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Senior Issues Focus Group

With specific emphasis on healthcare, poverty, unmet needs, and gaps in service as they relate to the senior community

Conducted for:
The Carle Foundation

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Purpose

The purpose of this focus group was to gather opinions from those who, through their employment, interact with seniors in Champaign County. Most respondents are employed by human care agencies which have services for seniors, and some are employed by a variety of health organizations. A couple of respondents are recently retired but previously had long careers in the senior care field. All participants except two represent Champaign-Urbana-based organizations. The exceptions include the East Central Illinois Area Agency on Aging, whose executive director participated. This agency is based in Bloomington, but serves 16 counties, including Champaign. The other exception is the University of Illinois Extension Service, which was represented by a staff member from their Piatt County office.

Topics discussed included identification and opinions about the perceived most profound problems facing seniors, those specifically related to poor seniors, health-related issues, and the different concerns faced by "younger" seniors, 50-64 years of age, and "older" seniors, 65 years and over. Specific subjects also included gaps and unmet senior needs and stumbling blocks related to solving these needs. Participants were also asked to evaluate the success in dealing with these senior issues and their opinions about different approaches, including collaboration.

Methodology

Gretchen Robbins, director of Public Relations of The Carle Foundation, identified potential respondents and Research Survey Service contacted and invited them to participate. A total of 19 potential respondents were asked to participate, with 14 actually attending. (A complete list of attendees can be found on page 9. Separate interviews covering subjects similar to those discussed in the focus group were also conducted. The results of those interviews can be found in the Addendum starting on page 10.)

The focus session was held at the Urbana Park District's Anita Purves Nature Center on Thursday, September 27, from 11:30 a.m. to 1:30 p.m. Gretchen Robbins introduced the session. In addition to Ms. Robbins, the following Carle executives viewed the session: Mike Billimack, vice president of Marketing & Strategic Planning; Lynne Barnes, vice president of Clinical Operation; and Robert Driver, vice president, the Carle Development Foundation.

The co-owner of Research Survey Service, Inc., Jan Kiley, moderated the group.

Discussion

Most Profound Problem Facing Seniors – When participants in this focus group were asked what, in their view, was the most profound problem facing Champaign county seniors, responses fell into three broad categories. Three panel members noted *transportation issues*, including the problems caused by a senior's loss of a driver's license, a lack of transportation services for those just above the poverty level, and the need for transportation to routine, non-emergency outpatient visits, especially for those living in rural areas. Four mentioned *health-related issues*, including general health maintenance, the cost of prescription medications, management of those medications, and a lack of access to psychiatric services. And the remaining seven talked about issues *facing seniors generally*, not just those in Champaign County. These latter comments were perhaps best summarized by one focus group member who said the paramount need is to keep seniors living in their own homes, and to keep them out of nursing homes.

Also included in the last group of issues were comments from two participants who said there is a lack of resources, including trained care professionals to aid the elderly. Another two noted that some seniors are not willing to take advantage of services that are available, with pride in self-sufficiency being a major factor. One said the most serious problem is the fact that many now, and in the future, will live one-third of their lives as seniors on fixed incomes. And still another noted that, while the affluent have sufficient means to pay for needed services, and there are low-cost or free services available for those in lower income groups, there are few comparable services for seniors in the moderate income category.

While these initial comments were reflected in the discussion that followed, by the time the session ended, a number of participants had highlighted three other issues – the need for *greater coordination among providers* of senior services, the *growing importance of volunteers* in maintaining and delivering services to seniors, and the need for *wider distribution of information* about the many senior services already available in Champaign County – as will be described later in this report.

Transportation – Focus group participants indicated several agencies are involved in providing transportation for seniors. However, most such services are "curb-to-curb" (the Champaign-Urbana Mass Transit District) or at best "door-to-door" (Family Service or Regional Planning). One panel member said seniors sometimes need "through-the-door" help with grocery bags or other parcels from shopping, and that kind of assistance is difficult to provide.

A shortage of volunteers is also a problem. Family Service relies primarily on volunteers to drive needy seniors where they need to go, and an increasing number of those volunteer drivers are seniors themselves. In addition, the rising price of gasoline has made it more difficult for drivers to afford the cost of providing volunteer transportation. This is especially true for volunteers serving

rural areas, where drives to clinics and stores in the cities are longer and more expensive.

One panelist noted that many of the MTD's vehicles aren't big enough or configured in such a way as to provide easy access for motorized wheelchairs and the like, although efforts are ongoing with vehicle manufacturers to solve the problem in newer models.

Health Care – Discussion in this area began with a focus on problems many seniors face getting the medications they need. Participants agreed that, while the *new Medicare Part D coverage* provides much-needed financial help to many, the program is needlessly complicated and frustrating. As one said, it's "so confusing, even for the [mentally] sharp elderly."

The confusion starts with the availability of a multitude of competing Part D insurance programs. While the government's website provides a means for seniors to try to determine which plan would best pay for their particular prescriptions, many don't have internet access. And others simply find the process daunting. Family members and helpful pharmacists have provided some assistance. But in many cases, the burden of helping individual seniors find their best Part D coverage has fallen on human care agencies (such as the Mental Health Center, Frances Nelson, Regional Planning, Family Service, and local clinics and hospitals) and their already overworked staffs and volunteers.

Then there is the "donut hole," the time when seniors with numerous expensive medications temporarily "run out" of Part D coverage and must cover several thousand dollars in prescription payments themselves, before Part D insurance kicks in again to cover most further costs. Participants said some seniors, when they reach the "donut," simply cut back on their mediations or quit taking them altogether, because they can't afford them.

While most seniors are aware of Part D coverage, some are not, and even fewer are knowledgeable about what a panel member called "one of the most generous pharmaceutical programs in the country." He was referring to a program, paid in part from state of Illinois funds, that provides free or discounted medications to needy seniors. Other focus group participants noted that such programs are limited to low-income groups, and one said the benefits "can take three to four months to kick in."

One panel member estimated that "more than half" of seniors are not getting or taking all the prescription medications they need, which can range from half-a-dozen to a dozen or more per day. A couple of participants said some seniors who can afford to pay for their prescriptions still don't get or take all they need, because of a belief that "they just cost too much." One described this as a "depression-era mentality," which rules out paying for expensive medications or even other pricy goods or services because the cost, while within reach, just seems "too high."

Others saw a problem of *managing all these medications*. The issues ranged from simply helping seniors fill daily or weekly pill boxes to coordinating medications prescribed by several different specialists. While several agencies through home health aides or others can provide this kind of assistance, the demand is growing and they are often overwhelmed.

One participant said a recent decision by the Champaign County Public Health District to shift funds and services away from the elderly to other populations has aggravated the situation. He said the loss of five Public Health RN's who had primary responsibility for assisting seniors has put greater burdens on others. He added the simple fact is, there are not enough qualified RN's available to dispense medications

At this point, the discussion expanded somewhat in scope to the broader issue of coordinating the overall health care of Champaign County seniors. This was referenced on two levels – the need for better cooperation and coordination among local agencies serving the elderly, and the requirements for *coordination and care management* for the individual senior.

On the latter subject, one focus group participant framed the issue this way: "We just don't have enough help at the professional and para-professional level to care for seniors in their homes." She said it's a "growing crisis" and that both public and private agencies need help. A representative of one agency followed up with this: "The minimum wage just increased," but the state didn't provide more money for the agency's workers – home health aides and others. She added, "We need to adequately compensate them for the difficult and important work they do."

Reference was made to the parish nurse programs coordinated by Carle through several churches. One respondent called these programs "wonderful" and praised their current expansion. Another said when public funds get tight, responsibilities shift to private organizations – whether churches or others – and efforts are made to recruit volunteers to take up some of the slack.

Several participants said they've seen changes in the nature of *volunteering*. While in the past volunteers would often stay with a human care agency for many years, that is less and less the case. There seems to have been a generational shift. Baby boomers appear more focused on short-term volunteer efforts. "They want to have an impact," is how one panel member put it. Once a particular project is over, they're likely to be gone. Others observed that boomers will be more likely than predecessor generations to work into their 60s, 70s, and beyond, making them less available for volunteer work.

One panel member said companies used to take on social service projects, using their employees as volunteers. But there seems to be less of that now. This respondent said she has six pages of seniors needing help – including home maintenance and yard work – but firms no longer seem willing to enlist their employees in such projects. And another added that, while less critical than

assistance with medications and health care, more seniors are seeking help with the mundane problems of keeping up the house and yard.

Focus group members generally agreed that recruiting more volunteers is critical for allowing human care agencies to help more seniors. But as one noted, "It's asking a lot of volunteers to have them take over… for trained social service workers."

Another said with more doctors and nurses retiring early, agencies can tap these folks to assist with seniors' care and case management. However, there are liability issues, which can make retired professionals reluctant to volunteer. Some agencies do have liability insurance covering these professionals, as well as other volunteers. A representative of Frances Nelson said Carle provides money to buy liability coverage for volunteer doctors and nurses there. And others made reference to Good Samaritan laws. But as one panel member noted, even with such laws and liability insurance, if an agency or individual volunteer is sued, there still can be legal expenses and the distraction of having to spend time responding to a lawsuit.

There was a relatively brief discussion about ways human care agencies can help family members, who in turn, are assisting aging parents or other relatives. The key seemed to be the availability of staff and services to help family caregivers avoid burnout. One participant noted that as we live longer, the age of those in the "sandwich generation" – caring for both children and aging parents – has moved from 40's to the 50's and 60's.

Panelists did identify some *bright spots*. A representative of the Area Agency on Aging noted that federal and state funds help local agencies through a variety of programs for seniors. For example, all seniors age 60 and over are eligible for case management services; there are no income or net worth qualifications. And the community care program helps needy seniors get access to medical care, including short-term prescriptions and devices such as hearing aids. He also mentioned changes toward "consumer-directed care," which lets seniors and the disabled have a greater say in who is hired to help them and how.

One participant suggested the time may have come for "social HMO's," organizations which would follow the medical HMO model but have seniors paying for "insurance" to cover their needs for in-home help, focusing mainly on social services.

"Early" vs. "Older" Seniors – At this point, the discussion moved to examining a point made earlier – "seniors" are not all the same, with identical problems and needs. One participant suggested looking at two groups by age – those age 50 or 55 to 65, and those 65 and older. But another suggested a third division, noting that the fastest growing segment of the population is those 85 and older.

Several panel members again noted different generational approaches. The older group, especially those with memories of the depression, generally are more

private and self-reliant. They are more likely to have private pensions, "live within their means" and refrain from seeking assistance or making use of government-funded programs. By contrast, the "boomers," the first of whom are now just entering their 60's, while more savvy shoppers (including for health care), are more likely to feel, as one participant put it, "they [the government] are going to take care of me."

Mention was made of local programs and services being developed, often by boomers for boomers as they age. These include unique education efforts from the University of Illinois and Parkland College, designed to keep seniors active and interested. And more boomers are building or buying one-story homes, which will be easier to live in as they age.

Participants noted that age qualifications can limit the ability of those under 65 to access some government-sponsored programs. Aside from the obvious – age 62 to quality for Social Security and age 65 to receive Medicare benefits – various other publicly funded programs allow access only at different ages, including 55, 60 or 65.

A couple of panel members also referred again to income limits on access to some programs. And this can be especially difficult for those in the lower- and middle-income categories who are also excluded from programs by age. As one participant described it, younger seniors in the $24,000 to $30,000 annual household income range "don't qualify for anything." She added that families in this situation, although denied access to some programs because they're above the maximum income limits, can drop into the poverty-level group after paying for services that the latter group receives free or at reduced cost.

One participant said there are a lot of neighborhoods in the Champaign-Urbana area where substantial percentages of the residents are age 50 and older. He said elsewhere in the country, neighbors in similar situations have pooled their efforts and arranged as a group for services to help them as they age. However, he noted that efforts along these lines can be hampered by "racial or cultural disparities."

A representative of the Champaign County Mental Health Board described efforts to assist the developmentally disabled, who in addition to their current problems, are more likely to develop dementia as they age. Government services can help ease the strain faced by the aging parents of these individuals.

At this point, the discussion turned to the problem of making aging adults in Champaign County aware of the multitude of programs and services available to them. As one put it – people don't think about these things until they're suddenly faced with a need. It was noted that the Mental Health Board and other funders help support information programs at various agencies, including Regional Planning and First Call for Help at Family Service.

One participant said knowing where to go or whom to call when seeking help with a specific problem is a challenge for anyone. But it's a special problem for

those who may find themselves overwhelmed by a personal or family crisis. And it was noted that there is some duplication of services among human care agencies in the county, and that there could be better coordination of such services.

Illinois is one of the few states that has yet to adopt the 2-1-1 universal access system, which provides for one-stop calling for information about human care services. Individuals needing help for a fire, crime, or other emergency know to call 9-1-1. In similar fashion, 2-1-1 callers in other states get information about help available to meet social and human care crises. One participant said Illinois is making progress toward establishing the 2-1-1 system, and he said Central Illinois might be a participant in a pilot program.

Other Issues – Toward the end of the focus session, participants had some additional thoughts, after being asked if there were significant issues relating to seniors in Champaign County that had not been addressed.

Several panel members mentioned shortages in certain professions, in addition to the nurses and home care aides noted earlier. Two specified the need for additional psychiatrists. One said the county currently doesn't have any psychiatrists who are board certified in geriatrics. He said this means that nursing homes may not recognize depression in their patients. Without proper treatment, depressed nursing home residents may not be motivated to continue the physical, occupational and other therapies that could help them become able to return to their homes.

Another participant said family physicians may not always recognize depression as the source of various physical symptoms in the elderly, thus leaving them without needed care and treatment if they're unable to get a timely psychiatric consultation. One panel member said local communities have too few certified gerontologists to provide the assistance seniors need.

Other issues raised included:

- The challenges elderly patients face going home after a hospital stay. They and family caregivers may not be adequately prepared to provide needed aftercare.

- "The extreme segmentation of local medical services." This participant added: "It's a challenge as you get older. You need a shepherd" to help you through the medical system."

- The need for more professionals qualified in case management. According to this panel member, Carle is taking part in a pilot program through Medicare where elderly patients have someone who keeps in touch with them and their health problems and needs.

- Education and information on nutrition and wellness. One participant said this is especially important for the aging population.

The Most Important Thing Discussed – Several of these participants' final thoughts related to what one called "the overwhelming complexity of senior issues," with a number touching on the need for coordination of services. One said he was "overwhelmed at all the different [human care] groups that are working together" for the good of seniors. Another remarked on the coordination needed for all ages and all types of service. Still another said it was "nice to see Carle put this together – looking at the big picture" and the need to have agencies working together. And as one put it, "care coordination – we've come back to that."

A couple returned to the volunteer theme – the need for more volunteers being trained to assist professionals and "the need to support and empower volunteers." And one described the discussion as important to "empowering healthcare consumers," suggesting this meeting could lead to others on the same topic.

Others said the most important things they would take away from the session included "planning for the future of the baby boomers," and "a future vision" recognizing the need for more workers to assist the elderly.

The advantages the Champaign County community has were recognized. One said: "The education level here is high, the income levels are high." Another noted that this community has more resources for seniors than nearby cities such as Danville or Decatur.

Several said they learned new things about the many programs and services available to help seniors. One said she would remember "the lack of homogeneity" in the senior population, with many different sub-groups and individuals requiring unique approaches.

A need to grow, what she called "the culture of caring," was the major thought one panel member said she would take away from the discussion.

And another brought a chuckle from the group as she summed things up this way: "We're trying to get it right before we all get there [as seniors ourselves.]"

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Those Attending:

Sheryl Bautch, Family Service of Champaign County; Don Brown, Stevick Center volunteer; Barb Dalenberg, Carle Case Management; Sandy Dunn, senior agency administrator (retired); Cindy Fraser, Carle Health System Research Center; Andrea Goldberg, Frances Nelson Health Center; Jo Hopkins, Retired and Senior Volunteer Program, Family Service of Champaign County; Kathy Kessler, Champaign County Mental Health Center; Nancy King, University of Illinois Extension Service; Darlene Kloeppel, Champaign County Regional Planning Commission; Rosanna McLain, Senior Resource Center, Family Service of Champaign County; Michael O'Donnell, East Central Illinois Area Agency on Aging; Ruth Shankin, The Windsor of Savoy (retired); and Mark Driscoll, Champaign County Mental Health Board. (Others were invited, but unable to attend.)

Additional input:

Separately, Jan Kiley interviewed Charlene Stevens and Gretchen Robbins interviewed Faith Roberts on topics similar to those discussed in the focus group. Summaries of those interviews are attached as an Addendum to this report. Initially, Carle officials sought input from Claudia Lenhoff, Champaign County Healthcare Consumers and Valerie McWilliams, Land of Lincoln Legal Assistance Foundation, Inc. Key points from that conversation, which are noted in the Addendum, served as a starting point for shaping the focus group discussion.

Addendum:

Key input from Claudia Lenhoff, Champaign County Healthcare Consumers, and Valerie McWilliams, Land of Lincoln Legal Assistance Foundation, Inc., with members of the Medical Debt Committee that meets regularly with officials from Carle Foundation Hospital.

The following were identified by this group as the largest needs in our community for seniors:

1) Dental services
2) Eye care
3) Programs provided by Family Service of Champaign County
4) Support to pay Part B Medicare Premiums
5) Support of programs supported by Department on Aging Funding for those in the 60+ year old age group
6) Services for people in the 50 to 64 year age range who are not able to work and are not eligible for Medicare

Summary of interview with Faith Roberts, coordinator, Community Parish Nurse Program. Conducted by Gretchen Robbins on September18, 2007.

Isolation is without a doubt the most serious problem facing seniors, according to Ms. Roberts. Granted, transportation contributes to this, but there's more to it. People don't like vans and don't like the inconveniences of spending a lot of time riding a van that stops in multiple locations. So, even when public or dedicated transportation is available, they often choose not to use it. This failure to use transportation that may be available to them leads to isolation. It then leads to inattention to their health—they don't get proper nutrition and don't have opportunities to socialize.

Possible solutions for transportation are use of the Faith in Action (parish nurse) and the Health Ministries programs to provide rides.

Isolation can be minimized by visiting nurses. But CUPHD is no longer able to fund this service at the same level it was previously supported. There is also a "Befriender" program that works in some communities—details of which can be found on the internet. Tele-home care is another innovative way to keep isolated seniors healthier and monitored.

Faith acknowledged the value of home care workers. Faith considers Family Service of Champaign County to be among the best agencies providing home maker services as well as addressing other senior needs in this community.

Another emerging issue is the management of medications for seniors. Home health nurses are no longer reimbursed for this service. So, the "setting up" of pills is now done by family or friends, if at all. However, Faith says that parish

nurses can provide this service and it can be done most effectively in drop-in or senior community centers.

That raised another issue: how can a community center health-based program effectively work to keep seniors healthier and socialized. Poor seniors struggle with transportation, nutrition, medicine management, hygiene and socialization. Organized programs utilizing nurse volunteers, EMT's, and perhaps a grant-supported nurse practitioner (NP)--if only once a week--can reach several people at once and get them re-directed to a higher level of care, if necessary. For example, a nurse can fill multiple pill boxes within a very short period of time; a NP can hold a diabetic foot clinic or a heart failure clinic; EMT's can take blood pressure. There are multiple health education programs that could be initiated. Another valuable service would be grief counseling. Faith mentioned that there is grant money available for these types of community centers and programs. One source that she was familiar with is life insurance companies.

When asked about challenges faced by the younger senior, it was clearly the "sandwich generation" issue. Today, grandparents also provide care for grandchildren and sometimes are the sole guardians.

Summary of interview with Charlene Stevens, nurse at the Champaign-Urbana Public Health District.

According to Ms. Stevens, the most severe problem facing seniors in Champaign County is the "huge" gap between people's needs and their eligibility for services and support from Medicare. Part of this stems from the inability to understand what is available and then a lack of accessibility.

She believes the East Central Illinois Area Agency on Aging and the Champaign County Regional Planning Commission are trying to deal with availability and accessibility, but that both Carle and Provena could help the process by providing more funding for social workers in general, and specifically more medical social workers. This nurse predicts that this problem will grow, especially with the large number of baby boomers reaching senior status. She also noted that Carle is "going to great expense to teach physicians about geriatrics, but we need more across the board."

Regarding the problems faced by poor seniors, her immediate response was "poverty and everything poverty brings." According to her, ignorance, specifically of medical issues, is uppermost in her assessment. Also, "They [seniors] don't have the tenacity to fight for things."

Throughout this discussion, the interviewer probed about current conditions and situations, but the respondent tended to brainstorm, trying to make suggestions about how to correct the problems addressed by the questions put to her. Obviously, suggestions were welcome, but after the assessment phase. As an example, when this respondent was asked which organizations are addressing the

concerns of poor seniors, she replied, "[What] we need is a war on poverty. We need a Mr. [President] Johnson again."

Regarding specifics about poor seniors, this health professional thought Family Service, the C-U Public Health District, adult day care at the Champaign County Nursing Home, Champaign County Regional Planning Commission, Champaign County Healthcare Consumers, the Champaign and Urbana Park Districts, and the Stevick Center are all trying to address issues facing poor seniors. But she thinks Carle needs to provide an adult day care center. She even suggested the former MAB paint store in Country Fair Shopping Center as a location.

She also believes minority groups are a missing factor in the poor senior equation. To illustrate this opinion, she noted that minority seniors don't come to lectures; they don't go the Hays Center (Champaign Park District). She can't explain why they don't take part in such activities, but she thinks Carle needs, through Faith Roberts, to work with parish nurses to reach out to the minority senior community.

As for the health-related senior issues, her response was, "You read the I Plan (a public health planning document). It [the most profound senior medical issue] is cardiovascular." Her suggested remedy reiterated her themes of life-long learning —"start early with health education," which would lead to prevention and also to her concerns about eligibility and accessibility of senior healthcare.

When the issue of "younger" and "older" seniors was posed, this public health nurse noted that one problem among younger seniors is that they aren't old enough for Medicare or Social Security, and many lack health insurance. She believes this is a big issue.

For all seniors, she explained that aging results in the loss of physical and mental abilities, a higher susceptibility to chronic disease, and the increased tendency to lose one's independence. She said, "Mike O'Donnell [Executive Director of ECIAAA and focus group participant] talks about this as aging safely in place." The concern, based in part on the factors outlined here, is for seniors, younger or older, to be safe in their own homes.

One major unmet senior need or gap expressed by this healthcare professional is that in-home personal attendants aren't paid enough—once they are trained, they are gone. "They can make more money flipping burgers." To help remedy this situation, she recommends paying a living wage to get them to stay. She said this constant turnover is very hard on seniors. Not only is it disruptive in general, and their care tends to be "hit and miss", but seniors lose trust in this in-home support which many need in order to stay in their homes.

Another gap relates to minority seniors, " Isolation of elder Afro-Americans is a problem." This nurse explained that minority seniors often do not have family support, that some families take advantage of their seniors, and that their neighborhoods aren't as safe as they once were.

Other gaps she sees are seniors getting food and transportation. She cited examples related to both of these factors, with seniors unable to go to a grocery story or take part in the Share program (a food program available to all ages) because they don't have any way to get there.

To summarize, this public health nurse was asked to identify the most important issue presented in this interview. "Poverty is the most important and then safety, feeling safe where you are." She returned to the theme of isolation and safety mentioned for minority seniors, but broadened it for all seniors, saying they don't leave their homes because they are afraid even to sit on their porches. According to her, drugs and crime have contributed to this feeling of lack of safety in many of the senior neighborhoods.

Other issues she thought should be recorded include the need for more senior housing, more mental health and dental care—"which are way under funded"—and an insufficient number of rooms for rehabilitation.

When asked to evaluate the biggest challenge in meeting these senior needs, this respondent quickly said "money." She continued, "I respect Carle for doing this [having the focus group and interviewing her about senior issues], but Carle… doesn't want to think outside the medical model. [We have] got to do something different here. We have the opportunity to do so much. We need a day care at Kraft, Carle could link with Stratton [elementary school] or partner with businesses and the U of I, but these need to be accessible. Can Carle have dental services [for seniors]?"