

HENNEPIN COUNTY AGING INITIATIVE

Community Focus Group Project: Health, Health Care and Aging Well

Becky Kroll, CLEAR LLC & Diane Morehouse, QED

For Hennepin County Research, Planning & Development Department
Sherrie Simpson, *Director*

May 2012



Hennepin County

Research, Planning & Development Department

HEALTH AND HEALTH CARE

Health and Health Care Preview. As mentioned in earlier sections, health and health care were significant issues raised across all of the focus groups conducted. Most people recognize the importance of health maintenance. Few had issues with the quality of their health care; one group expressed concerns about maintaining choice; all had issues with health care costs.

We found relatively few people report planning to use insurance to pay for long term care (13 percent); some are ineligible and for others the costs are simply out of reach.

In most groups, we heard about resistance or aversion to moving to some form of long term care, particularly nursing homes. About 31 percent of participants currently have a health care directive. In more than five of the focus groups, participants reported believing this cost money, similar to going to a lawyer. In two of the groups (uncoupled women and GLBT) participants acknowledged difficulty in finding another person who could be named in the directive. GLBT participants also expressed fear that their legal arrangements would not be respected or upheld, particularly if a proposed constitutional amendment passes.

The greatest number of challenges we heard about, however, concerned cost and affordability. The costs of maintaining health insurance, as well as copays, spenddowns and medications are a burden for many. We heard many cases of recommended health care deferred or delayed due to cost considerations. Over and over again we also heard about the challenges of navigating the complexity of insurance systems, particularly Medicare Part D. Perhaps the best way to summarize the issues and concerns raised in this section are through comments about the overall health care system.

“The whole system’s broken. I don’t understand why we have this huge insurance industry making gazillions of dollars between us and doctors, why that is in there at all. The system’s so broken that, you know, I don’t agree necessarily with any of the solutions that have been thrown around, but our country spends, what, seven, eight times as much per person, and we get much less effective healthcare than any other industrialized country, so we really have to fix the system somehow. I don’t have all the answers for you, but it’s really broken.”

“I have some seriously high hopes for that Accountable Care Act, and I hope it works. The ObamaCare, as some people call it, but, hopefully, that, you know, is the light at the end of the tunnel for some people.”

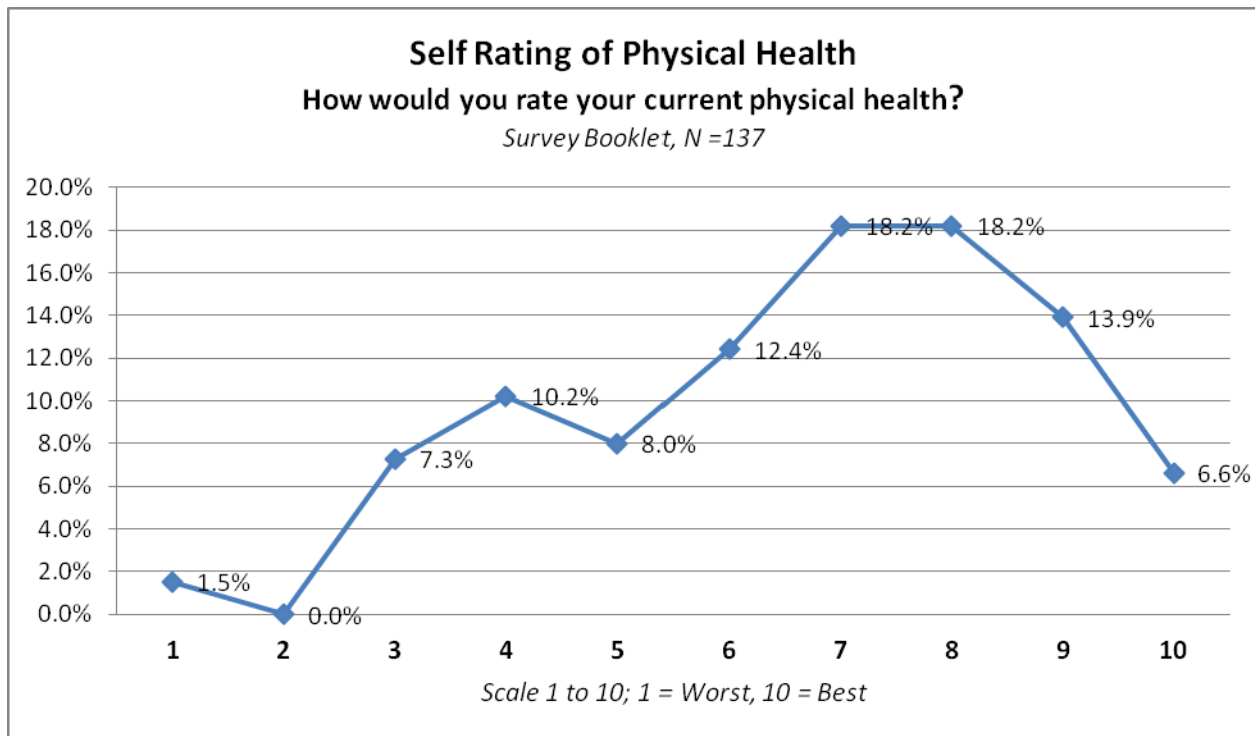
“I’m hoping — I’m positive — even though I have great concerns, I’m positive — I’m hoping for the best. I am hoping and praying for universal healthcare. That’s what I’m hoping for. All we can do is pray and hope for the best.”

The overriding issue we heard, not just in this section, but throughout the report, is concern about the cost of health care. We heard relatively few complaints and a number of compliments about the quality of current health care. The concerns are about a system which is complex, difficult to navigate and for those faced with copays, deductibles and spend-downs, very challenging and sometimes leading to delay or deferral of needed or recommended medical attention. While boomers are concerned about whether they remain healthy and cognizant of how health events would affect their aging, these

concerns are dwarfed by alarm at rising costs, uncertainty about available and accessible access to health care. While one group expressed highly negative perceptions of health care reform, across all other groups there was a wish, or desperate hope, that affordable access to health care would considerably improve their next 15 years.

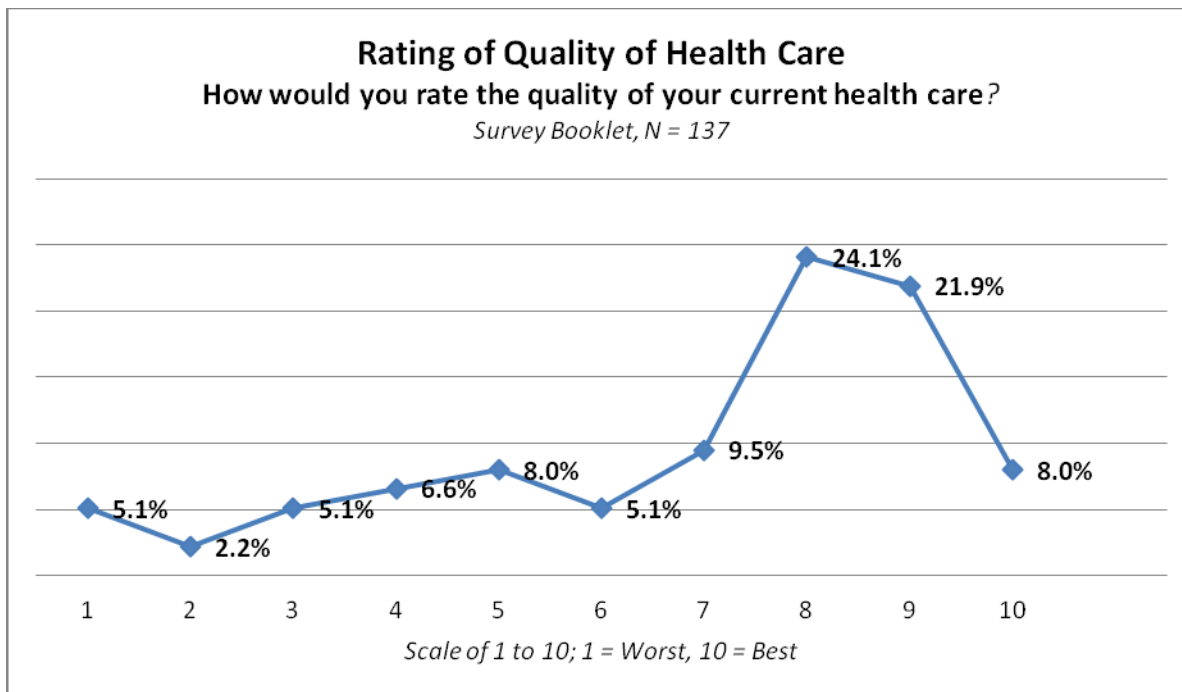
Concerns about health and paying for health care took center stage in all but one of our focus group discussions. These concerns about health (especially the costs of health care and health insurance) have far-reaching effects including decisions to continue working, and decisions to forego retirement. They also affect people’s mental and emotional health. In all groups, no matter what income level, paying for health care was the most significant issue raised. In this section of the report, we report on the responses to written questions, as well as the themes and comments from the focus groups.

Health rating. We asked participants in written questions to provide several ratings related to health. On average, participants’ rating of their physical health was 6.7; 50 percent of participants rated their physical health at 7 or better.



In focus group discussions, we heard repeatedly about the importance of health and the desire or hope to remain healthy in the coming 15 years. In some cases, this came from people who have already experienced major health issues. Most recognize that a single health issue or an accident can be game changing. Most also acknowledged the importance of maintaining their health through diet and exercise.

Quality of health care. In response to a written questions, most participants rated the quality of their health care quite highly. The average rating was **6.9** and 50 percent of participants rated the quality as 8 or above on a 10-point scale.



In general, we heard few complaints about the quality of health care participants receive.

“I think it's fine. I have no complaints about my doctors or nothing like that. They're right on the ball. Once you get on it, you know, and you go through what you have to do 10 times or 20 times, it's good here. I think the medical is good in Minnesota.”

“But I can only talk to you about what I've experienced, because I have enjoyed the healthcare here. It's some of the best that I have ever experienced.”

We heard the greatest number of comments about the quality of health care in the focus group of people with chronic health conditions. We also heard some concerns about culturally specific education for persons with chronic health conditions, and from the GLBT community about other issues in health care.

“Well for myself it's when a doctor doesn't understand the ramifications of paraplegia. You know if they don't understand my disability. I just had a hysterectomy seven weeks ago and my doctor knew nothing about how this might affect my paraplegic situation. And it's anytime I'm going, how does my paraplegic interact with that. And as an example, hysterectomy you're not supposed to lift anything over ten pounds for several weeks. Well how am I going to transfer myself? Oh we never thought of that. You know? And that's the case all the time.”

“Diabetes is an issue, my mother, my father and I have diabetes. Even myself I did not know about diabetes type II and did not know what this means. But when I go and say should I eat chicken chow fun, how about if I eat mango, how about if I eat cocoanut, if I eat durian, I talk to them, they say, we don’t have that. If you eat cheese, they have a system. But if I ask rice, curry, how much should I eat, they don’t have system about it.”

“We were there about ten years ago when I had an accident. My partner came. I was really sick, and this doctor was asking me, "Who is this person that's here?" And I mumbled something like, "Well, she's my partner," and he wrote down "business partner," and then explained that they would have to find the next of kin, while my partner is upset about what's going on with me and trying to explain the relationship. And that happens time and time and time again.”

In the exurban focus group, concerns about health care quality focused on choice, with less concern about cost. Most of the group had negative views about “Obamacare” or health reform, and feared that it would both limit choice and allocate “D” or less qualified physicians to them with no alternative.

“I mean, you see how many doctors are now having difficulty staying in business. There are a lot of doctors that are leaving. A lot of it has to do with ObamaCare and the things that are in that. Oh, it’s going to be much more difficult for — and there are a lot of doctors that are just plain leaving now because they know the impact it’s going to have on them. And unless that goes away, I think that we’re going to see a lot less doctors available. Not being able to choose who I want to go see. Being told I’ve got to go see some guy that’s 120 miles away. Well, it may not be an A plus doctor. It might be a D doctor.”

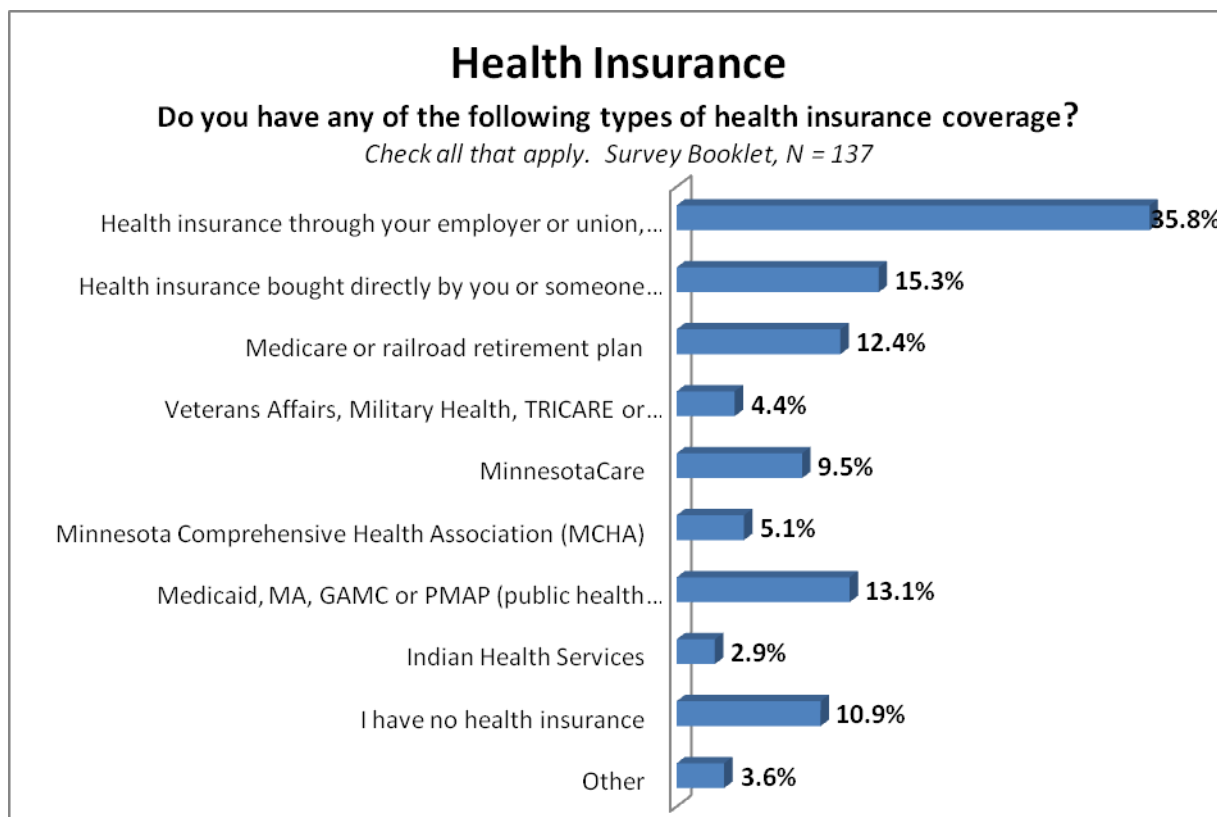
“So the idea that the system has to be tinkered with, that it’s going to become nationalized, that you’re going to drive private insurers out of the marketplace, that you’re going to have limited choices in terms of who you want to see and what their level of competency is are of great concerns to me, and I want to make sure that I can have and afford the absolute best in healthcare. If that’s a combination of Medicare or Medicaid entitlements that most people feel they’ve paid for the system and have a certain entitlement to — and to be able to supplement that with private insurance, you know, is the way I planned in the middle of my life, that I would have supplemental insurance or my own private savings to take care of that which Medicare would not.”

In another group, someone who would soon be eligible for Medicare commented on the issue of choice.

“But so far I've been able to manage to be able to go to the medical facility of my choice, and I think that once I — with no other option besides Medicare, I think that option is disappearing. So you think Medicare might save you some money but it will obviate your choices of providers...Well, I think as more and more of us get into and taking from the Medicare pot, we're going to find our options more limited. I've been reading some things, and it sounds like more and more providers, healthcare providers, are refusing Medicare patients. They don’t want them anymore.”

Health insurance. Thirty-six percent reported they have employer sponsored insurance, 15 percent individually purchased insurance, and about 13 percent of the participants are on a public health program such as Medicaid, MA, GAMC or PMAP, and 4 percent on VA, Military Health or TRICARE. At the time of this study, 12 percent are on Medicare, and nearly 11 percent report having no health insurance. This

included in one case, a woman who has not had health insurance since 1987, paying privately for all health care. The others without insurance included people who recently lost jobs and a number of people who are ineligible for public insurance programs due to immigration status.



Complexity and navigating insurance systems and Medicare. Many of the comments about insurance heard in the focus group discussions focused on the complexity of the systems and the difficulty navigating through complicated, confusing information. This particularly applied to Medicare Part D.

“Medicare is very complicated....I got a book last year, picked it up here, it was for 2010 and this coming year I’ll be turning 65, and it’s just really complicated. I read that book and then they said the Medicare is going to change for next year. It changes all the time, I guess.”

“It’s really hard. My brother in law is a legal aid attorney out in California. His wife just went on Medicare, and he said it took him weeks to figure out, you know, what her benefits would be. I think the system gets so complicated, it’s just hard for people to even know.”

“I get tossed around and I feel really frustrated with the whole Part D situation. I think it’s been a disaster. And every year I go through a couple hours on the phone trying to figure out which plan to pick for the next year because of that pretty complex regiment of medications and I have to make sure they’re all covered. Just think how it’s going to be when you’re 75 or 80 trying to figure that out.”

Some pointed out that in addition to the complexity and confusion, some of the available options did not work for them.

“Every single year I've had to go through Medicare Part D and re-assess which plan I'm going to be on for the next year to cover my drugs. And this year there was so many cuts in my drugs that are covered that I've actually had to go to a plan that I pay for because the only plans that are available to me at no cost through the government are ones that don't cover my medications. It's a long stressful ordeal I go through every year to find out which coverage I'm going to be able to get for Medicare Part D and as far as I'm concerned, MA was much better because it would cover everything. And this Medicare Part D has been a big mess as far as I'm concerned.”

There were also concerns about coverage, and changes from year to year.

“I'm concerned that they just cut dental care in half. I used to get my teeth cleaned twice a year and now it's once a year. Which you know I have to say is actually a great luxury to be able to get your teeth cleaned when you don't have any money, but it's still just another one of those things where it's been cut in half. I think I used to be able to get glasses, my eyes checked once a year, now it's once every two years. And if the MA glasses they give me break, I can't get new MA glasses for two years. And it just feels like things are just being cut more and more as things get tighter and tighter. And it worries me that it's just going to keep getting worse.”

Usual place for medical care. As the following table and graph indicate, the vast majority of participants go to a clinic or doctor’s office. Few go to the VA; about 4 percent go to an urgent care center, 3 percent to a clinic in a drug or grocery store. About 5 percent indicate no usual place, which we might assume is also the case for those who did not answer this question. Of greatest concern are those that use an emergency room for their medical care, about 6 percent of all participants.

Chronic diseases and effects. Fifty-three percent of participants indicated they have a chronic disease. We also asked about limitations due to their impairment or health problem. As the following table indicates, for 44% of those with chronic conditions, impairment or health issues affect their ability to work; 7% need assistance with personal care needs, and 22% need assistance in everyday activities.

Chronic Disease	N	Percent	
Do you have a chronic disease?	72	52.6%	
Because of any impairment or health problem:	N	Percent of all (N = 137)	Percent of those with chronic conditions (N=72)
Do you have difficulty in getting, keeping or working at a job or business?	32	23.4%	44.4%
Do you need help from another person with personal care needs such as eating, bathing, dressing or getting around your home?	5	3.6%	6.9%
Do you need help from another person in handling routine needs such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?	16	11.7%	22.2%

Health care directives. We asked in the survey booklet, and in the focus groups, about health care directives, also known as living wills. Response to the written questions indicated that only 31 percent of participants have a health care directive. Some said they didn't have enough information about health care directives, some said they knew enough but simply had not "gotten around to it." Some expressed concern about costs.

"I mean, I think people don't always know they need to do that. That is something where workshops on doing that and having the forms available and someone to help you at all the libraries and that sort of thing probably would be useful."

"So it's been on my New Year's list to do this living will and do my power of attorney, and eventually I'm going to do it"

"Some people say, that to do health care directive, you have to have money and you have to pay. Is that true?"

In two of the groups (the GLBT group and the independent/uncoupled woman group) there were participants who indicated they wanted to do this, but did not have a person who they could name to make decisions and assure their wishes are carried out.

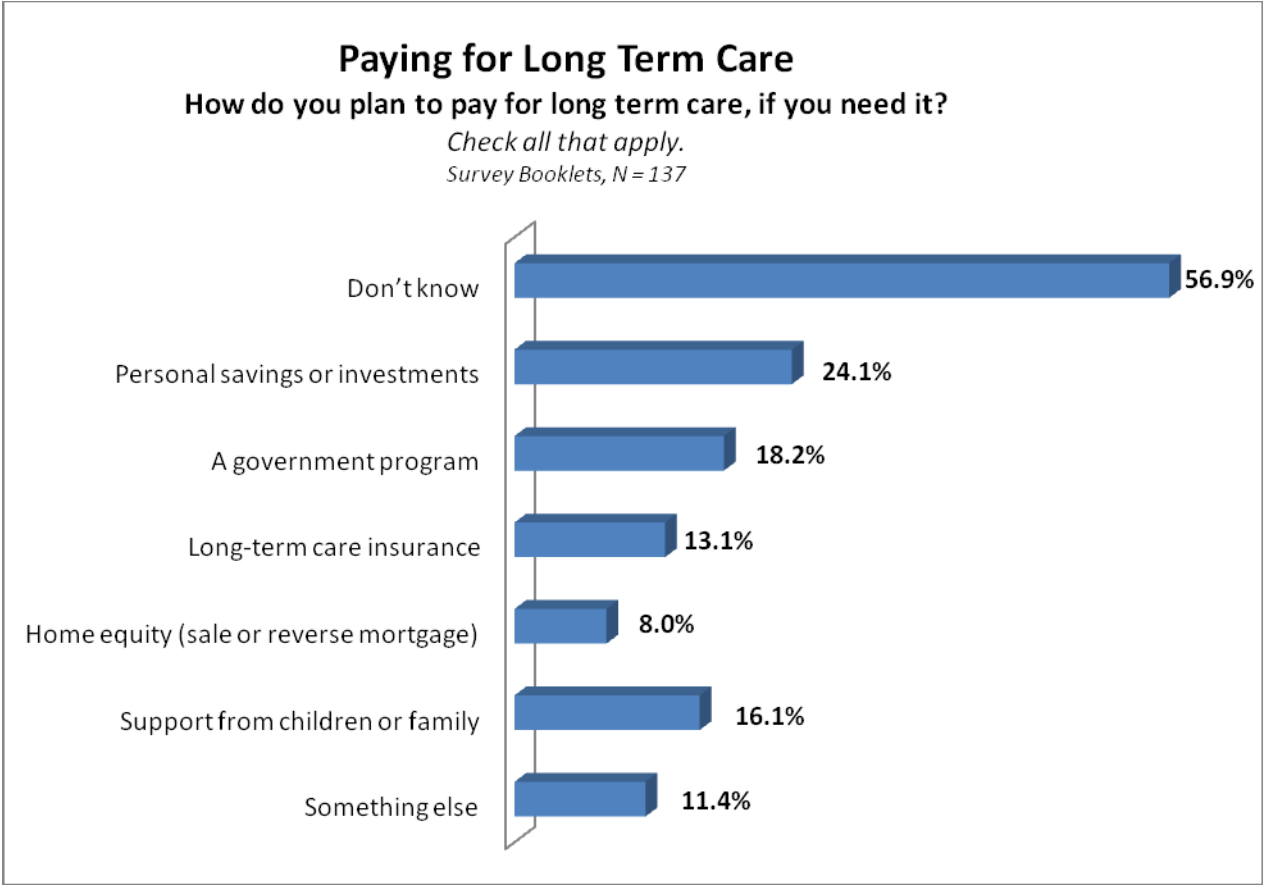
"My problem is with the power of attorney and all like that, I don't have anybody that I could trust. There's no one in my family that I could trust to take care of things like that. The friends and family that I do have have their own issues going on, and I really don't want to get involved in that. So that's – you know, if you're alone, what do you do?"

"I just haven't done it, and I think more and more, almost as time goes one, one of the things that I realize is that, you know, just a question along the lines of who do I really want to assign this responsibility to. I have a brother here, but I'm not – he probably assumes that he would be, but I'm not sure that that's the way I would necessarily want it. And I asked a friend, and she said she doesn't want that responsibility, that it's really family."

We also heard in the GLBT discussion concerns about legal arrangements of all kinds, including health care directives.

"So I think this is a unique issue in the GLBT community, that even when there are legal precautions put in place, that sometimes those aren't honored. And certainly we know that they aren't honored sometimes in hospitals. The nursing home suggests that I go ahead and prepare — make all the arrangements ahead of time, because when the time comes, I'm not going to be able to — the State says I'm not related to him. I can't do it. Now, fortunately for me, it was like if you want me to pay for it, we'll do it my way, and so I'm paying for it, so they're doing it my way. That was upsetting."

Paying for Long Term Care. We asked how people plan to pay for long term care, if needed. Well over half (57 percent) don't know how they will pay for long term care; just 13 percent report they plan to pay for long term care with insurance.



Aversion to institutional care. Throughout the focus group discussions, we heard people speak about their desire to avoid institutional – nursing home – care. This theme cut across all groups, from immigrant to exurban.

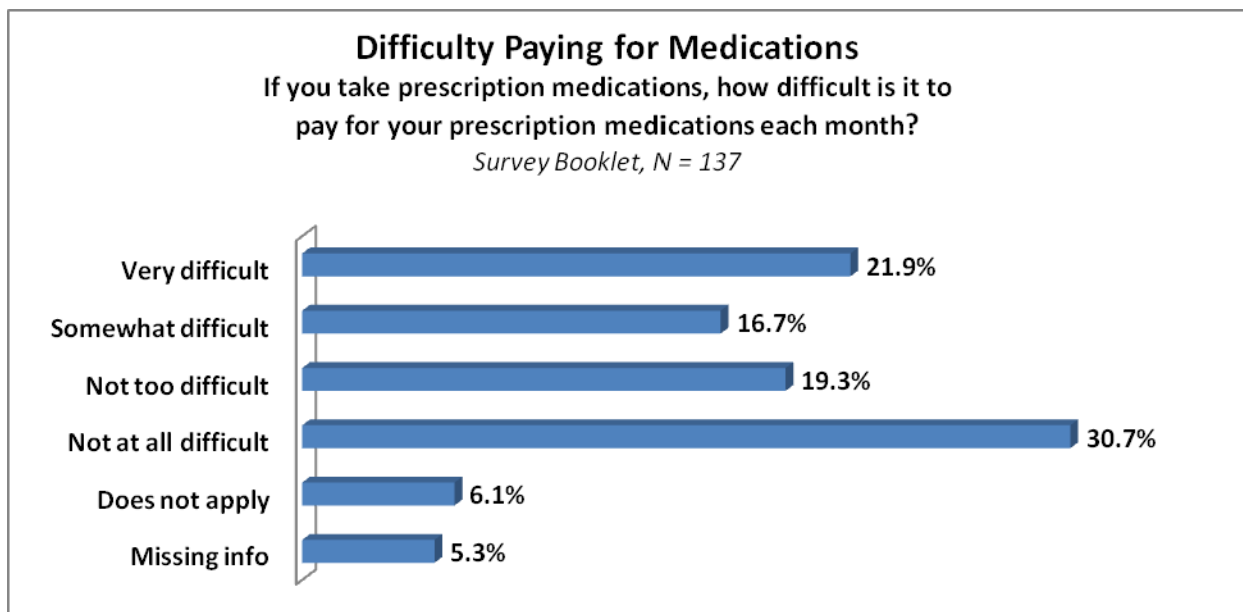
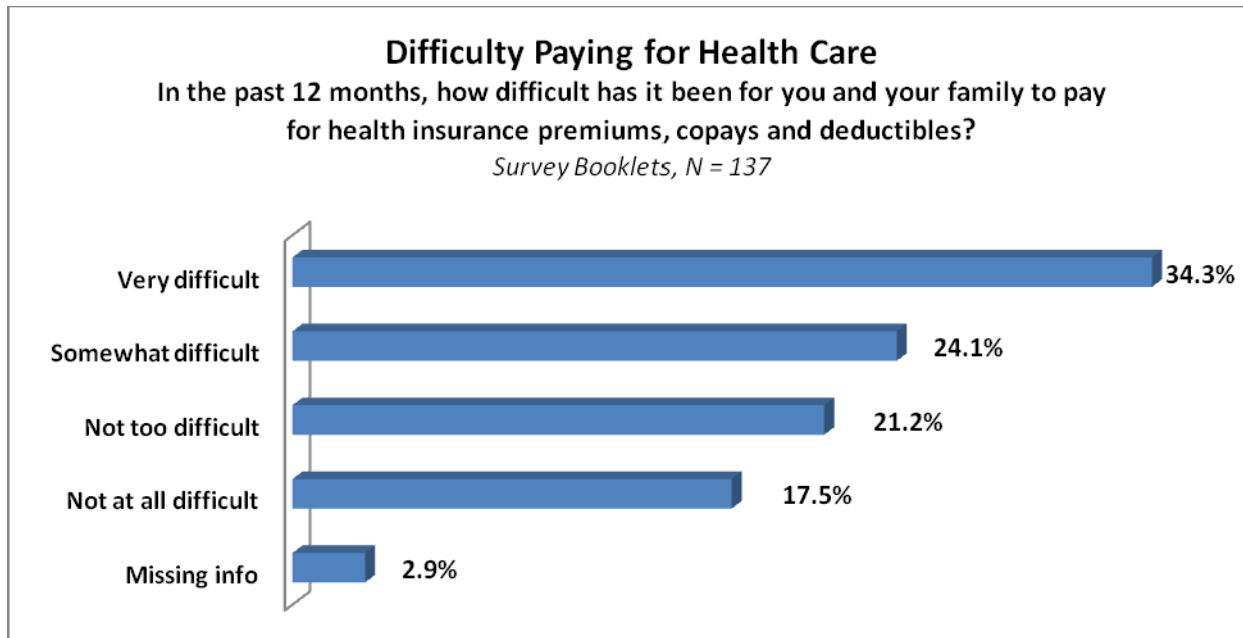
“I don't wish that on anybody. That is one place — I don't want to be in a nursing home. I don't want to be in assisted living. I want to be with my family. If I ever got to that place where I couldn't take care of myself, change my clothes, clean myself, keep myself clean, it's time to go.”

“We are scared of nursing homes, because we don't have nursing homes in Africa. In Africa, your family takes care of you. So we are scared of nursing homes. Not to say we think they do bad to us, but we don't like them, we don't want them. They don't have our food. They don't understand us.”

“You know, God please shoot me before I get to a nursing home, because I don't want to be there. I mean, it would be the worst thing in the world. So it is frightening for all of us. You know, and watching those nursing homes, they're godawful places. I haven't seen one I like yet.”

“Because we believe, again, that the senior center living is probably not going to be an option that's going to be comfortable at all being in the GLBT community. I mean, they're cruel. Cruel. Some of the staff.”

Difficulty paying for health insurance and medications. Written question responses confirm this concern about affordability of health care. As the following graphs indicate, about 30 percent of participants find it very difficult to manage the costs associated with their health insurance, and 22 percent find it very difficult to pay for their medications each month.



Cost and affordability. We heard concerns about paying for health care early and often through the various focus groups. As the section of this report on financial security indicated, the issue of cost and affordability are paramount issues and significantly affect people’s sense of financial security.

“You cannot afford to get sick. All the people that got all that insurance, 100 percent, all them folks, they can get sick as much as they want, because they get all the care in the world. We

cannot afford to get sick. I can't afford to go to the hospital. You can't afford none of those things."

"I went to get pills one time...I said you're taking out over \$600 a month for insurance and you want me to pay and you want me to come over here and pay \$57 for this?"

"You know, I need a procedure done on my teeth. And my healthcare won't cover it. Well, look here, I'm barely making it as it is now, and to assume another debt and stuff, you know, I don't — what am I going to do? If I don't do it, I might lose my teeth. And if I take on that expense, I've got to cut out something else."

People voiced concerns about the high costs of getting and using health insurance.

"Between my partner and I, and we have good insurance, we're paying \$1,800 a month. There's no way I'm going to be able to do that in two years."

"Well, I think the other thing that's scary is — I mean, for people who get their health insurance largely paid through their employer so that your hit isn't all that much, it's a rude shock to then go to Medicare and then pay supplemental policies."

"Before I went to this pharmacy, at the beginning of the year, I went to my pharmacy at work, which is a health organization, and when they gave me all my prescriptions, they said it would be \$468 and I said cancel them, I'm going somewhere else."

We also heard repeatedly about people deferring health care because they simply could not afford it.

"I had a problem with my blood pressure for some reason, and the doctors suggested I go get a stress test, but I couldn't afford to go get it yet. I had to wait until my insurance changed back, which was the 1st of October, I think, last fall. Then I was able to go get the stress test. So that's a shame. You've got to wait, hope you don't drop dead or something before you get your insurance straight so you can have yourself checked up."

"Like myself, I need to replace my teeth. Know how much is it to replace teeth? \$3000. Yes, I am suffering from my teeth. I went to doctor and they said \$3000 to \$4000 to make a bridge. So I cannot afford that. So I am suffering. I can't eat hard food, I can't eat salad, I can't eat on this side, one is missing from this side."

"It's very difficult for me. It's \$25 per visit, and \$60 for medications, I'm having financial struggle. Sometimes it's very difficult to the point you just want to hang yourself. My doctor said I should get medication, and I said I don't have any money. If I'm going to die, I die."

"Well I'm on private disability insurance. I'm not on social security. So I have Minnesota Care. And my Minnesota Care benefits, there's like a \$10,000 limit for in-patient now and I need kidney surgery and there's no way I can go in and have it done for \$10,000 so I'm putting it off and it's \$10,000 a year in-patient cap and then I think its 10 percent that I would be responsible for too, so that's basically \$1,000 too above and beyond that. So yeah, Minnesota Care, it's not really good insurance anymore."

Importance and success in navigating the health care system. We also heard a great deal of discussion in the focus groups about the importance of figuring out and making use of the health care systems, in order to have the best chance of optimal health. This included comments about preventative care as well as persisting in navigating through insurance information and health care systems.

“You stay on top of it. You have to stay on top of it. And, you know, you always, always apply for anything that you’re eligible for, eligible to get. You’d be amazed how many things that you can do or what you’re eligible for. You know, people are not informed of all these things, and it’s not easy. Like I said, you might get a bunch of paper, stacks of paper that you hate to read, but you need to be informed. Yeah, and then you talk about knowing to ask the right questions. A lot of people don’t know the questions to ask.”

AGING WELL

Aging Well Preview. Focus group participants, across all demographic categories, clearly understand the importance of diet and exercise, including mental exercise, in maintaining their health and independence. Most recognize that their well being depends a good deal on their own behavior. As a result, most engage in physical activity, ranging from household chores, lifting and playing with grandchildren and dog-walking, to working out at the gym. Participants worry a great deal about cognitive health issues, and so engage in various activities which they hope will prevent or delay them. Most have social connections, including communities of faith.

For many groups, the idea of community centers – gathering places – was suggested as a way in which government, or government and private entities working together, could share information, provide services and, in general, assist older persons in aging well.

We asked a number of questions, drawn from the literature on aging, to find out about how participants currently view their physical and mental health, and about the things they do to stay physically and cognitively active and healthy, as well as socially connected. Nearly all of our focus group members are aware of the need to eat well, exercise regularly (both their bodies and their minds). Although Most try to lead healthy lifestyles.

Staying healthy. In focus group discussions, we heard from people their ideas about how to maintain optimal health. Comments reflected the importance of eating well and exercise. .

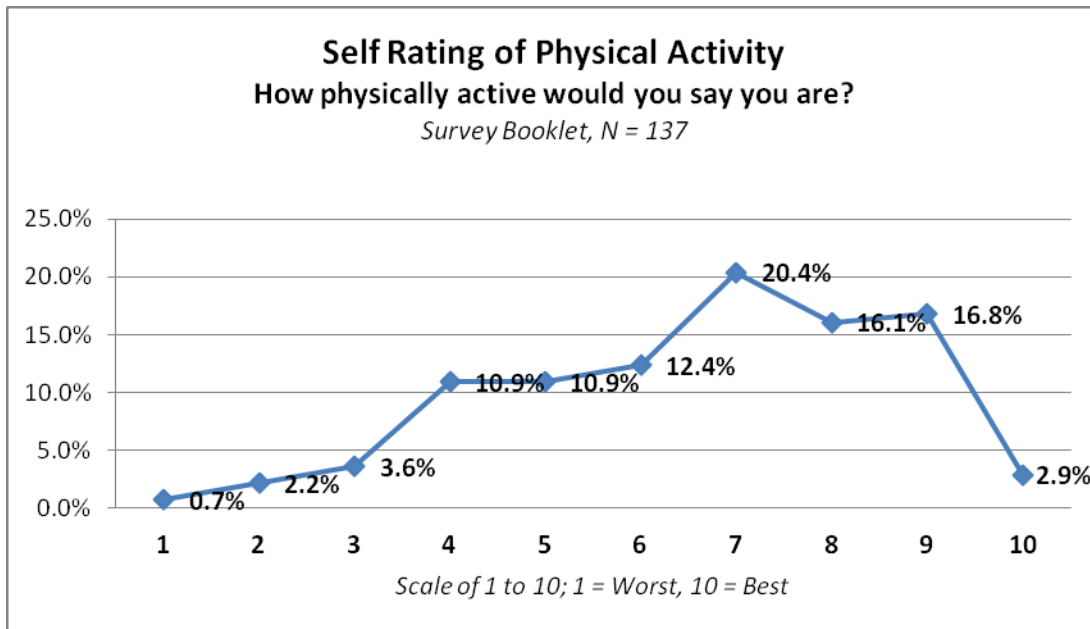
“We need to eat healthy foods and exercise more. Exercise more, better health, more strength, with God’s blessings we can make it.”

“Number one, to live longer, I have to have a better diet, a better diet and exercise. If you’ve got a better diet, a healthy diet, then I probably could live longer, but if I just eat fatty foods, sweets, with that come cholesterol, heart disease, diabetes, and if I don’t exercise, walking and riding a bike and stuff like that, you know, I’ve got a problem. If I would do those two things, you know, I’d have a better chance of living a longer life.”

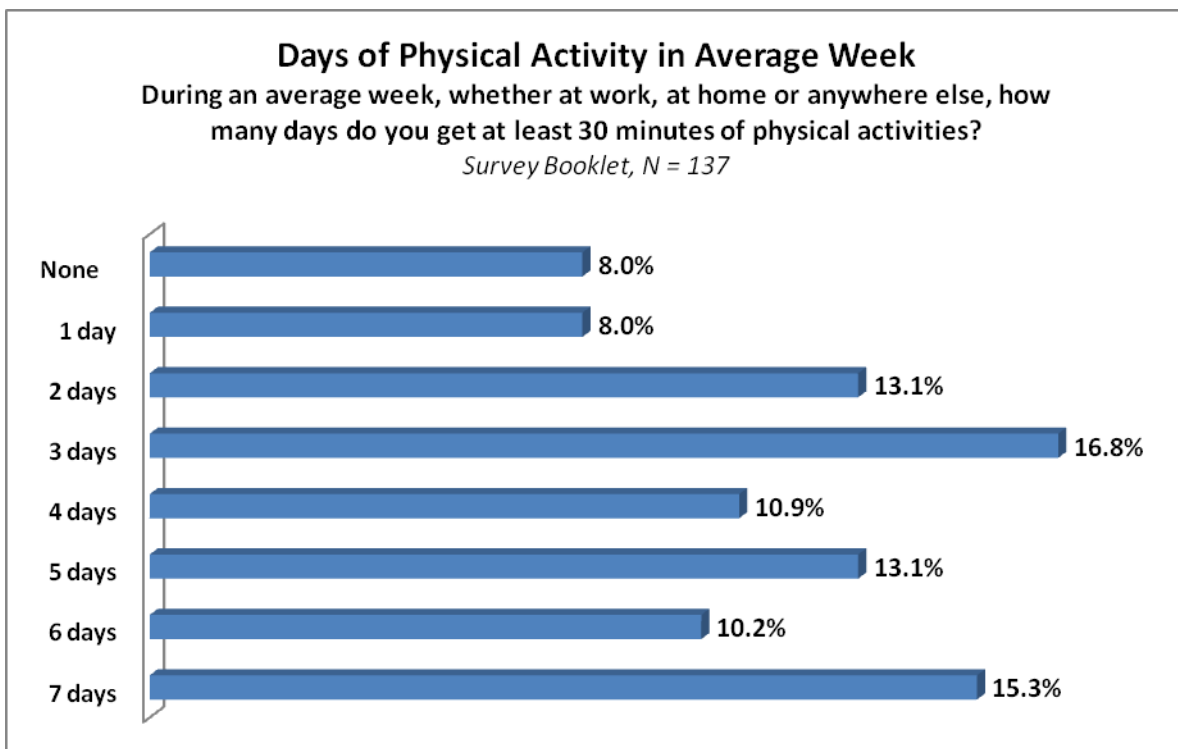
“We have the opportunity to figure out how to maintain our health and our activity and our body flexibility in the next 15 years. If I weigh 210 pounds, that’s not helping. If I sit and watch television and eat bonbons, that’s not helping. There has to be some real proactive kind of...We have to take care of ourselves as much as we possibly can.”

While many commented on the importance of eating well, some noted that the costs of doing so are high, making healthy diets difficult for low income persons.

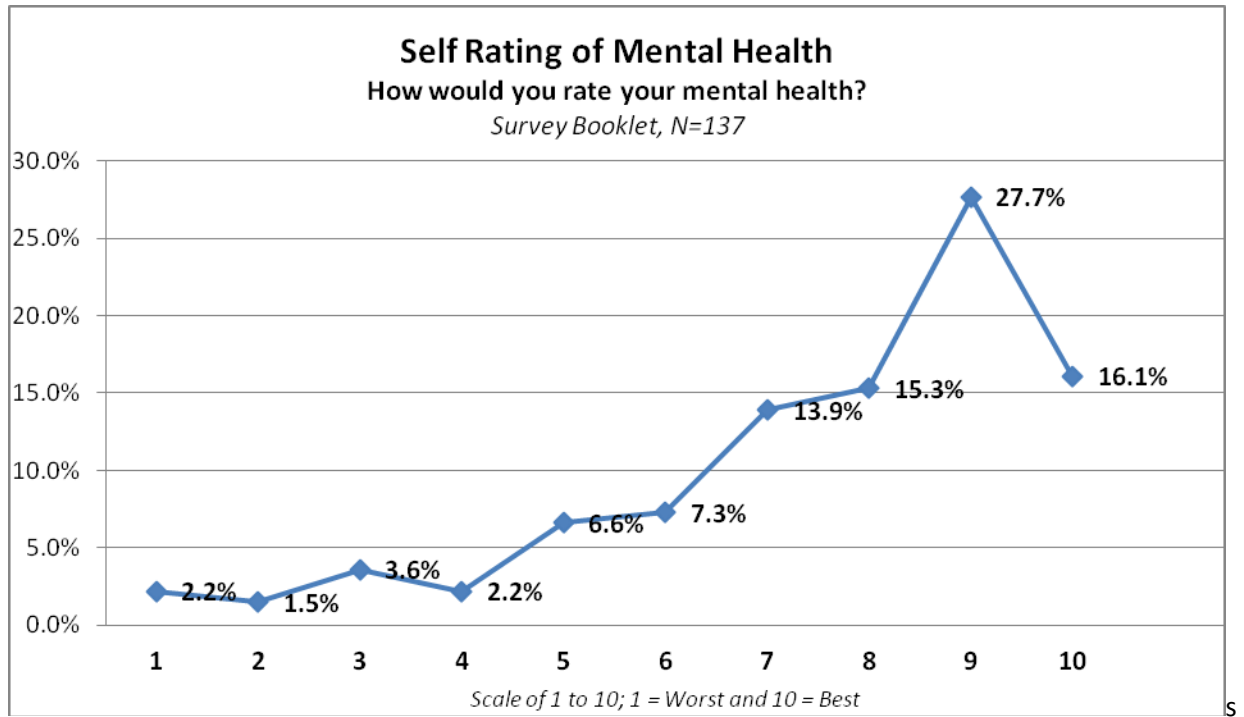
Physical activity. We asked participants in written questions to rate how physically active they would say they are, using the scale of 1 to 10, with 1 = Worst and 10 = Best. The following graph displays those ratings.



We also asked people to indicate the number of days in an average week when they get at least 30 minutes of physical activity. On average, across all groups, participants reported they engaged in 3.79 days of physical activity in an average week.



Mental health. We asked participants a written question, asking them to rate their mental health. On average, these ratings were fairly high at **7.59**; 50 percent of participants rated their mental health a 8 or higher on a 10-point scale.



In the focus group discussions of mental health, we heard of no specific difficulties with access to mental health therapy or treatment. Participants feel stress and tension, much of it caused by job losses and economic conditions (see Financial Security). In several of the immigrant groups, participants spoke of post-traumatic stress disorders, as well as stigma attached to mental health issues. However, for most of our participants, the issues they wished to disclose were largely stresses concerning their economic well being.

At the same time that a number of participants describe these issues, they indicate the ways they try to avoid stress and depression through activity and social interaction. Many described things they do to “keep spirits up” including various forms of physical activity or exercise, and socializing with others.

“For myself, I want to be happy...laughing with friends, talking about kids, not worrying. Right now I am 65 years old, smoke and have one drink every day. Don’t think anything about the bad things, like I need more money...oooooh, not enough left for living, have to reduce living, don’t think about it. Try to not worry and stay happy.”

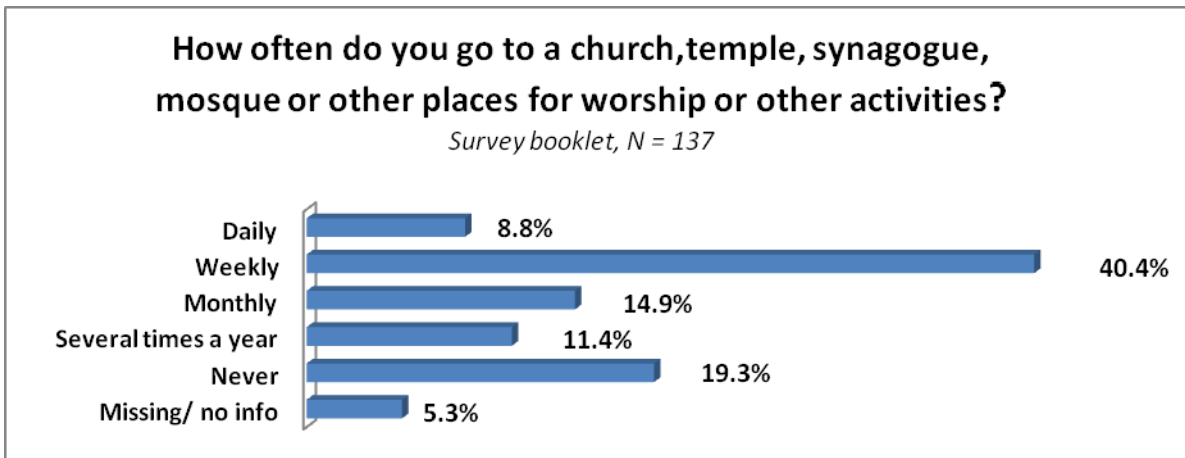
“I am concerned about it, mental health, I exercise, I do things, I not let mental health take over me. So I will control my own mental health.”

“I try to enjoy life, let it go, do something else, have fun. If I think about things over and over, not good. So leave it, try to do exercise, work around the house, keep myself busy.”

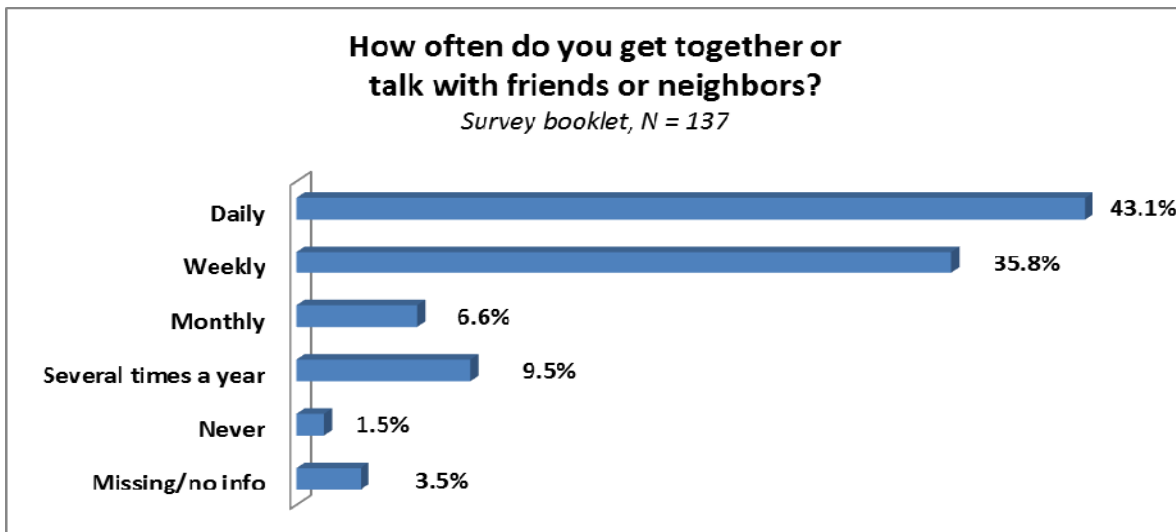
“Sudoku and crosswords...Yes, right, just to keep the brain working. I think some woman who just recently died was 112. She played Scrabble every day. I've been playing every day since. If it will help, just go with it.”

“I also have a fear of losing cognitive abilities and have found reading, conversation groups, mental quizzes, computer sites, regular writing quizzes, crossword puzzles, those kinds of things, and I do try to stay pretty active.”

Social Interaction. We asked a number of questions about social interaction. Of all participants, 81 percent indicate that they consciously do things to help them avoid isolation and stay socially connected. As the graph below indicates, nearly half of all participants (49.2 percent) go weekly or more often to church.



Even more often, participants in the focus groups report getting together with friends or neighbors. Nearly 80 percent get together with friends or neighbors weekly or more often.



In a number of groups there were comments about the importance of nurturing relationships.

“I'm kind of more drawn to nurturing the relationships and investing in them, because I think that even if you're poor, if you've got people around you who love you, that's what's going to make it tolerable. And, you know, you might outlive all those people, but — anyway, so I think it's nurturing relationships.”

“I think one of the things that we have as women, and it was kind of touched on, is that we have the ability to create our families of choice as our families of birth relationship either scatter or like our parents or siblings pass away. I think that women are more able and open, especially in today's society, to create those situations where they find support, and I think we're really lucky to be living at this time.”

“So I think socially is probably the most important to me. I can live on nothing if I have friends who I love and I know love me.”

In culturally specific groups, there was also discussion of the importance of seeking or providing opportunities for socialization with peers.

“And for the seniors, they need, they don't have get together, they are stuck in the home... if their children aren't drive, if they can't go anywhere. We need some place to get together, some community, so they can socialize, talk with each other and I think all the benefits from the county, but they don't have a social life. They can't go to the church, they can't go to the place to get together.”

“I do agree that Somalis seniors should be made active. Actually the people that need the most are Somali women because they don't come out like the men. The men can go to the coffee shop, they usually walk around. Not that many women can do that so you need a space for them where they could exercise, can pray, rest and come together and socialize. It's important that whether it's a center or that they get a space that seniors could socialize and maybe have activities where some training there could lead them a little exercise or they also need to find some kind of vocation or work sometimes.”

“Places where Native people...We feel really comfortable going to...and this is one of the places [Minneapolis American Indian Center]. There's eating here, that's a good service. For a lot of the elders, this is the only time they get out. Get to visit with people, and the company's good.”

Community centers, perhaps housed in parks or libraries, were mentioned in most groups as possibilities for increasing both physical and mental health, and decreasing isolation among the elderly. Such centers could serve as places for socialization, exercise, information, education, even preventive health care. Many suggested a role for the County in promoting such centers.

“There's empty and for lease buildings all over the city. Why not take one of them, staff it...and let the seniors gather there...there's not enough of them.”