trained medical personnel, older adults managed by lay leaders showed gains in levels of physical activity and general health status, and also had fewer self-reported falls and other risk factors that are known to contribute to falls. Challenges to the model executed in Texas include participant attendance; rural areas experienced difficulty in achieving desired enrollment numbers.

Zijlstra et al. (2012) detail the implementation of a falls prevention program in the Netherlands modeled on A Matter of Balance. This program seeks to minimize the physical and psychosocial risks associated with falling amongst adults 70 and older. With the use of pre-test and post-test written questionnaires, the program showed that participants' frequency of falls, fear of falls, avoidance of activities perceived to cause falls, and depression symptoms were all significantly lower 4 months after its end. While positive short-term effects were measured at 2 and 4 months from the conclusion of the program, more research is warranted regarding its long-term effects.

### *CDSMP and MOB Structure*

CDSMP and MOB share similarities in terms of the characteristics and roles that each subgroup of participants holds (Figure 1). Typically, the individuals who enroll in CDSMP and MOB (referred to as "students") receive referrals to join classes from doctors, nurses, family members, friends, and other community groups. Students attend weekly group classes that are

taught directly by “Class Leaders” in CDSMP terminology, or “Coaches” in MOB terminology (Class Leaders and Coaches alternately referred to as “teachers”).

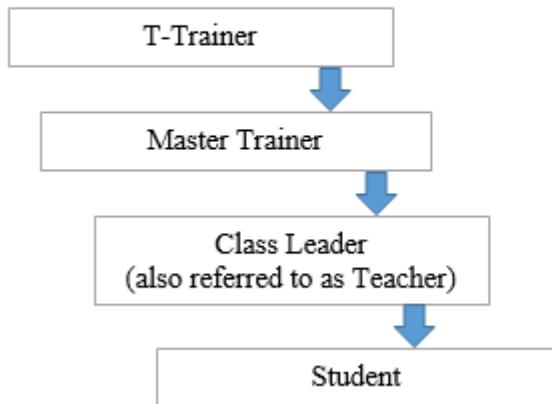
Teachers in the east central Illinois region are typically volunteers who learn of the opportunity to get involved via faith- or community-based organizations, in medical facilities, their workplaces, or after completing the program themselves. Teachers may have a background in healthcare, such as in physical or occupational therapy or nursing. Many, though, have no such experience and simply want to get involved in order to give back. Common occupations include school teachers, corporate employees, and retirees. Teachers become certified to lead sessions by attending a workshop which lasts for several days and is conducted by individuals known as Master Trainers. During these workshops, teachers receive a manual that is essentially a teachers’ edition of the same workbook that students receive. Teachers alternate during the training workshop between playing the role of teacher and of student, so that they may experience the program from multiple perspectives. Teachers are required to lead classes in groups of two or more, which allows them to share the burden of planning and facilitating, and also gives students varying outlooks on the material. CDSMP teachers often are personally facing a chronic disease of their own, and it is a requirement that at least one of the two teachers has a chronic disease or is a caregiver for someone that does. This requirement is intended to build empathy and understanding between teachers and students. CDSMP teachers sign an agreement to teach a minimum of two workshops per year, and so long as they fulfill this obligation, they do not need to be retrained. If they let their time lapse, they must attend a refresher training before teaching another class. MOB teachers must lead two classes during their first year of certification and attend annual training refresher classes.



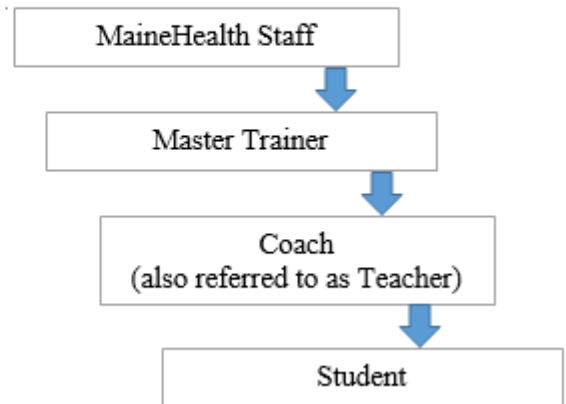
A step up, Master Trainers (alternately referred to as “trainers”) are generally individuals who have extensive experience working with older adults, whether in healthcare or the social services. In the case of ECIAAA, a Master Trainer is traditionally a person who is employed by one of the Agency’s funded service providers. Staff at these organizations identify someone who would be a good fit, and then this person becomes certified by attending a workshop similar to the teachers’ workshop in which they alternate between the perspectives of Master Trainer and teacher. Master Trainers occasionally teach classes directly, but at other times, they play more of an administrative role by identifying venues and scheduling teachers to lead sessions and, occasionally, aiding in participant recruitment.

**Figure 1.**

**CDSMP Participant Structure**



**Matter of Balance Participant Structure**



### **III. Methodology**

This capstone project is a formative evaluation of two evidence-based programs—the Chronic Disease Self-Management Program (CDSMP) and A Matter of Balance (MOB)—which are funded by the East Central Illinois Area Agency on Aging. According to Patton (1980), formative evaluations provide a useful platform for agencies to improve programs that are already in existence. A formative evaluation aims primarily to elucidate the strengths and weaknesses of a program for the purpose of making improvements. Ideally, formative evaluations are conducted during a program’s earlier years in order to document the implementation process and tailor it accordingly. Formative evaluations may be conceived as the inverse to summative evaluations, which serve to make conclusive statements and decisions regarding the success or usefulness of a program. Seeing as the efficacy of these evidence-based programs is already well-documented and ECIAAA will continue to fund the programs into the foreseeable future, a formative evaluation functions as a suitable method for offering commentary to the Agency for strengthening the programs and starting a dialogue with service providers to implement any improvements that should be made. Patton (1980) notes that formative evaluations “focus on gathering descriptive information about the quality of program activities and outcomes, not just levels or amounts of attainment” (p.73). Therefore, a naturalistic approach that incorporates detailed, qualitative data complements the goals and objectives of a formative evaluation.

This formative evaluation comprises semi-structured interviews and focus groups to elicit the perspectives of key players involved with CDSMP and MOB. These two programs were selected for inclusion in this study because they share commonalities in form and function; participants engage in regularly scheduled, weekly meeting in groups of around 8-12 individuals to practice exercises, become better educated about how to manage their unique health concerns,

and discuss intervention strategies. Both programs rely on Master Trainers to educate lay volunteers on leading classes in the community. In addition, both programs target the physical and emotional side effects of health-related issues and offer strategies for participants to gain a sense of control of their health.

## KEY INFORMANT INTERVIEWS

Five interviews were conducted in total. During interviews, subjects discussed the quality of the training and/or class sessions they attended, in what ways they have found students to benefit from the programs, drawbacks or difficulties with the programs, and suggestions for improvement. Interviews lasted approximately 45 minutes and were recorded with a digital audio recording device. They occurred either at the subject's workplace, in a coffee shop, or over the telephone if logistical concerns were present. I facilitated the discussions using a semi-structured guide (Appendix A) that was developed in cooperation with the ECIAAA Executive Director.

Two of the interviewees were Master Trainers. The CDSMP Master Trainer works as an administrator for programs for seniors in the Champaign area. The MOB Master Trainer works at a hospital in Decatur. These informants were selected using purposive sampling, in collaboration with the ECIAAA Executive Director, to participate in one-on-one interviews regarding their experience with administering evidence-based programs in the region. These professionals are employed with local agencies that have contracted with ECIAAA to provide evidence-based programs, among other responsibilities.

Two subsequent interviews were conducted with the programs' teachers. The first interview was with a CDSMP Class Leader who taught three workshops approximately five years ago in Macon County. The Class Leader is now retired, but continues to serve as an

advocate for seniors throughout the east central Illinois area. The second was an interview with two current MOB Coaches who are retired corporate employees. The MOB Coaches taught two MOB workshops together in McLean County recently, and are very dedicated to the program's expansion in the area.

The fifth interview involved a former CDSMP Student. This participant received an invitation to join the CDSMP focus group and was unable to attend due to scheduling conflicts, but still expressed interest, and so we arranged for a one-on-one telephone interview. The CDSMP Student is a retired school teacher living in Piatt County, is dedicated to maintaining a healthy and active lifestyle, and participated in CDSMP roughly five years ago.

## FOCUS GROUPS

Two focus groups—one for former members of A Matter of Balance and the other for former CDSMP members—were also conducted. The decision to incorporate focus groups into the research design was based on the ability to target a larger sample size than would be feasible with individual interviews, and also because focus groups mirror the group structure of MOB and CDSMP classes. The use of focus groups also addresses the “call for more research *with* older people rather than *on* them” (Scheidt and Windley 2006, p.359), such that participants have a voice in the research findings. Focus groups were beneficial in that the conversational, group dynamic tended to generate deeper and more thoughtful discussion than that which may have occurred during individual interviews or other forms of data collection, in line with Morgan (1997).

The CDSMP focus group was held at a large room in a community health center in Champaign County that often hosts healthy aging programs and other events for seniors. The

MOB focus group was held at an independent/assisted living facility in Macon County, in a common gathering space. I determined locations by gathering input from Master Trainers and other informants who are involved with the funding and administration of CDSMP and MOB via their relationship with ECIAAA. In choosing the locations, priority was given to community hubs that were easily accessible for older adults and familiar to people who were involved in the programs. I recruited participants by contacting two individuals who are employed with service partners of ECIAAA and administer these programs, to request a list of past participants. Both organizations had privacy policies that prevented me from accessing the rosters directly. Therefore, I printed invitations (Appendix B), placed them in stamped and sealed envelopes, and asked that my contacts at the partner organizations address and mail the invitations. Since the entire sample pool for either program was relatively small, I used a convenience sample in which the sampling frame consisted of all individuals who had attended at least one class session of MOB or CDSMP. Each partner organization addressed focus group invitations to 125 individuals—for a total of 250 invitations sent—beginning with those who participated most recently. The invitations described the purpose and procedure of the research project, location, time, and my contact information for questions and to confirm attendance. In total, four subjects participated in the CDSMP Focus Group (Figure 2) and three participated in the MOB Focus Group (Figure 3).

**Figure 2. CDSMP Participants**

<b>Identity</b>	<b>Age</b>	<b>Description</b>
CDSMP FG Participant #1	60s	Retired geriatric nurse. Attended a training to become certified as a CDSMP Class Leader, but decided against teaching.
CDSMP FG Participant #2	80s	Enrolled as a CDSMP student approximately 5 years ago to learn how to manage various injuries.
CDSMP FG Participant #3	50s	CDSMP Class Leader since 2010.
CDSMP FG Participant #4	70s	Enrolled as a CDSMP student approximately 5 years ago to manage a serious, persistent chronic illness that was diagnosed 20 years ago.

**Figure 3. MOB Focus Group Participants**

<b>Identity</b>	<b>Age</b>	<b>Description</b>
MOB FG Participant #1	70s	Enrolled as an MOB student several years ago.
MOB FG Participant #2	80s	Enrolled as an MOB student several years ago.
MOB Participant #3	50s	Assisted Living activities coordinator who has observed several MOB classes and plans to attend Coaches' training in the near future.

Participants were asked to discuss physical and social effects of their respective program, any difficulties that they encountered with classes, to what degree they recall and use the skills that they learned while attending classes as well as any long-term friendships that resulted, and suggestions for improving the program. I led the focus groups using a semi-structured interview guide (Appendix C) that was developed in cooperation with the ECIAAA Executive Director. Each focus group lasted for approximately one hour and was recorded with a digital audio

recording device. Participants wore name tags with their first name and I addressed them by name throughout the discussion, which helped foster a balanced and inclusive conversation in which all members shared their views to the extent that they were comfortable.

#### **IV. Results**

In general, subjects reported great satisfaction with the Chronic Disease Self-Management Program and A Matter of Balance. Ample benefits for students were discussed. Prominent themes for students included: positive social interaction with individuals who have similar experiences, the ability to receive and share information about products and services that help maintain good health, feelings of increased self-efficacy, empowerment, hope and belonging, and becoming more educated on how to maintain a healthy lifestyle. Students, teachers, and trainers, though, also voiced certain hesitations related to the programs and their efficacy, as well as concerns regarding teachers' and trainers' qualifications and levels of dedication to the programs. Further, several factors were identified as barriers to participation in and administration of the programs. Some subjects relayed that these barriers may discourage or prevent people from becoming involved as teachers or participants in the first place, and/or diminish potential results. Such barriers included a strict mandate for teachers' to adhere to program curriculum, difficulties with outreach and marketing, and a large time commitment for all involved parties.

#### **BENEFITS OF PARTICIPATION**

##### *Socialization*

The CDSMP and MOB Master Trainers, teachers, and students generally were pleased to report that the programs serve as excellent sources of socialization for older adults. This is especially important for frail and isolated seniors who reside throughout east central Illinois. Their isolation is both social and geographical; many older adults are unmarried or widowed, and may have no family or close friends nearby, especially if they live in rural settings. Therefore,



the opportunity to meet with a close-knit group for several hours per week can be uplifting and rewarding.

A few subjects reported that participants tend to come to classes on their own and form new friendships, whereas others saw that participants would attend with existing friends from groups to which they belonged. Several subjects recounted that, throughout the course of their six- or eight-week program, class members fostered a strong and trusting community in which they felt supported. CDSMP Focus Group Participant #2, a student in the class, said, “I don’t remember the teachers but I remember the people who were in the group. We helped each other! We really did.” Echoing this sentiment, MOB Coach #1 recalled, “They helped each other. The participants really bonded and there was a lot of discussion and problem solving and brainstorming among them, for solutions to things that they were encountering in their lives.” CSDMP Focus Group Participant #4, a student who subsequently participated in A Matter of Balance, spoke of the profound friendships that develop over the period of a month and a half: “It happens only gradually over time. Not two or three classes. We were a great group after [A Matter of Balance]. After the last class, we were like, ‘Whoa, man!’” The participant, exuberant, clapped her hands and continued, “No, no, we don’t want the class to end!”

The vast majority of subjects found social interaction to be an important—and, in many cases, one of the most important—benefits of the programs. The CDSMP Class Leader, however, expressed some hesitation in that it is appropriate to acknowledge that socialization can be a pleasant ancillary effect of the program, but should not be the primary driving factor for joining. This Class Leader concluded that it is a disservice to both the students themselves and the teachers when students prioritize other objectives above those related to achieving a healthier lifestyle, as the program intends.

### *Information and Referral*

Another noted aspect of the programs was their capacity for the transfer of knowledge. Older adults benefit dually from receiving new information and from sharing valuable information that they know. Multiple teachers and Master Trainers told stories of their students bringing in various gadgets, such as reachers used for grasping items, shower grab bars, and flashlights that have served as effective aids in navigating their homes and activities of daily living. These objects may spark another student to purchase something similar, but in addition, the act of sharing in itself can be of value for the possessor of the object. MOB Coach #1 told of a student who brought in three pairs of special tennis shoes to present to the group, and said about it: “We gave her the show and tell time. That was important from her.”

Teachers and Master Trainers also recounted gathering and distributing information about relevant programs and services in their area. The CDSMP Master Trainer, who has professional experience with guiding seniors to available resources in the community, would sometimes bring in fliers and place them on a table for interested students to collect during a break. The Matter of Balance coaches went a step further and contacted local agencies for information about health and exercise-related programs that they offer for older adults, and then typed and printed a handout to give to their students so that they could enroll and continue to stay active upon their completion of MOB.

### *A Sense of Normalcy*

Another resounding benefit was the students’ ability to recognize that they were not alone in their struggles. The older adults who enroll in classes are, understandably, facing many of the same issues related to physical and emotional health concerns. Therefore, as mentioned by the

CDSMP Class Leader, it is extremely meaningful when “people find out that there are others with the same problems. That in itself is sometimes a comfort to an older person.” Likewise, the CDSMP Master Trainer spoke of the profound moment when students share stories and realize, “Wow, I’m not the only one. I’m not the only one.” Students feel validated and comforted when they share their circumstances and find that their peers reciprocate the feelings.

CDSMP Focus Group Participant #4 stated that one of the program’s highlights was “just to know that I get the blues and someone says, ‘Geeze, I get the blues too, with pain.’ It wears me out and brings me down.” CDSMP Focus Group Participants #4 and #2 were first acquainted roughly five years ago through their CDSMP class. Since then, they participated together in A Matter of Balance, and they frequently encounter one another at events for older adults that are sponsored by a local senior health center. The two interacted in a collegial manner throughout the focus group and, at several points during the discussion, relied on one another to help convey a message or reiterate a point. The following exchange illustrates the feelings of support and reciprocity that were often exchanged during their class sessions:

CSDMP Focus Group Participant #4: Another benefit for me was to not only manage my symptoms but to understand the emotional roller coaster. There were times I thought I was going crazy, like something was wrong with me. But that chapter of dealing with the emotions was vital, along with the hope and the socialization—the knowledge about all the various aspects of the chronic disease.

CSDMP Focus Group Participant #2: Yeah, we told you that if you’re crazy, we’re all crazy with you!

### *Self-Efficacy*

Subjects also conveyed that the programs helped offer students a sense of hope and increased competence in dealing with their health conditions and concerns. CDSMP Focus Group Participant #4 was a widowed woman in her 70s with very limited financial resources. She shared her emotional story of managing a serious chronic disease for the past 20 years holistically, refusing to take harsh, high-risk treatments that had been recommended by healthcare professionals. Recalling the day that she found a flier for CDSMP, she dramatically panned her hands in front of her eyes and exclaimed, “I saw this: ‘MANAGING CHRONIC DISEASE’ [flier]. I got that! It’s made for me, baby! And so that strengthened and helped pulled me out of a depression.” She later explained how the program, and in specific, the participant manual, helped her feel more hopeful and regain forward motion in her life:

[CDSMP] gave me hope. And that was, for a single old lady... I don’t know how you can measure it on your little graph, but I felt hopeful. And that [manual], I still go back to. So the class helped me get out and the more I got out, the more I got to see the same people now and then in class and connect, and the better I felt.

The CDSMP and MOB Master Trainers agreed that they generally observe a lack of change in students’ physical conditions at the end of the six- or eight-week sessions. This, however, is countered by noticeable increases in confidence to self-manage health issues. Additionally, MOB Coach #2 explained that each student has her or his own unique limitations and concerns regarding health, so “one of the messages [...] from the program is you can do better than you are now.” Regardless of the starting point, said MOB Coach #2, the program helps students set goals and strive to do more. On a parallel note, the CDSMP Master Trainer stated that the program instills a variety of new tools and knowledge in participants, such that their self-efficacy grows and they are better able to address health concerns. She emphasized, “We have to learn how to be assertive in our own medical care. And I think this gives people

some tools to do that.” This, said the Master Trainer, is crucial for older seniors who are accustomed to an authoritarian-type relationship with their doctors. The Master Trainer feels that the changing medical landscape, in which the passive patient is transforming into an informed consumer, demands that older adults feel comfortable advocating for themselves in medical settings, which is quite a foreign role from that which they have taken throughout much of their lives.

When asked about the motivating factor for joining A Matter of Balance, MOB Focus Group Participant #2 replied, “I think we’re all aware of falling. Maybe we haven’t been affected, but it’s probably at the top of the list of accidents to happen.” The participant had not personally experienced a fall, but desired to gain the appropriate knowledge and skills on how to prevent falls. The participant’s statement also highlights a key feature of evidence-based programs for the elderly: preventative care. The time and financial resources devoted to A Matter of Balance by the aforementioned participant are miniscule in comparison to the possible outcomes of one injury-producing fall. Similarly, the interviewed CDSMP Participant explained of her classmates, “I think there were many people like me who had good health, who didn’t have any real serious health issues at the time.” This participant and her peers were quite active, often taking walks of up to three miles together to ward off symptoms of aging.

### *Accountability*

One factor that subjects identified as a cause for students’ success in the programs was the level of accountability that the programs’ developers have ensured. Both programs include weekly tasks or goals to be completed at home, and students are asked to report on their success or difficulty achieving the tasks at the start of each new class. CDSMP also encourages students

to choose a “buddy” to call midweek, to check in and encourage one another to complete their weekly action plan, which is an assignment in which students identify a goal that they desire to achieve and delineate steps to complete it. The CDSMP Master Trainer explained that, when teaching a workshop, students frequently make such statements as, “I wouldn’t have done this if I didn’t have to report on it! But I didn’t want to come in here and tell you I didn’t do it.” MOB Coach #1 told of a married couple who excelled in the course because, in addition to coming to class together, they also exercised at a local gym together regularly and held each other accountable. The MOB Master Trainer instilled a sense of accountability which dually served as a safety measure for students:

One of the things we go over on the first day [is] if you’re not going to be here, let us know. Otherwise, I don’t know if it’s the common practice, but if you’re not there I will call you and make sure you’re okay.

In a similar vein, several subjects praised CDSMP and MOB for encouraging students to get up and moving. When asked if the interviewed CDSMP Student found that she was achieving the goals that she set for herself, she retorted, “Yeah, but there were some mornings when I thought, well, I’m going to stay in bed [laughter], but no!” The CDSMP Student increased her awareness of her activity levels by completing her weekly action plans, and was thereby more apt to exercise. The MOB Master Trainer told a comparable story of a student in her 90s who attended classes every Wednesday morning. According to the MOB Master Trainer, “She said, ‘I just look forward to Wednesdays because I have to get up and take a shower and get ready to go.’ She said, ‘If I didn’t have this, I wouldn’t do it.’”

## HESITATIONS RELATED TO PARTICIPATION AND EFFICACY

### *Uncertainty Surrounding Program Efficacy, Follow-Through*

There were conflicting views related to if, and if so, how long students tend to use the skills and knowledge from their classes in their daily lives during and after their six- or eight-week involvement. The MOB Master Trainers and Coaches all noted that they often have students who express interest in joining another healthy aging or exercise program after their time with MOB. However, they acknowledged that since they do not have contact with students after the course, it is difficult to determine if they follow through. Nevertheless, it is common to hear success stories during the program. MOB Coach #1 remembered a student who said that she was practicing her ankle rolls, which are an exercise taught during MOB classes, at the movie theater. The CDSMP Master Trainer recalled another student who, after a class session on preparing legal documents, went home and had a family meeting to work on drafting the documents. CDSMP Focus Group Participant #3, who is a Class Leader, described a borderline diabetic student who opted to make healthy lifestyle changes in lieu of beginning medication to regulate her blood sugar levels. The timeline coincided with a CDSMP class on communicating assertively with one's doctor. The Class Leader said,

We encouraged her to talk to her doctor and tell him what she was doing and what we were talking about in the class, and try to talk him out of insisting on the meds. She ended up going sometime within that week, and he agreed to it. And she did really well.

Sometimes, too, it is difficult to gauge the level to which students are interested or involved because it takes some longer than others to want to change. The CDSMP Master Trainer recalled a student with diabetes who devised a seemingly simplistic action plan to clean off her tabletop for five consecutive weeks,

Until the last week, at which point she said, ‘This week I got out my carb counter and started looking at it, and I think I’m going to start doing that again. I think I’m going to start counting my carbs. I think that would help my diet and my health a lot.’ So it took her 5 weeks, but she finally had a health-related action plan that it sounded like she was going to try to carry out. So you don’t know what’s going through peoples’ heads.

Similarly, it was striking to hear the number of instances in which teachers and trainers spoke of a specific student who seemed at first to be a complete enigma in regard to their motivation for coming to class. The anecdotes generally focused on a man or woman who participated very minimally and acted distant during classes, and yet had perfect attendance. As the weeks progressed, though, the trainers and teachers came to understand that these seemingly aimless students were indeed benefitting from attending, albeit perhaps not in a way that was intended by the programs’ developers. For instance, the CDSMP Master Trainer recounted of one gentleman with serious health concerns:

He didn’t participate much- you know, you have an action plan where you’re supposed to complete an action and come back. He didn’t do those. He said, ‘I just like to sit here and hear what people are doing.’ He came every single week and I doubt if he offered three statements the entire time but he was *with us* the entire time. He was watching, he was listening. Who knows what he went away with? Not my problem, you know? [Laughter] But it was of value to him.

On the other hand, many subjects also expressed a bit of hesitancy regarding whether or not the programs were efficacious, especially in the long-term. Most of this uncertainty stemmed from the individuals’ perceived tendencies to fall back on undesirable habits, or to lose sight of their goals when difficulties arise. The CDSMP Class Leader in particular voiced mild disappointment with students who attend classes but do not challenge themselves to make any substantial changes. The Class Leader noted that students often developed action plans that seemed too simple, citing, “[That’s] the nature of human beings. They like to take the easier road if they can.” The Class Leader called participants roughly six months after the completion of



their CDSMP sessions and felt that students were practicing concepts that they learned very minimally, if at all. The Class Leader noted, “I got the feeling that most of them were glad that they’d been exposed to the material, but I don’t think that they did 100% of what it could have been.”

The CDSMP Student interview reiterated this sentiment by acknowledging in regard to the weekly action plans, “I probably made them too simple.” When discussing the lack of observable physical health improvements during the six-week session, the CDSMP Master Trainer had some doubts about whether students were actually practicing their exercises, stating, “If they do the exercise, the benefit is obviously there, but more often than not it would be ‘Well, I meant to do them...’” One of the MOB Coaches recognized a disconnect in herself between her actions and her intentions and confessed, “You know, they do have to put in a little effort and I do feel a bit concerned; maybe it’s my own self because I go to physical therapy and then I don’t do the exercises at home!” MOB Focus Group Participants #5 and #6 lamented that, since their move to an independent living facility, their activity levels have declined sharply despite occasional attendance in exercise-based programs at the facility. Chronic pain and fatigue have become increasingly difficult to manage, and concerning her back pain, Participant #5 stated, “It just hurts all the time. The doctor tells me to walk.... (laughter),” implying that she rarely heeds the doctor’s advice.

#### *Conflicting Views on Teachers’ and Trainers’ Qualifications/Dedication*

Subjects also displayed a lack of consensus on the topic of teachers’ and trainers’ quality. More positive than negative comments about teachers and trainers were offered. Students often spoke of warm, compassionate, and helpful teachers. Likewise, teachers commended their competent and organized Master Trainers, as well the quality and thoroughness of the training

manuals developed by MaineHealth (the organization that manages A Matter of Balance) and Stanford University. On if the interviewed CDSMP Student enjoyed the Class Leader’s teaching style, the participant responded, “Oh my goodness, yes absolutely. She’s a very vivacious and charismatic person, and an encourager, and just a fine person.” CDSMP Focus Group Participant #3, who is an active Class Leader, explained that out of a group of 20 peers that attended the teachers’ training, almost all of them have a chronic disease themselves, which enables them to teach “empathically, not just sympathetically.” MOB Coach #1 spoke of the acceptance that she and Coach #2 aim to foster, and their steadfast dedication to the program:

As a coach, it’s great inspiration for *us* to do something to help them. And what we see toward the end [is] they’re just lovely people. But I think, too, we set it so that it’s a very calm atmosphere. And no one’s embarrassed about anything, and we make it an easy class for them.

The Matter of Balance Master Trainer was also impressed with the individuals who conducted her training, known as T-Trainers. This subject explained that there were two individuals of diverse professional backgrounds who team-taught the Master Trainer workshops, which is similar in structure to the actual classes. The MOB Master Trainer appreciated this approach in that the two trainers had unique experiences and therefore emphasized different aspects of the course material:

It was particularly helpful that the two ladies that taught—one [had a] background in occupational therapy, so her spin on it was more toward functional status. You know, showing how to do the exercises properly. And then the other person is a registered nurse. So her take on it was a little different and it was very helpful to have both points of view in the training because what’s important to one wasn’t the same as what was important to the other.

The MOB Master Trainer also seemed to enjoy the comprehensive manual that the program provides their trainers and teachers. As someone with limited exposure to direct health

education, and who identified as introverted, the subject appreciated that the manual helped her easily navigate classes. The CDSMP Class Leader also spoke favorably about the training and materials that were distributed, stating that the training was “very well handled,” and that it allowed Class Leaders to experience the program “as a bona fide class participant.”

Despite the abundance of positive feedback regarding the quality of teachers and trainers, the more critical comments are equally valuable because ultimately, students’ experience with a program can be largely affected by the quality and characteristics of their teachers. CDSMP Focus Group Participant #4 voiced concern about teachers who “are a little bit more flip and quick, and that’s really not a service for those of us who are trying to be self-empowered.” Participant #4 also was worried that certain teachers may not have extensive personal interaction with a chronic disease, in that it makes it difficult to relate to students:

Sometimes some of the comments that the teachers gave made me wonder how much they themselves were facing—of a serious chronic condition—to understand the depth of the pain, fear, terror, and sorrow, rather than coming out with “Oh, it’ll be better! Have a positive attitude!” It’s like: don’t. Don’t say that if you’re not living it. See, and that’s the part of me that’s very concerned. If you don’t have a chronic condition and you can’t be in that skin, how can you be more empathetic and helpful?

The CDSMP Class Leader echoed Participant #4’s apprehension, stating concern regarding a younger teacher’s ability to connect with her older students:

What we found in our area was the next leader turned out to be a much younger lady. And it’s possible that that younger flavor of the Leader made a different impact with the older generation. But I was concerned that it didn’t because my partner and I were older, both retired at the time, and I had a feeling that we related better to the class than the younger lady that followed us.

The two MOB coaches had a less than desirable experience when they went to teachers’ training. Their Master Trainer was relatively new to the job and perhaps a bit disengaged. The

coaches explained that in their training, it was repeatedly stressed that coaches simply had to read the instructional manual to students. They were upset with this lack of guidance because they felt that high-quality, passionate teachers are much too involved and personable to read directly from a book. The CDSMP Master Trainer noted that many teachers are quite committed. However, when leading a teachers' training, the Master Trainer sometimes inquires about teachers' motivations and finds surprising results which imply that work obligations may occasionally trump personal investment:

A lot of our people that come to [Class Leaders'] training never hold a class. And we spend *a lot* of time in our training talking about "What's your target audience? Why are you here?" If you're here because, "My boss made me come," then what does your boss expect to get out of this? We ask, "When is your first class going to be? Where is it going to be? How are you going to invite people?" If they don't know, we start talking about, "What populations do you work with?" and, "Who are your contacts in your sphere of influence that might help you set up a class?" And we do all this *stuff* to help them prepare to have a class, and yet probably better than 50 percent of the people who we've trained in the past 2 or 3 years never did a class.

## BARRIERS TO PARTICIPATION IN AND ADMINISTRATION OF PROGRAMS

Several factors were identified as barriers that prevent people from becoming involved as MOB and CDSMP teachers and students in the first place. There were also factors identified that potentially prevent or diminish positive results. Among these barriers are strict standards to program fidelity, trouble with outreach and marketing, and a large time commitment necessary for both students and teachers.

### *Program Fidelity*

CDSMP and MOB stress high program fidelity, or ensuring that Coaches and Class Leaders adhere strictly to the programs' outlined script and procedures. Master Trainers are supposed to conduct period fidelity assessments, in which they come to a class to monitor area

teachers and ensure compliance. The purpose is to maintain a high level of similarity to the programs' original design, such that CDSMP and MOB can guarantee that students in any location have a uniform experience.

While a high level of fidelity has advantages in certain realms, it may also impose some limitations regarding individualized care. For example, if students raise a tangentially related question pertaining to a topic that is not discussed in the programs' curricula, Master Trainers and teachers are instructed to defer the question. In regard to the limitations of CDSMP, the Master Trainer stated, "The program is set up to meet some very finite and limited goals. And that is sometimes constraining." However, teachers and trainers often resolve these tensions by addressing participants' unrelated concerns outside of class time. In the words of the CDSMP Master Trainer, who works at a social service agency and is well-versed in connecting older adults to available resources:

If you see [unrelated] issues come up among the people in your class, you're not free to address them. [*Pause, contemplative*] There are ways, though. If I see somebody that's struggling to get their medication because they don't have finances, I'm going to throw some of our case worker cards on the table that say we help you with your finances, or a brochure or something. [...] Obviously, if we see somebody in distress, we're not going to let them leave in distress. We're going to do something.

The Master Trainer explained that one effective strategy for disseminating useful information to students is to leave cards or pamphlets near the refreshments or water bottles during a break, during which time students may peruse the tables and take resources. The CDSMP Class Leader also spoke of participants browsing handouts during breaks, as well as how the two teachers collaborated to address their students' request to receive more information about preparing legal documents despite noncompliance to CDSMP curriculum. The CDSMP Class Leader recalled:

We told them ahead of time that we were going to be doing this and how it possibly violated the terms of our teaching, but it was so welcomed by the group that we said “It’s for the good of the cause.

### *Outreach/ Marketing*

Another barrier to successfully conducting classes is, according to the CDSMP Master Trainer, “It’s really hard to get a group together.” It has been, in the CDSMP Master Trainer’s experience, extremely challenging to reach enough people to hold a class, especially when faced with very limited funding. In one instance in the past, the Master Trainer was able to advertise an upcoming CDSMP workshop in a popular local newspaper and had an impressive turnout. In most cases though, outreach is conducted via smaller organizations’ newsletters, fliers, and word of mouth. The Master Trainer further explained that poor student involvement triggers teacher burnout because it is not uncommon for teachers to “try 2 or 3 times to do a class and they can’t, and then they just get frustrated with it and quit trying,” because there is not enough student interest or effective outreach conducted.

The MOB Master Trainer had serious difficulty building sufficient student interest in classes initially as well, but those challenges waned before long: “We had to have 8-12 participants in the class. In the beginning it was hard to find enough people. But once the community was more aware of it, it was not uncommon to have a waiting list.” This Master Trainer credits much of the program’s later popularity to the location. Several workshops were held in churches, and although other external organizations such as the local hospital displayed fliers, participants were almost exclusively church parishioners who enrolled after reading an advertisement in the bulletin or being invited by a friend who was attending. The Master Trainer also tends to see a large, reliable participant base when workshops are held at assisted living

facilities, where there is a somewhat captive audience. The CDSMP Class Leader, though, noted that it is important to maintain a diverse group of participants in which the hard-to-reach are included. After completing a CDSMP workshop at an assisted living facility, the Class Leader reflected:

I think that we missed the opportunity to hear people who were living in their own home as opposed to having everything handled for them at the assisted living. There's a different attitude of those kind of people. And so I had the feeling that we missed that aspect of differences.

Aside from isolated seniors, subjects revealed that another hard-to-reach population is men. In every focus group and interview in which the question was posed, subjects responded that a significantly greater number of women participate in the programs than do men. Master Trainers, teachers, and students alike claimed that their classes were comprised mostly or entirely of women. Subjects offered several possibilities for this trend. A few subjects blamed male underrepresentation on personality differences, citing that men are more stubborn or less likely to search for help in regard to their physical health, or that they simply are not interested in the classes. Another line of thought was that men's lifestyle choices are often based on their wives' advice. The interviewed CDSMP Student, for example, said, "I'm not sure that [men] think about eating healthy unless their wives tell them to do that." In a similar vein, MOB Focus Group Participant #6 offered that men may not involve themselves in as many health-related activities because they have "women at home to take care of them."

A final factor that is crucial to effective enrollment is to make the programs available at no cost or as low cost as possible, and to market the programs as such. In many cases, despite initial interest, seniors simply do not have sufficient disposable income to comfortably afford preventative care programs. This holds true even when the program is moderately priced. MOB

Focus Group Participant #1, for example, attended a session of A Matter of Balance several years ago but was discouraged because of the fee:

“It was good, but I didn’t like having to pay for it; five dollars. I don’t know if that was every class or just one time—I think every class. I thought it was very informative and I’d like to continue it but I didn’t want to pay.”

MOB Focus Group Participant #3, who is a relatively new staff member at the assisted living facility where Participant #1 resides and will soon be a certified teacher, clarified that at the time Participant #1 joined the class, the facility required a flat fee which the facility matched to help cover the cost of course materials. This however, is no longer the case; the assisted living facility has made the commitment to provide the course at no cost to residents. Since Participant #1 did not complete all sessions previously, Participant #3 asked if Participant #1 would be interested in enrolling again in the class the next time that it is offered, to which Participant #1 consented.

### *Large Commitment*

The most commonly voiced source of dissatisfaction with CDSMP and MOB was that the programs entail a large commitment in terms of time and devotion. The lengthy time commitment is taxing for students, and perhaps even more so for teachers. MOB classes are two hours each for eight weeks, whereas CDSMP classes are two and a half hours each for six weeks. As was expressed during interviews and focus groups though, in order to feel comfortable and confident, teachers must dedicate more time than the bare minimum and often feel inundated from the beginning upon attending their training sessions. CDSMP Focus Group Participant #1 attended a teachers’ training but ultimately decided not to lead a class, partially due to the intensity of the training: “There’s only so much you can absorb in a period of time.” The MOB



Coaches, though they are extremely passionate about teaching, expressed stress for the same reasons. Regarding their teachers' training, MOB Coach #1 said, "It was a lot of material. I felt that it was really too much to take in to try to get together eight weeks of classes," to which MOB Coach #2 replied, "I didn't know what to expect and I was totally overwhelmed. Because it's a lot of material and it was just kind of read to us." This led to the MOB Coaches meeting independently, after their training and before they started their first course, to review the material and feel more prepared. The CDSMP Class Leader stated, "It was a big commitment to my time because I had to go to the training and I also had to do all the planning. But because I am retired, it seemed like a good thing to do and so I finally signed up to be trained." Although many CDSMP and MOB teachers are retired and become involved with the programs as a way to fill their time and give back to their communities, other teachers are full-time working professionals. CDSMP Focus Group Participant #3, for example, is a Class Leader who works in healthcare and said of fellow teachers: "We're always there at least 45 minutes to an hour ahead of time to set up and then we're there at least 15 minutes to a half hour to break down and put stuff away." Factoring in travel time, this amounts to a potential commitment of around four hours per week on class days, and does not include other preparation or coordination that may occur during the other days of the week.

Teachers and Master Trainers worried that potential students are deterred from joining the course due to the perceived intensity of the commitment. CDSMP Focus Group Participant #1 thought that community seniors tended not to attend because "it is too long, too much involvement. A lot of information. And too much commitment." The CDSMP Master Trainer echoed this thought and showed some pushback against the program's developers, explaining:

Its two and a half hours. That's a *long time*. You always plan a break, of course, in the middle. But you tell someone you're going to go to a class for two and a half hours-

especially an old person- that sounds really hard for them. And Stanford won't let you break it out any other way. So I think that's a perceived barrier that keeps people from signing up. But there's not much we can do about that.

CDSMP Focus Group Participant #3 offered similar feedback, sharing an anecdote of a mother in her 80s who has mobility issues and enrolled in the course with her daughter, who is in her 60s. Participant #3 explained that, although there is a 20-minute break during each class, this is hardly a suitable amount of time for the daughter to help her mother to use the restroom. In addition, it is uncomfortable for the mother to sit for such a long amount of time. Perhaps most telling of all, on the topic of whether or not the interviewed CDSMP Student would recommend the program if it was offered again in the community, the Participant responded:

I don't know. It's a big commitment. I don't know how to answer that because I can't speak for others. I know what busy schedules some of these younger people have and whether it would go over this time, I don't know.

## **V. Recommendations**

Data from qualitative interviews and focus groups with students, class teachers, and administrative trainers of two evidence-based, healthy aging programs funded by the East Central Illinois Area Agency on Aging show that the programs encourage socialization and health-related self-efficacy for older adults. Most students were very complimentary of their teachers, although careful attention should be given to their selection. Subjects voiced that the ideal teacher possesses characteristics such as empathy, engagement, and personal experience managing one or more of the programs' targeted health concerns. While the majority of teachers presumably become certified because of an intrinsic desire to help older adults and they genuinely enjoy leading classes, it may be the case that other individuals feel pressured to become involved because of workplace obligations, or shy away teaching because of the perceived intensity of the workload. Therefore, in the case of organizations that presently encourage or require their employees to become certified as teachers of evidence-based, healthy aging programs, I recommend that they consider allowing staff to become trained on a voluntary basis. I also advise that organizations conduct a thorough screening process with individuals who plan to attend teachers' trainings to ensure that they are dedicated to the role and that there is a plan for implementing classes after the training.

The more pressing issue at play is perhaps that individuals at times endure training to become certified teachers, and then attempt to lead a class to no avail because too few participants enroll. Effective recruitment has proven to be problematic in the east central Illinois region. A contributing factor to recruitment difficulties is that human service organizations feel increasing pressure to stretch their limited dollars. With limited or no discretionary funding, Master Trainers for both programs reported that they have, currently or in the past, had trouble

attaining desired class sizes. Larger community media efforts have been successful in recruiting a greater number of prospective participants but the reality is that such sizable efforts are not always feasible, which points to the continued need to evaluate additional avenues for outreach. I advise service providers to think innovatively about recruitment methods that incur limited costs and time, and that may help reach individuals who are isolated from preexisting social networks. In an Implementation Manual developed by Stanford University, which is free to the public online, there are many tips for strengthening recruitment efforts. For instance, they recommend making announcements or presentations during community events or congregate meals, distributing information in utility bills, using fliers on local bulletin boards and in neighborhood stores, and encouraging past participants to talk to their friends and loved ones (Stanford University 2008).

As the majority of subjects voiced that they noticed a greater degree of psychosocial benefits than health effects, it would be prudent to consider better educating healthcare facilities on advising their patients to enroll in evidence-based programs throughout east central Illinois. The students and teachers with whom I talked largely became familiar with their respective programs from church bulletins or other faith and community-based programs. Therefore, it seems reasonable that these individuals were perhaps more incentivized to join programs for the social aspect whereas physician-driven referrals would spur people with more serious health concerns, who could benefit to a greater degree, to enroll. One method that has been attempted in other areas of the country, and is certainly worthy of trying in east central Illinois, as a way to engage doctors in the referral process is to recommend that they utilize prescription pads; in essence, the physician writes a mock “prescription” for clients who present relevant symptoms and may benefit from evidence-based, healthy aging programs to enroll (Appendix D). The

Stanford Implementation Manual, however, cites that this may not be an overly effective method, as doctors and hospitals are inundated with materials and information to sort through. They recommend instead that advocating organizations request physicians and health centers to distribute informational letters about the programs to clients. This method still has a relatively low response rate of approximately 10 percent, but it could serve as a significant first step in garnering the interest of healthcare professionals in the east central Illinois region.

Apart from locating interested seniors, another major issue with recruitment is the target audience's lack of familiarity with evidence-based programs and their value in general. To this end, key players in health and aging in Illinois recognize that a coordinated and unified front is needed to make a more recognizable brand for programs such as CDSMP and MOB. Hence, the Illinois Community Health and Aging Collaborative was formed from a statewide, interagency union between various Area Agency on Aging staff and hospital personnel. Initial meetings for the Collaborative commenced several years ago, and the group is working to attain 501(c)(3) status at present. A current objective of the Collaborative is to gather data on the statewide participation rates and effectiveness of several large, nationally recognized evidence-based, healthy aging programs including CDSMP and MOB. With this data, the Collaborative will apply to grants and appeal to health plans to invest in evidence-based programs as a form of preventative care. To succeed in this initiative, it will be necessary to continue to promote research that shows a positive return on investment resultant from participation in evidence-based programs. In order to show cost savings, though, much more data is needed on participants' health status, hospitalization rates, medication expenditures, and so forth.

To help address the dearth of information that shows positive health effects amongst students in the east central Illinois region, organizations may consider implementing more

systematic follow-up procedures after students have finished their evidence-based programs. Most Master Trainers and teachers with whom I spoke said that they have no formal contact with their students after the six- or eight-week sessions are over. Stanford University maintains an abundance of health-related surveys on its website, which are available for agencies to use without permission as needed (see Appendix E). MaineHealth, too, offers a pre- and post-class survey as well as a class evaluation on its website (see Appendices F and G). ECIAAA partners and other statewide agencies that conduct evidence-based programs may choose to administer these instruments directly, or to modify content as they see appropriate. I strongly recommend that Area Agencies on Aging commit to guiding their evidence-based program partner agencies to conduct brief six-month follow-up surveys with participants. This would vastly increase the amount of data on health effects resultant from participation in evidence-based, healthy aging programs, thereby providing evidence to health plans that the programs are an important source of preventative care for aging adults.

## **VI. Conclusion**

The findings from this formative evaluation of the Chronic Disease Self-Management Program (CDSMP) and A Matter of Balance (MOB), as administered by partners of the East Central Illinois Area Agency on Aging, have implications for gerontological and social policy, as well as practical implications for practitioners and participants of the targeted evidence-based, healthy aging programs. Concerning policy, these and other evidence-based programs reflect a shifting focus in healthcare delivery, from a system that has traditionally focused heavily on reactive treatment, to a more precautionary, preventative approach. Senior service agencies at local, state, and federal levels are ushering in a new era of care which recognizes the cost benefits associated with working to improve or simply maintain older adults' health before injuries and illnesses become gravely serious, as opposed to combatting these conditions after they have taken their toll. A wide selection of evidence-based programs have demonstrated, through randomized, controlled trials and community-based studies, that preventative health education can result in reduced hospital and nursing home stays, visits to the emergency department, injuries, and prescriptions. As such, older adults are not only maintaining their physical health, but also their psychosocial health and quality of life. Self-management skills and self-efficacy have proven to be fundamental advantages of evidence-based programs for seniors. Broadly speaking, evidence-based practice is indicative of a prominent interest in developing scientifically-driven, cost effective, proactive courses of treatment for clients across the social and medical sciences. Further, evidence-based programs often are the product of strong partnerships between academia and service practitioners (Rahman and Applebaum 2010). This cooperative approach holds great promise in marrying reliable research findings with practical considerations surrounding implementation, which results in high-quality, feasible programs that can often be replicated successfully in a variety of settings.

From a practical, or applied perspective, interviews and focus groups showed that trainers, teachers, and participants involved with A Matter of Balance (MOB) falls prevention program and the Chronic Disease Self-Management Program (CDSMP) were generally very supportive of the role of their respective program in promoting healthy lifestyles for older adults in the east central Illinois region, and of the training and materials provided by the programs. Subjects conveyed that the weekly group classes serve as welcoming communities for older adults, many of whom may be considered socially and/ or geographically isolated. Several Master Trainers and teachers expressed that they had encountered participants in the past who have appeared not to be completely invested in the targeted health effects of the programs, but who nevertheless faithfully attended classes because of some ancillary motivation, such as to be with friends or to fulfill a sense of staying active. Further, the classes may encourage vulnerable seniors to become embedded into social networks and, in doing so, receive referrals to useful services and products. As such, participants gain valuable social capital and informational resources which empower them to better navigate their daily lives.

Subjects voiced that they tend to notice only minimal changes in students' physical health by the end of class sessions, which was rather unexpected considering that a review of the literature showed great promise for the programs' potential to improve health status. However, subjects largely agreed that they have observed secondary effects in themselves or their students which are equally, if not more, significant in maintaining quality of life standards. CDSMP and MOB participants tend to display greater confidence, decision-making abilities, and self-efficacy in managing their health concerns. In addition, both programs promote the use of assertive communication for older adults to self-advocate when discussing health concerns with their friends, family, and medical personnel. In a changing medical climate, wherein doctors are



perceived as becoming increasingly more dependent on technology and less informed about the individual patient, it is crucial for older adults to communicate effectively and become educated on how to make healthy lifestyle changes. Subjects also reported frustration with the length of class sessions and intensity of preparation needed for teachers and trainers. As the developers of these programs do not allow for flexibility in terms of altering the course contents or timeline, this will seemingly be a persistent issue of which participants should be informed before committing to get involved.

This project is limited in that it evaluates only two of the five evidence-based programs that are currently being funded by ECIAAA. Therefore, the results may not be indicative of the Agency's evidence-based efforts as a whole. In addition, given constraints on funding, time, and population size that necessitated research efforts to remain small and local, findings should not be applied to a statewide or national context. Rather, the findings from this project reflect a small sampling of individuals' beliefs, attitudes, and perspectives. In the spirit of taking a naturalist rather than a positivist approach, I recognize that each subject has a diverse set of life experiences that have shaped her or his interpretation and opinion of CDSMP or MOB (Rubin and Rubin 2012). Therefore, there are many possible truths related to the efficacy of CDSMP and MOB and it is vital to recognize that that any one experience should not be generalized to the entire population. Findings from this project underscore the need to continue to research the effects of evidence-based, healthy aging programs, with serious consideration given to administering follow-up measures with participants that contain items related to psychosocial as well as health-related changes. This will enable advocates of CDSMP and MOB to more accurately determine whether or not changes in health status result from participation in the programs, as well as if effects are sustained over time.

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## **APPENDIX A: Key Informant Interview Guide**

### **Introduction:**

Thank you for making the time to talk today. As an ISU Stevenson Center Fellow at the East Central Illinois Area Agency on Aging, I am conducting a research project to evaluate two evidence-based, healthy aging programs that ECIAAA offers—A Matter of Balance and Chronic Disease Self-Management Program (CDSMP). My project involves focus groups with former participants and interviews with Master Trainers of these programs. Your perspectives, as a Master Trainer, are important in providing feedback to ECIAAA to strengthen and improve programs.

This interview will last for approximately 45 minutes. I will ask questions about the role of a Master Trainer, the role of a coach/ class leader, the history and structure of [A Matter of Balance/ CDSMP], and participants' experiences with [A Matter of Balance/ CDSMP]. As a reminder, you are in no way obligated to participate in this study, and a decision to discontinue participation will not affect your standing with your employer or your relationship with ECIAAA. Also, please only respond to questions that you feel comfortable discussing. Do you have questions before we begin?

**To start off**, can you tell me the story of your involvement with [program]?

*Probes for follow-up, if not addressed organically:*

### **Role as a Master Trainer:**

1. What got you interested in becoming certified as a Master Trainer in the first place?
2. Can you walk me through the process of becoming a Master Trainer?
3. How long have you been a Master Trainer?
4. Tell me about your responsibilities as a Master Trainer.
5. Can you tell me about the training you received to become a Master Trainer?
  - What aspects of training were especially helpful?
  - What additional training might help?

### **Role as a Coach (AMOB terminology)/ Class Leader (CDSMP terminology):**

Shifting topics, I would like to ask some questions about coaches'/ class leaders' perspectives.

1. Were you a coach/ class leader before becoming a Master Trainer?
  - *If yes*, What got you interested in becoming a coach/ class leader in the first place?
  - *If yes*, How long were you a coach/ class leader?
2. Can you walk me through the process of becoming a coach/ class leader?
3. Tell me about the responsibilities of coaches/ class leaders.
4. Can you tell me about the training that people receive to become coaches/ class leaders?
  - What aspects of training do coaches/ class leader report to be especially helpful?
  - What additional training might help coaches/ class leaders?

### **Program Information:**

Now I would like to ask some questions about the history and structure of [program].

5. Can you tell me about the history of [program]?
  - Nationally?
  - In East Central Illinois?
6. Before [program], what services or resources existed for individuals who experienced [falls *or* chronic disease]?
  - In what ways is [program] different from these previous services?
7. Tell me about the structure of [program's] curriculum.
  - How strictly do coaches tend to follow this structure?
8. Can you walk me through a typical class session?
9. What materials are provided by [program]?
  - Scripts? Workbooks? Handouts? Exercise equipment? Other?
  - How effective are these materials in assisting with the course?

### **Participants' Perspectives:**

10. In your experience, tell me about how participants usually perceive [program].
11. What aspects of the program, do you think, are most beneficial for participants?
  - Aspects of physical health? Aspects of emotional health? Aspects of socialization?
12. What aspects of the program, do you think, could be changed so that participants experience greater success in achieving goals?
13. In your experience, how common is it for a participant to enroll in a course but not complete it?
  - What do you think causes participants to not complete the course?
14. Have you noticed any trends, since the time of your involvement with [program], as far as attendance is concerned?
  - E.g., steady increase or decrease over the years? Lower attendance at certain times or seasons?

- *If yes*, What do you think is causing those trends?
15. Does your agency do any follow-up with participants after they finish the program?
    - Does your agency follow-up with participants 6 months and 12 months after completing the program to document ER visits?
    - *If yes*, are the rates of ER visits any lower?
  16. What opportunities do participants have to leave feedback about the program?
  17. In your experience, do participants tend to express interest in continuing to practice the skills they have learned beyond their time in the program?
  18. In your experience, do participants tend to express interest in staying in contact with friends beyond their time in the program?

**Looking Forward:**

19. In your \_\_\_ years with [program], what are some of the most important lessons you have learned about providing health education to older adults?
20. What aspects of your role as a Master Trainer, if any, do you do differently now than when you first started?
21. What are some things that ECIAAA could do to better support you as a Master Trainer?
  - To better support coaches? To better support participants?
22. Is there anything else you would like to add?

Thank you for your assistance with this interview.



## **APPENDIX B: MOB/CDSMP Focus Group Guides**

### **Introduction:**

Welcome! Thank you for taking time to participate in the discussion today. My name is Katie Raynor, and I am a graduate student in Sociology at Illinois State University, and a Fellow in their Stevenson Center for Community and Economic Development. This academic year, I am placed in an internship at the East Central Illinois Area Agency on Aging (ECIAAA) in Bloomington.

ECIAAA's mission is to provide services to individuals 60 and over, adults with disabilities, and their caregivers, to allow them to live independently in good health. One way that they accomplish this is by partnering with agencies that offer evidence-based, healthy aging programs, such as [Catholic Charities, who offers A Matter of Balance classes/ Family Services, who offers Chronic Disease Self-Management Program classes] in collaboration with local organizations in communities across east central Illinois.

As part of my Master's Degree, I am conducting research for ECIAAA. My research project is an evaluation of two evidence-based, healthy aging programs that ECIAAA offers—A Matter of Balance and Chronic Disease Self-Management Program. My project involves focus groups with former participants and interviews with Master Trainers of these programs. Your perspectives, as participants in [A Matter of Balance/ CDSMP], are important in providing feedback to ECIAAA to strengthen and improve these programs.

This focus group will last approximately one hour. The questions will focus on your experiences with [A Matter of Balance/ CDSMP] and how you benefited, as well as aspects that you feel could be improved. As a reminder, please only respond to questions that you feel comfortable discussing. Also, please do not talk about the details of our conversation or who attended this focus group once you leave this room. This is to protect everyone's confidentiality. Are there questions before we begin?

### **A MATTER OF BALANCE/ CDSMP FOCUS GROUP:**

1. To start off, please tell me your first name, approximately how long ago you participated in A Matter of Balance [CDSMP], and about how many of the eight class sessions you attended.
2. What made you decide to get involved in A Matter of Balance?
  - a. Where did you first hear about A Matter of Balance?
  - b. What was your experience with falling prior to starting classes?
    - How did these experiences affect you? Physically? Emotionally (fear of falling)? Socially?
  - c. How aware were your family, friends, and primary care physician of your decision to get involved? How supportive were they of your decision?

3. What was your coach like?
  - a. Knowledgeable? Helpful? Prior experience working in health/medicine?
4. What was your favorite part about A Matter of Balance?
  - a. Tell me about one class that you enjoyed the most.
  - b. Physical benefits?
  - c. Emotional benefits (fear of falling)?
  - d. Social benefits?
5. What would you like to improve about A Matter of Balance?
  - a. Quality of instruction?
  - b. Availability/ times of classes?
  - c. Transportation issues?
  - d. Opportunities to continue to apply skills after completion?
  - e. Opportunities to continue to socialize with friends from class after completion?
6. To what extent has A Matter of Balance affected your life after you stopped attending the program?
  - a. What has been your experience with falling since?
  - b. Have you noted any changes in your need to visit the ER or hospital?
    - Over the past 6 months? Over the past 12 months?
  - c. What changes have you noticed, if any, in the confidence of your ability to manage falls?
  - d. Tell me about how, or if, you still practice the exercises you learned.
  - e. Which lessons from the program, if any, do you still incorporate into your daily life?
  - f. What is your experience with participating in any other healthy aging or exercise programs since you finished A Matter of Balance?
  - g. Have you stayed in touch with your friends from the program?
    - In what way(s)? (Phone, face-to-face, etc.)
  - h. Has your coach followed up with you after the program?
  - i. What opportunities have you had, if any, to voice feedback about the program?
7. Do you have other comments or suggestions to make the program more effective?

## APPENDIX C: FOCUS GROUP INVITATIONS

[Date]

Dear “A Matter of Balance” Participant,

My name is Katie Raynor and I am conducting research as a graduate student in Sociology at Illinois State University for the East Central Illinois Area Agency on Aging (ECIAAAA) in Bloomington. ECIAAAA’s mission is to provide services to individuals 60 and over, adults with disabilities, and their caregivers, to allow them to live independently in good health.

One way that they accomplish this goal is by partnering with agencies that offer evidence-based, healthy aging programs, such as Catholic Charities, who offers A Matter of Balance classes in collaboration with local organizations in communities across east central Illinois. This research project is an evaluation of two evidence-based, healthy aging programs that ECIAAAA offers—A Matter of Balance and the Chronic Disease Self-Management Program.

You have been selected to participate in this project as someone who has previously enrolled in A Matter of Balance. You are invited to attend a focus group with approximately 6-10 people who have also participated in A Matter of Balance. The focus group is to be held at (location) on (date) at (time). It will last for approximately one hour.

Your perspectives are important in providing feedback to ECIAAAA to strengthen and improve this program. You will be asked questions that focus on your experiences with A Matter of Balance and how you benefited, as well as aspects that you feel could be improved.

Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time there will be no penalty. Efforts will be made for your responses to remain confidential and any information that might allow someone to identify you will not be disclosed in the findings. The findings from this project along with recommendations for program improvement will be presented to ECIAAAA staff members, as well as Illinois State University faculty and students.

As spaces are limited, we ask that you **please RSVP to Katie Raynor by (date) at (phone number) or (email address) to confirm your attendance.** If you have questions, I will gladly answer them. You may also direct questions to the Illinois State University Research Ethics and Compliance Office at 309-438-2529.

Thank you for your assistance.

Sincerely,

Katie Raynor

## APPENDIX D: A Matter of Balance Prescription Pad

### DO YOU HAVE CONCERNS ABOUT FALLING?

Many older adults experience concerns about falling and restrict their activities. A **MATTER OF BALANCE** is an award-winning program designed to manage falls and increase activity levels.



Insert your  
logo here.

Name: \_\_\_\_\_

Referred by: \_\_\_\_\_

From office/organization: \_\_\_\_\_

A Matter of Balance-8 session workshop will help you learn ways to reduce falls and the fear of falling. You will learn exercises to help with balance.

For more information and course listings, call **XXX-XXX-XXXX**.

A Matter of Balance: Managing Concerns about Falls Volunteer Lay Leader Model ©2006.

This program is based on *Fear of Falling: A Matter of Balance*.

Copyright©1995 Trustees of Boston University. All rights reserved.

**This program emphasizes practical strategies for managing falls.**

#### YOU WILL LEARN TO:

- View falls as controllable
- Set goals for increasing activity
- Make changes to reduce fall risks at home
- Exercise to increase strength and balance

#### WHO SHOULD ATTEND?

- Anyone concerned about falls
- Anyone interested in improving balance, flexibility and strength
- Anyone who has fallen in the past
- Anyone who has restricted activities because of falling concerns

#### A Matter of Balance Lay Leader Model

*Recognized for Innovation and Quality in Healthcare and Aging, 2006, American Society on Aging.*

A Matter of Balance Lay Leader Model was developed by a grant from the Administration on Aging (#90AM2780)

**APPENDIX E: CDSMP Questionnaire**

Name \_\_\_\_\_

Address \_\_\_\_\_

City, state, zip \_\_\_\_\_

Telephone: day \_\_\_\_\_ Date of Birth \_\_\_\_\_

                  eve \_\_\_\_\_ Sex (circle) Female Male

Email \_\_\_\_\_

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DATE \_\_\_\_\_

ID \_\_\_\_\_

WSID \_\_\_\_\_

WSTYP \_\_\_\_\_

DOB \_\_\_\_\_

SEX \_\_\_\_\_

DIAB2 \_\_\_\_\_

DIAB1 \_\_\_\_\_

ASTH \_\_\_\_\_

COPD \_\_\_\_\_

LUNG \_\_\_\_\_

HTN \_\_\_\_\_

HEART \_\_\_\_\_

ARTH \_\_\_\_\_

CANC \_\_\_\_\_

DEPR \_\_\_\_\_

MH \_\_\_\_\_

O1 \_\_\_\_\_

O2 \_\_\_\_\_

O3 \_\_\_\_\_

MAR \_\_\_\_\_

HISP \_\_\_\_\_

RACE \_\_\_\_\_

**Background**

1. Please indicate below which chronic condition(s) you have (*check all that apply*)
  - None
  - Type 2 diabetes/high blood sugar
  - Type 1 diabetes/high blood sugar
  - Asthma
  - Chronic bronchitis, emphysema or COPD
  - Other lung disease *describe* \_\_\_\_\_
  - High blood pressure
  - Heart disease *describe*: \_\_\_\_\_
  - Arthritis or other rheumatic disease *describe*: \_\_\_\_\_
  - Cancer *describe*: \_\_\_\_\_
  - Depression
  - Anxiety or other emotional/mental health condition
  - Other chronic condition *describe*: \_\_\_\_\_
  
2. Are you currently married, or living as married?
  - No
  - Yes
  
3. Are you Hispanic/Latino?
  - No
  - Yes
  
4. What is your race?
  - American Indian or Alaska Native
  - Asian
  - Black or African American
  - Native Hawaiian or other Pacific Islander
  - White
  - Two or more races
  - Other *describe*: \_\_\_\_\_

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5. Please circle the **highest** year of school completed:

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23+  
(primary) (high school) (college/university) (graduate school)

6. What type of health insurance do you currently have? (check all that apply)

- None
- Medicare
- Medicaid (provided by government for low income individuals)
- SSI (federal disability benefits)
- Veterans benefits
- Private insurance (through employer or purchased)
- Other *describe:* \_\_\_\_\_

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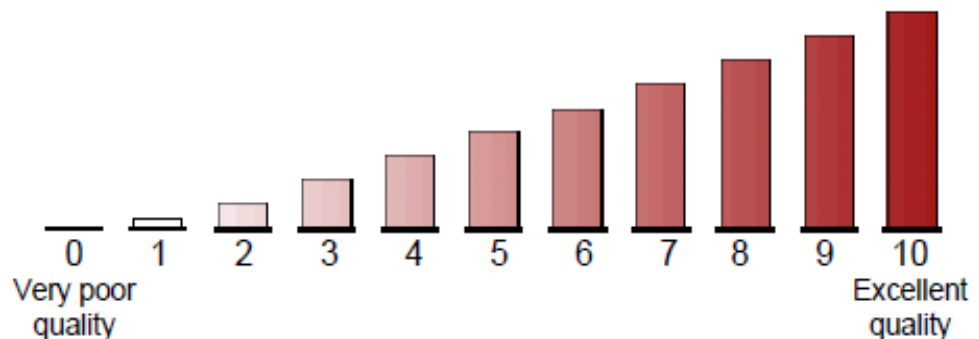
### General Health

---

1. In general, would you say your health is: (circle one)

Excellent ..... 1  
Very good..... 2  
Good ..... 3  
Fair ..... 4  
Poor ..... 5

2. How would you rate your overall **quality of life**? Please circle the number below that describes your **quality of life** in the **past week**:



## Daily Activities

LEAVE THIS AREA BLANK

During the **past week**, how much...

*(circle ONE)*

- |   | Not<br>at all | Slightly | Moder-<br>ately | Quite<br>a bit | Almost<br>totally |
|---|---------------|----------|-----------------|----------------|-------------------|
| 1. Has your health interfered with your normal activities with family, friends, neighbors or groups?..... | 0             | 1        | 2               | 3              | 4                 |
| 2. Has your health interfered with your hobbies or recreational activities? .....                         | 0             | 1        | 2               | 3              | 4                 |
| 3. Has your health interfered with your household chores?.....  | 0             | 1        | 2               | 3              | 4                 |
| 4. Has your health interfered with your errands and shopping?.....  | 0             | 1        | 2               | 3              | 4                 |

DA1 \_\_\_\_\_

DA2 \_\_\_\_\_

DA3 \_\_\_\_\_

DA4 \_\_\_\_\_

## Physical Activity

During the **past week**, even if it was not a typical week for you, how much **total** time *(for the entire week)* did you spend on each of the following? *(Please circle one number for each question.)*

- |  | none | Less than<br>30 min/wk | 30-60<br>min/wk | 1-3 hrs<br>/week | More than<br>3 hrs/wk |
|--|------|------------------------|-----------------|------------------|-----------------------|
| 1. Stretching or strengthening exercises (range of motion, using weights, etc.)..... | 0    | 1                      | 2               | 3                | 4                     |
| 2. Walk for exercise.....  | 0    | 1                      | 2               | 3                | 4                     |
| 3. Swimming or aquatic exercise.....   | 0    | 1                      | 2               | 3                | 4                     |
| 4. Bicycling (including stationary exercise bikes) .....                             | 0    | 1                      | 2               | 3                | 4                     |
| 5. Other aerobic exercise equipment (Stairmaster, rowing, skiing machine, etc.)..... | 0    | 1                      | 2               | 3                | 4                     |
| 6. Other aerobic exercise .....  | 0    | 1                      | 2               | 3                | 4                     |

STR \_\_\_\_\_

WALK \_\_\_\_\_

AQUA \_\_\_\_\_

CYCL \_\_\_\_\_

EQUIP \_\_\_\_\_

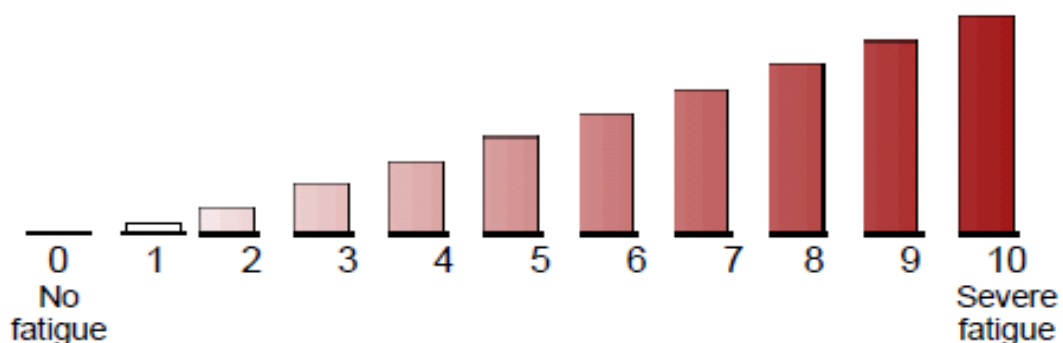
OAER \_\_\_\_\_

*Describe other* \_\_\_\_\_

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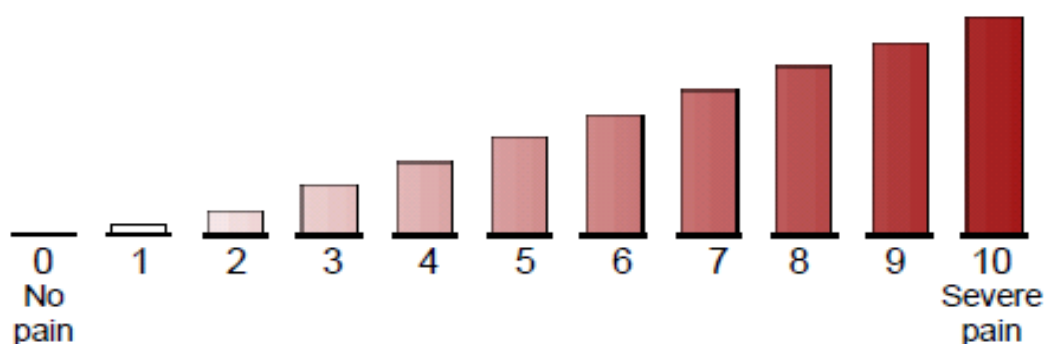
## Symptoms

1. We are interested in learning whether or not you are affected by fatigue. Please **circle** the number below that describes your **fatigue** in the **past week**:



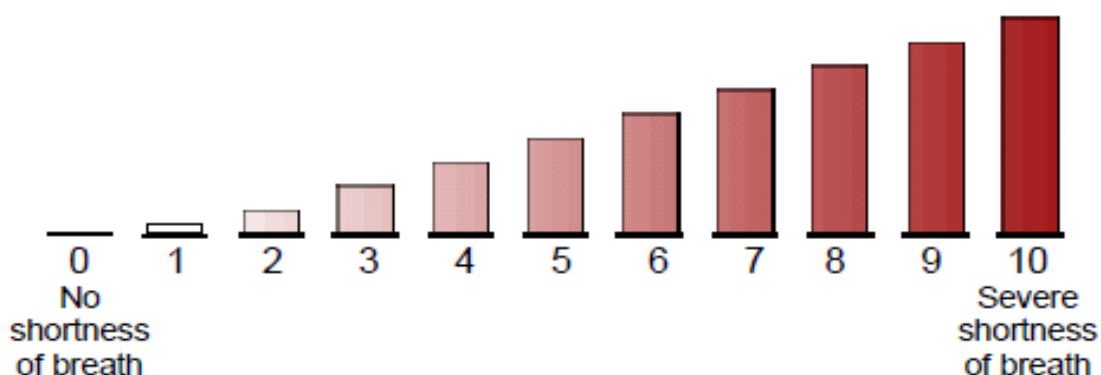
VNSFAT

2. We are interested in learning whether or not you are affected by pain. Please **circle** the number below that describes your **pain** in the **past week**:



VNSPAIN

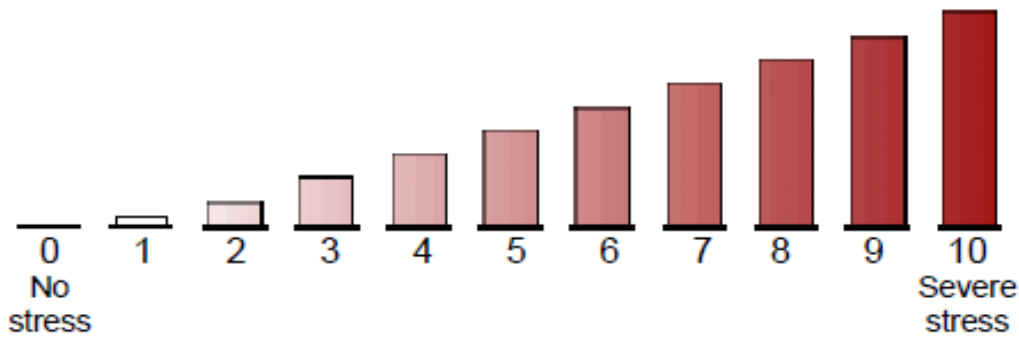
3. We are interested in learning whether or not you are affected by shortness of breath. Please **circle** the number below that describes your **shortness of breath** in the **past week**:



VNSSOB

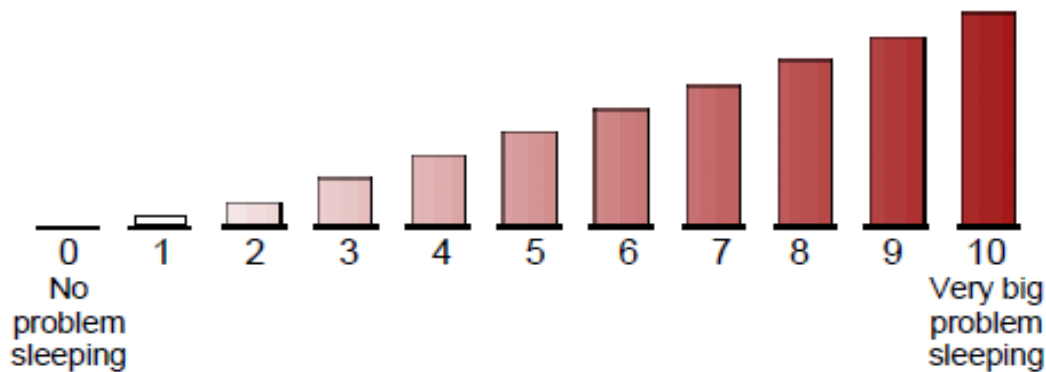


4. We are interested in learning whether or not you are affected by stress. Please **circle** the number below that describes your **stress** in the **past week**:



VNSSTRS

5. We are interested in learning whether or not you are affected by sleep problems. Please **circle** the number below that describes your **sleep** in the **past week**:



VNSSLP

### Recent Health

1. Thinking about your **physical** health, which includes physical illness and injury, for how many days during the past **month** was your **physical** health **not** good? ..... \_\_\_\_\_ days in the month **NOT** good
2. Thinking about your **mental** health, which included stress, depression, and problems with emotions, for how many days during the past **month** was your **mental** health **not** good? ..... \_\_\_\_\_ days in the month **NOT** good
3. During the **past month**, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? ..... \_\_\_\_\_ days in the month

HDAY1

HDAY2

HDAY3

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### Physical Activities

---

1. During the past week, other than your regular job, did you participate in any physical activity or exercises, such as brisk walking for exercise, running, dancing, biking, water exercise, etc.?  No  Yes
- EX1 2. How many **days in the past week** were you physically active or exercising for at least 30 minutes, such as brisk walking, running, dancing, bicycling, water exercise, etc., that may cause faster breathing or heartbeat, or feeling warmer (it does not have to be all at one time)? ..... days / past week
- EX2
- EX3 3. How many **TOTAL minutes in the entire last week** were you physically active or exercising at the same level as described above (it does not have to be all at one time)? ..... minutes / past week
- EX4 4. How many **days in the past week** did you do **stretching or strengthening** exercises, such as range of motion, using weights/resistance, yoga, tai chi, Pilates, etc.? ..... days / past week

---

### Medicines

---

- MED1 1. Do you ever forget to take your medicine?  No  Yes
- MED2 2. Do you ever have problems remembering to take your medicine?  No  Yes
- MED3 3. When you feel better, do you sometimes stop taking your medicine?  No  Yes
- MED4 4. Sometimes if you feel worse when you take your medicine, do you stop taking it?  No  Yes

---

### Medical Forms

---

- Circle *one* number:
- |  | Extremely | Quite a bit | Some-what | A little bit | Not at all |
|--|-----------|-------------|-----------|--------------|------------|
| HL 1. How confident are you filling out medical forms by yourself? ..... | 4         | 3           | 2         | 1            | 0          |

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**Feelings**

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How much time during the **past week**...

**Not at all**      **Several days**      **More than half the days**      **Nearly every day**

1. Were you bothered by little interest or pleasure in doing things? .....0 ..... 1 .....2..... 3

PHQ1 \_\_\_\_\_

2. Were you bothered by feeling down, depressed, or hopeless? .....0 ..... 1 .....2..... 3

PHQ2 \_\_\_\_\_

3. Were you bothered by trouble falling/ staying asleep, sleeping too much? .....0 ..... 1 .....2..... 3

PHQ3 \_\_\_\_\_

4. Were you bothered by feeling tired or having little energy? .....0 ..... 1 .....2..... 3

PHQ4 \_\_\_\_\_

5. Were you bothered by poor appetite or overeating? .....0 ..... 1 .....2..... 3

PHQ5 \_\_\_\_\_

6. Were you bothered by feeling bad about yourself – or that you are a failure or have let yourself or your family down? .....0 ..... 1 .....2..... 3

PHQ6 \_\_\_\_\_

7. Were you bothered by trouble concentrating on things, such as reading the newspaper or watching television? .....0 ..... 1 .....2..... 3

PHQ7 \_\_\_\_\_

8. Were you bothered by moving or speaking so slowly that other people could have noticed - or the opposite – being so fidgety or restless that you have been moving around a lot more than usual? .....0 ..... 1 .....2..... 3

PHQ8 \_\_\_\_\_

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### Medical Care

---

1. When you **visit your doctor**, how often do you do the following (*please circle one number for each question*):

Never      Almost never      Some-times      Fairly often      Very often      Always

a. Prepare a list of questions for your doctor..... 0 ..... 1 ..... 2 ..... 3 ..... 4 ..... 5

b. Ask questions about the things you want to know and things you don't understand about your treatment..... 0 ..... 1 ..... 2 ..... 3 ..... 4 ..... 5

c. Discuss any personal problems that may be related to your illness ..... 0 ..... 1 ..... 2 ..... 3 ..... 4 ..... 5

2. **In the past 6 months**, how many times did you visit a physician? *Do not include visits while in the hospital or the hospital emergency department*..... \_\_\_\_\_ visits

3. **In the past 6 months**, how many times did you go to a **hospital** emergency department?..... \_\_\_\_\_ times

4. **In the past 6 months**, how many TIMES were you hospitalized for one night or longer? ..... \_\_\_\_\_ times

5. How many total NIGHTS did you spend in the hospital **in the past 6 months**? ..... \_\_\_\_\_ nights

---

### Future Questionnaires

---

How do you wish to receive future questionnaires?

- U.S. Mail  
 Internet  
 Telephone interview

**If you have type 2 diabetes, please continue to the next page.**

If you do NOT have type 2 diabetes, you're finished! Thanks!

\_\_\_\_\_ DOC1

\_\_\_\_\_ DOC2

\_\_\_\_\_ DOC3

\_\_\_\_\_ MD

\_\_\_\_\_ ER

\_\_\_\_\_ HT

\_\_\_\_\_ HN

\_\_\_\_\_ CALLED

\_\_\_\_\_ CODED

\_\_\_\_\_ CHECKED

\_\_\_\_\_ ENTERED

\_\_\_\_\_ VERIFIED

\_\_\_\_\_ ACCESS

APPENDIX F: A Matter of Balance Last Session Survey



**A MATTER OF  
BALANCE**

MANAGING CONCERNS ABOUT FALLS

# Last Session Survey

---

Today's Date:      **Month**      **Day**      **Year**  
                            □ □ / □ □ / □ □ □ □

Your Name:      **First**      **Last**  
                          □ □ □ □ □ □ □ □ □ □      □

---

Please mark the circle that tells us how sure you are that you can do the following activities.

How sure are you that:	Very sure	Sure	Somewhat sure	Not at all sure
1. I can find a way to get up if I fall	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I can find a way to reduce falls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I can protect myself if I fall	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I can increase my physical strength	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I can become more steady on my feet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the last 4 weeks, to what extent has your concern about falling interfered with your normal social activities with family, friends, neighbors or groups?

- Extremely     
  Quite a bit     
  Moderately     
  Slightly     
  Not at all

Mark **ONLY ONE CIRCLE** to tell us how much you are walking or exercising now.

- I do not exercise or walk regularly now, and I do not intend to start.
- I do not exercise or walk regularly, but I have been thinking of starting.
- I am trying to start to exercise or walk.
- I have exercised or walked infrequently for over a month.
- I am doing moderate exercise less than 3 times per week.
- I have been doing moderate exercise 3 or more times per week.

APPENDIX G: A Matter of Balance Class Evaluation



A MATTER OF  
BALANCE

MANAGING CONCERNS ABOUT FALLS

**Class Evaluation**

Today's Date:    

--	--

 /    

--	--

 /    

--	--	--	--

Thank you for participating in *A Matter of Balance*. To help us further meet the needs of others throughout the community, please take a few minutes to complete this evaluation form. We appreciate your feedback.

**Please tell us your thoughts about the *A Matter of Balance* class.** Mark the answers that apply on the front and back of this page.

1. The leaders were well prepared.  
 Strongly agree     Agree     Disagree     Strongly disagree
  
2. The classes were well organized.  
 Strongly agree     Agree     Disagree     Strongly disagree
  
3. The participant workbook helped me better understand the classes.  
 Strongly agree     Agree     Disagree     Strongly disagree
  
4. As a result of this class, I feel more comfortable talking with others about my fear of falling.  
 Strongly agree     Agree     Disagree     Strongly disagree
  
5. As a result of this class, I have made changes to my environment.  
 Strongly agree     Agree     Disagree     Strongly disagree
  
6. As a result of this class, I feel more comfortable increasing my activity.  
 Strongly agree     Agree     Disagree     Strongly disagree

*Please turn this paper over  
and fill out the other side.*

## A Matter of Balance Class Evaluation (continued)

---

7. As a result of this class, I plan to continue exercising.

- Strongly agree    Agree    Disagree    Strongly disagree

8. I would recommend this class to a friend or relative.

- Strongly agree    Agree    Disagree    Strongly disagree

9. Are you:    Male    Female ?

10. How old are you?

- Less than 60 years    75-79 years  
 60-64 years    80-84 years  
 65-69 years    85-89 years  
 70-74 years    90 years or older

What other changes have you made as a result of this class?

Other comments or suggestions?