State of Illinois
Pat Quinn, Governor

Illinois Department on Aging
Charles D. Johnson, Director

Identification of Consumers' Long-Term Care Needs in Illinois

Prepared by
Paul H. Bennett
University of Illinois at Chicago
Department of Disability and Human Development
College of Applied Health Sciences

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In Appreciation

A number of people and groups were particularly helpful in identifying participants for the focus groups. A special thank you goes to the Illinois Association of Area Agencies on Aging and the directors of our thirteen Area Agencies on Aging; the Illinois Chapters of the Alzheimer's and Parkinson's Associations; staff of the Illinois Department on Aging, and members of the Services and Coordinated Point of Entry workgroups of the Older Adult Services Advisory Committee. Without their assistance, it would not be possible to thank the 240 participants who shared their personal experiences and thoughts concerning what programs and services would improve the quality of life for the older citizens of Illinois.

Executive Summary

This report is in partial fulfillment of the agreement between the University of Illinois at Chicago (UIC) Department of Disability and Human Development and the Illinois Department on Aging (IDOA) and IDOA's Centers for Medicare and Medicaid Real Choice Systems Change grant. It is the third in a series of reports examining various Illinois systems and processes directed to older adults to realize the goals of the Real Choice Systems Change grants.

For Illinois, the Real Choice Systems Change grant is to help our state build the infrastructure that will result in effective and enduring improvements to reform Illinois' long-term care system. This includes a shift in the balance from nursing home to home and community-based care. These efforts are being initiated in order for older adults, including persons with disabilities, to live in the most integrated community setting suited to their needs, to have meaningful choices about their living arrangements, and to exercise more control over the services they receive.

This report analyzes the results of twenty-four focus groups consisting of 240 participants representing:

- Older adults, defined as persons over the age of 60,
- Adult caregivers to older adults,
- Providers of Home and Community-based Services (HCBS) to older adults.

The discussions in each focus group meetings concentrated on:

- Access to HCBS services, particularly how programs and services are identified,
- Thoughts about current HCBS services,
- Resource gaps or programs and services that are needed in their community.

All focus group discussions were audio-taped and transcribed. Transcriptions were analyzed looking for patterns and themes. The data was also examined looking for similarities and differences between Illinois communities and amongst the three participant groups.

In general terms, the results indicate Illinois has a plethora of programs and services targeting older adults, but there are disparities between communities. For example, some communities have available transportation programs and others have none. Some communities offer a number of options in home delivered meals and others have extremely limited home delivered meal choices. Overall, consumers and caregivers spoke highly of most existing programs and appreciated their presence. These included publicly supported programs through the state and federal government, as well as private pay services. However, there were strident voices heard across the state expressing concerns relating to quality, hours of service delivery, availability and costs. There were reports of government funded programs and services having waiting lists and/or running-out of funds before all in need are able to participate. There were reports of persons reported to be slightly over income eligibility standards or not able to afford cost-sharing requirements. Private pay services were perceived to be expensive for almost all income brackets. Cost of services whether the expenses was to be fully or partially paid for by the consumer resulted in many whom self select-out of a program or accept less service than would appear to meet the presenting need.

Included in this report are quotes made by the participants that emphasize a point or theme. The themes that have been identified should be viewed as areas suggested by participants to which communities, organizations and groups should take in hand. This examination should focus on programs and services to be developed or current programs and services to be improved.

Methodology

Between July 2006 and April 2007, a total of 240 participants were recruited and participated in twenty-four (24) separate focus groups using a purposive sampling approach. Targeted sites were identified by contacting existing HCBS providers and service organizations across the state serving varied populations and likely to provide participants. The key researcher at UIC made contact with a variety of known sources who in-turn offered names of others to contact. Announcements were also made asking for assistance in identifying potential focus groups at meetings of the aging network of HCBS services. Examples of these targeted and known sources were the directors of the thirteen (13) Illinois Area Agencies on Aging, members of the Older Adult Services Advisory Committees and its workgroups, the Alzheimer’s and Parkinson’s Associations and a number of faith-based not-for-profit organizations with the particular thought of reaching consumers residing in congregant housing.

Once contact was made with a site’s key administrator or leader, each site was then asked to put together a focus group or groups representing one of the three (3) targeted populations of older adult consumers, caregivers or providers. Willing sites agreed to identify participants by reaching-out to either persons known to them who met the criteria for group participation or using a snow-ball sampling approach where one volunteer participant identified other volunteer participants.

A recruitment flyer was developed and given to the potential focus group sites for their recruitment of the volunteer participants. This recruitment flyer discussed the purpose of the focus groups and what would be expected of each participant. The key contact at each of the sites that agreed to hold a focus group made the arrangements for the actual focus group meeting. This included setting the time and location and the engagement of the participants. On-going in this process was confirmation of these arrangements with the researcher.

Actual focus group participants had no contact with the researcher/interviewer prior to the beginning of the focus group session. No incentives were used to identify or encourage the participant. A few of the sites provided refreshments during the focus group session at the expense of the site.

Each session began the exact same way with the researcher explaining the study and purpose of the focus group as indicated in the recruitment flyer. Subsequently, the researcher presented the Informed Consent and either read the document to the group or as the participants were reading the Informed Consent, summarized each section of the document whereby questions were answered, clarification provided and the request was made to sign the Informed Consent. Once the Informed Consents were signed by all participants, they were asked to complete a demographic worksheet. The purpose of this demographic worksheet was to obtain data on who was participating in the group in terms of four (4) variables of community, gender, race/ethnicity and income. Upon completion of the demographic worksheet, the tape recorder was turned-on and the discussion began. Once the discussion appeared to have covered the topic areas and no further comments were made, the focus group ended.

Each focus group session lasted about 1.5 hours and was tape recorded. The discussions in each focus group meetings concentrated on:

- Access to HCBS services, particularly how programs and services are identified,
- Thoughts about current HCBS services,
- Resource gaps or programs and services that are needed in their community.

Structured questions were used as a guide in each focus group. The specific questions may be found as appendices to this report. The researcher/interviewer did respond to the flow of the discussion and persons responses to questions were explored and clarified as needed.

Following the conclusion of each focus group session, the information obtained in the demographic worksheet was reviewed to provide to the researcher information on who were the participants in relationship to the variables. This information was used to target other sites and to obtain diversity in the sample of participants.

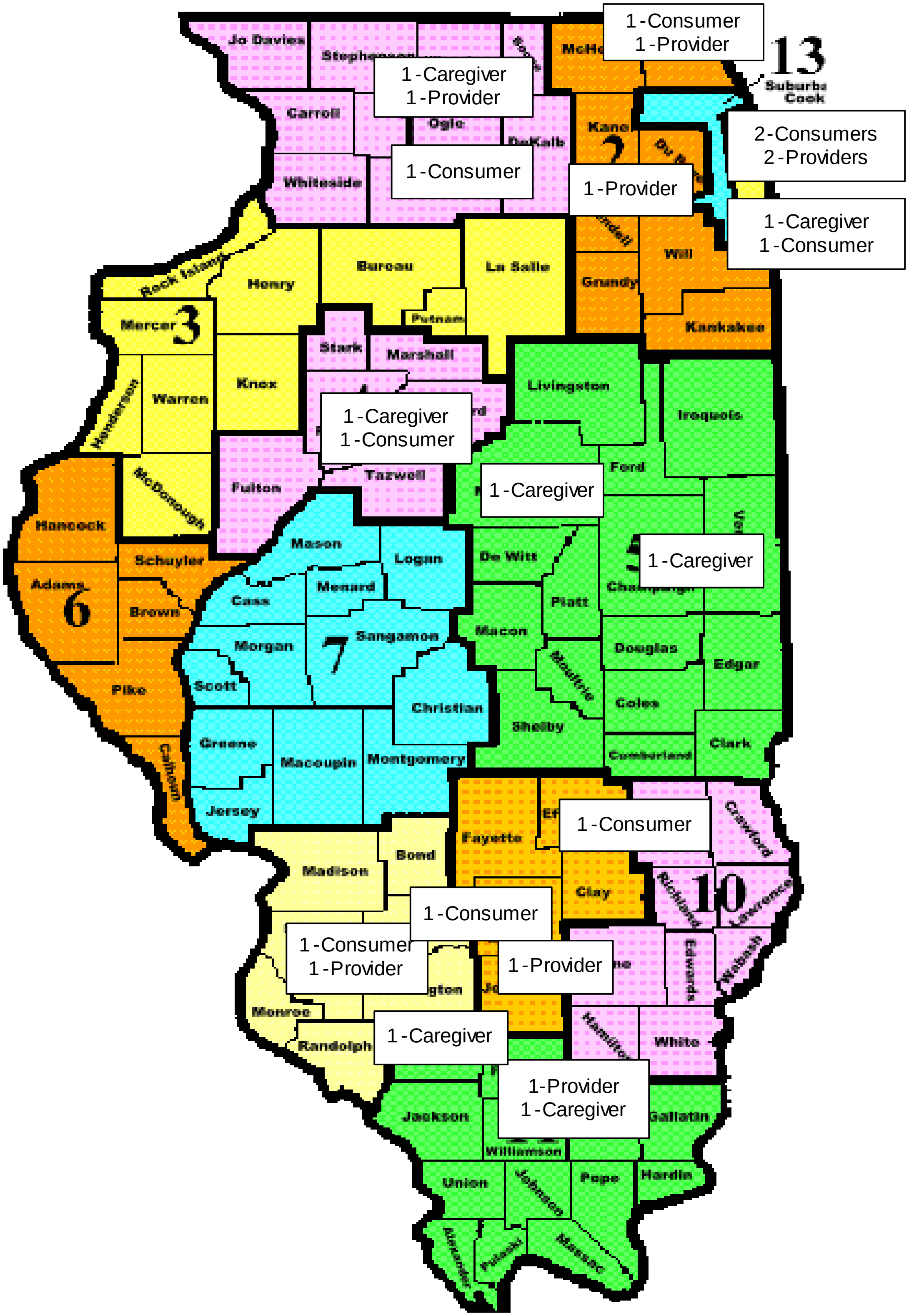
The audio tapes were transcribed using conventional methods of listening to the tapes and typing the dialogue. This was completed following the conclusion of many of the focus groups and by the end of the data collection period. By reviewing data from each interview immediately following the sessions, data collection was useful in subsequent focus groups to insure that critical elements learned were explored in subsequent sessions. Key concepts or themes that were identified from the transcriptions were labeled. A degree of significance was attributed to a particular labeled concept or theme based on its frequency.

All procedures involved in the research were approved by the Institutional Review Board (IRB) of the University of Illinois at Chicago. It should be noted that no risk to the participant in the focus group was identified possibly other than fatigue, and what could not be controlled were comments from other participants. Various methods were employed including keeping all records and audio-tape recordings in locked file cabinets to secure the identity of participants and to avoid contamination or theft. However, while no violation occurred, if it had, one could draw no linkages between the participation of focus group members and the audio tapes and transcriptions. In addition, the demographic worksheet had no participant identifiers on it. All of these potential risks and concerns were discussed in the Informed Consent.

Focus Group Sites

The following represents a listing of all focus group sites, including location. The word in parends indicates the types of group of focus group that it represents.

1. Addus Adult Day Care, Homewood, IL (Caregivers)
2. Alzheimer's Support Group in Peoria, IL (Caregivers)
3. B'nai B'rith Apartments, Peoria, IL (Consumers)
4. Calumet Park Seniors, Chicago, IL (Consumers)
5. Cardinal Bernardin Apartments, (Calumet City, IL (Consumers)
6. Chicago Department on Aging, Chicago, IL (Providers)
7. CLESE, Metropolitan Chicago, IL (Providers)
8. Clyde C. Jordan Senior Citizens Center, East St. Louis, IL (Consumer)
9. Congregant Meal Program in Mt. Vernon, IL (Consumers)
10. East Central Area Agency on Aging, Bloomington, IL (Caregivers)
11. Egyptian Area Agency on Aging, Carterville, IL (Providers)
12. Family Service of Champaign County, Champaign, IL (Caregivers)
13. Lake County Aging Coalition, Fox Lake, IL (Consumers)
14. Lake County Providers, Libertyville, IL (Providers)
15. Marillac House, Chicago, IL (Consumers)
16. Midland Area Agency on Aging, Centralia, IL (Providers)
17. Northeastern IL Area Agency on Aging, West Chicago, IL (Providers)
18. Northwestern IL Area Agency on Aging, Rockford, IL (Providers)
19. Northwestern Illinois Area Agency on Aging, Rockford, IL (Caregivers)
20. Our World Adult Day Services, O’Fallon, IL (Caregivers)
21. Senior Center in Oregon, IL (Consumers)
22. Southern IL Healthcare/Parkinson's Support Group, Carbondale, IL (Caregivers)
23. Southwestern VNA, Swansea, IL (Providers)
24. Western Clinton County Senior Services, Breese, IL (Consumers)



1-Consumer
1-Provider

1-Caregiver
1-Provider

2-Consumers
2-Providers

1-Consumer

1-Provider

1-Caregiver
1-Consumer

1-Caregiver
1-Consumer

1-Caregiver

1-Caregiver

1-Consumer

1-Consumer

1-Consumer
1-Provider

1-Provider

1-Caregiver

1-Provider
1-Caregiver

Participant Data

The following charts provide demographic data of the participants concerning variables pertaining to: Type of Group, Gender, Race/Ethnicity and Income.

Focus Group Participant Data				
	# of Providers Participants	# of Caregiver Participants	# of Consumer Participants	Percent of Total
White	60	58	55	72%
African American	6	10	39	23%
Hispanic	3	0	1	2%
Native American	1	0	1	1%
Chinese	1	1	0	1%
Japanese	1	0	0	0%
Korean	2	0	0	1%
Additional Asian	1	0	0	0%
Total	75	69	96	100%

No income data was asked of or collected from HCBS provider participants.

Annual Total Family Income for Consumers & Caregivers		
	Frequency	Valid Percent
Under $12,830 (Federal Poverty Standard for 2-person household	24	16%
Between $12,830 & $19,000	32	22%
Between 19,001 & $39,000	45	31%
Between $39,001 & $59,000	22	15%
Between $59,001 & $79,000	12	8%
Between $79,001 & $99,000	10	7%
Over $99,001	2	1%
	147	100%

Data regarding the age of the focus group participants was not collected. It should be noted however that caregiver and provider participants through their signature on the Informed Consent declared themselves to be at least 18 years of age and older, and older adult consumers declared themselves to be at least 60 years of age. Caregivers represented adult children caring for their aging parents or older adult spouses caring for a spouse with impairments. A number of the older adult caregivers were caregivers to a sibling.

Analysis

The discussions in each focus group were analyzed looking for patterns and themes in the responses from each of the targeted populations. These targeted populations were older adult consumers over the age of 60, caregivers to persons 60 years of age and older, and providers of HCBS services to older adults. The analysis included the identification of similarities and differences in each of the groups and these similarities and differences were categorized by geographic locations across the state.

It had been hoped that the analysis would identify specific needs in specific communities. However, the methodology used in the research design, specifically the use of focus groups to obtain the data, was in retrospect less effective than perhaps the completion of a survey to a large population sample. Yet, the focus groups provided a rich commentary from persons actively engaged in HCBS services. Saturation had also been reached whereby towards the end of the data collection, the same comments were heard from each of the targeted populations. Consequently, it is believed that the analysis provides critical information. It shows that older adult consumer needs are not so different whether a person resides for example in the Westside of Chicago or in rural Clinton, Illinois.

§ Community and Universal Disparities

There appears to be an array of programs and services offered throughout Illinois in addition to those programs and services that are statewide and offered in the same manner everywhere in the state. Comments regarding the strengths and weaknesses of the statewide programs were fairly consistent. However, across the state, all participant groups raised concern about disparities in local, county, privately sponsored programs and services or provided through the Area Agency on Aging. These disparities relate to capacity. As an example, a home delivered meal program in one area may be offered seven days per week, with two meals provided five days per week, yet in another area the home delivered meal program may only offer one meal per day, five days per week. Furthermore, in another community, there may be virtually no home delivered meal programs. In addition, one community may have established a waiting list for home delivered meals in response to a need for meals that is greater than the number of budgeted meals being provided.

Transportation was often cited as another example of having service disparities. Transportation was stated to be available in one area and in other rural regions there were no reported transportation programs. However, in the greater or more generalized region, these services were reported as being available. The analysis will speak to these services and issues in more depth.

Also a universal disparity, but expressed more frequently by consumers was not being able to afford a telephone. There was a concern of how they could reach-out for services, particularly in a time of crisis.

Access to Services

Questions for all three participant groups relating to access to services asked the participants to name services in their communities, how did they find out about these services, particularly if they were users of services and if they needed help now or in the future, how would they reach-out or access these services.

§ Word of Mouth

Regardless of type of focus group, the number one way Illinois citizens access HCBS services is through “word of mouth.” Repeatedly focus group participants spoke of speaking to a neighbor, a relative, friend or church member and hearing about resources for older adults. Many participants reported that they specifically reach-out to these people because of a perception that they will know something or be able to help.

§ Hospital and Medical Personnel

The second most common source for access to services was stated to be through someone at the hospital. Often times, this person was cited by consumers and caregivers to be their doctor. When questioned, this access to HCBS services usually occurred through contact with someone assisting with discharge planning, usually stated to be the hospital social worker or nurse. Focus group participants also reported calling the hospital if the need arose in the community seeking information about HCBS services. Providers spoke of older adults having some type of medical episode that necessitated referrals to the aging network of HCBS providers.

There were a number of other additional themes that emerged from the three participant focus groups concerning access to services. The following section summarizes the more frequently stated themes relating to how one finds out about services.

Themes Cited by Older Adult Consumers

§ Key Informant

Overwhelmingly, consumers that are currently receiving HCBS services or attend some type of formal program stated that a single source becomes his or her key informant for most information and a link to resources. Specifically, if the consumer attended a support group, then it was the facilitator or a fellow support group member who became this key informant. Consumers that were residents of congregant housing spoke of the Resident Service Coordinator (RSC) as the access point for information and services.

It was often difficult to discern if it was the person or the position of the key informant that was the source of access. For example, consumers had a difficult time separating the position of the RSC and the person that was in the RSC position. Consumer participants would state that “I go to Barbara with everything.” It appears that persons such as a RSC or the support group facilitator successfully engage the consumer with some minor assistance that subsequently leads the consumer to reach-out to this same key informant with a greater need. Also, if the consumer was satisfied with the information or help received from this key informant, then they would use this key informant again and again. It is critical to note that this key informant was described to have skill, knowledge and someone they could trust.

"Once you are linked with one group, then you find out about other services."

Key informants were cited to be fellow members and leaders in their church , a neighbor or friend. It was usually someone that was identified because it was known that they had a personal experience or knowledge of HCBS services. Additionally, consumers stated that they would simply ask if they made an observation of someone receiving services such as seeing a neighbor accept home delivered meals and then ringing the door bell to ask how these services were obtained.

§ Printed Material

Another frequently commented source of access cited by consumers was learning about HCBS services from printed material. They spoke of reading about a program or service in the newspaper. Newspapers were cited across the state; however it was more commonly mentioned by participants in the cities outside of Chicago and in the rural communities. The information seemed to be obtained more from an article or advertisement seen in community papers. Consumers representing lower economic participants referenced newspapers such as the *Pennysaver* or free papers or pamphlets obtained at the entrances to restaurants. Others mentioned articles in some of the faith-based newsletters such as the *Keenager* printed by the Archdiocese of Chicago.

Consumers appear to pick-up and read individual program brochures. Some of the participants came to the focus group session with a folder whose pockets were cramped full of Department on Aging, Area Agency, private pay and/or Medicare brochures.

Consumers expressed some negative comments about direct mailings of printed material. Many stated that they never read them or they get frustrated if the direct mailing did not pertain to them or after reading it, they decided they did not qualify. In the suburban areas of Chicago, consumers reported being bombarded, particularly with mail from doctors seeking their business and offering to bill Medicare. Consumers complained of similar mail from dentists.

It appeared that consumers picked-up the brochures in a number of places. Participation in health fairs were often cited, as well as, attendance at formal presentations. Actively engaged consumers appear to go to programs at senior centers or lectures and attend presentations at their church or community college. It is at these locations where they picked-up materials concerning HCBS services. The less actively engaged consumer appeared to obtain the brochure from their key informant.

Depending on a persons community and level of engagement, consumers that attend senior centers appeared to obtain their information from senior center staff, or from a rack of brochures placed somewhere in the senior center. More often cited in the suburban Cook County area was information obtained from their Township Office. Consumers spoke of being told by a key informant to go to the Township Office or they received some type of welcome packet that contained information concerning all of the township services or they received a township mailing that included information concerning HCBS services in their community.

§ Confusion on Where and How to Access HCBS Services

Relating where to access HCBS services, consumers appeared to express confusion concerning entities labeled as the "Department on Aging." This term was used interchangeably by consumer participants when it appeared they were referring to a number of organizations or groups such as IDOA, their local Area Agency on Aging (AAA) or the Case Coordination Unit (CCU). Consequently, when questioned, they shared many definitions.

"If your pipes are broken, you know who to call."

There were two clear exceptions to this confusion. Consumers residing in the City of Chicago knew "311" and the Chicago Department on Aging. The other exception appeared to be in communities where the CCU appeared to have completed a fair number of engagement activities such as presentations, lectures and outreach even with a roadside billboard. Consumers in Southern Illinois consistently named Shawnee Alliance for Seniors as the CCU and knew to call them as a starting point to access HCBS services.

§ Medicare Part D Enrollment

Perhaps in part due to the timing of the focus groups, consumers at every single focus group spoke about their Medicare Part D enrollment experience, and this was their point of reference to knowing where to go to for programs and services in the future. They stated that they would not have been able to enroll in Medicare Part D without the direct help from a key informant or representative of social service agency usually arranged for or provided by their local AAA.

Consumers were overwhelmingly appreciative of outreach efforts made by a variety of sources, but most often cited was their AAA. Consumers also stated that information obtained from some outside sources that they thought they could trust turned-out to be misleading and perceived it to be biased. These outside sources were cited to be insurance providers or pharmacies. There appeared to be a respect for the independence or neutrality of the AAA.

§ Other Commonly Shared Themes

Many consumers who reported that they had been to a nursing home following a hospital stay shared dissatisfaction about their personal experiences concerning access to information.

"No one told me I could get the therapy at home. When I found out I left (the nursing home) after two weeks."

Only a handful of consumers remembered speaking to a CCU representative, with most saying that they were told by the doctor or hospital staff that they had to go to a nursing home for rehabilitation. There was a sense that this time of transition from hospital to nursing home was a blur to them.

In addition, consumers who previously received HCBS services appeared to know best how to access services again or have services resumed if they had been in the hospital. However, consumers that were experiencing the need for HCBS services for the first time or did not have a key informant whom they trusted were more vocal in not knowing how to access services.

Chicago area consumers frequently mentioned their HMO as a point of access. This was not heard outside of metropolitan Chicago.

Finally, consumers expressed a desire that there be clarity in the names of programs and services. They wanted the name of the program to describe what it does.

Themes Cited by Caregivers to Older Adults

- Key Informant

In a similar fashion to consumers, caregivers most often spoke of identifying a single source who becomes their key informant for access to HCBS services and information. The key informant cited more frequently by caregivers were case managers, the support group facilitators, or staff members at a particular HCBS service such as adult day service or senior center.

The key informant may also be a place. For example caregivers who sought assistance from a social worker at a family service agency mentioned that agency as their source of information and access. However, caregivers spoke of having great difficulty initially identifying this one source or the right program or place for help. Again, similar to consumers, if the caregiver had a connection, then they used it to link to other HCBS services; otherwise they appeared to wander through a maze either on the Internet or by telephone until the “right” initial connection was made with someone they felt trust. Searching for HCBS services was frequently a totally new experience for them.

“You find the right service by luck.”

It should be noted that many caregivers spoke of obtaining excellent information and “I would not have know about . . . if it had not been for my case manager.” However in several caregiver focus group meetings there were comments of, “Oh, my case manager did not mention that program to me.” There was a sense that services were provided for the presenting need, but an assessment exploring an array of needs did not occur. At the end of almost 100 percent of the caregiver and consumer focus groups, participants stated that they had learned a great deal just by participating in the focus group.

- Printed Material

Caregivers, probably even more than consumers, collect brochures. Folders full of brochures were observed in the hands of caregiver focus group participants who were attending an ongoing support group. The caregiver participants in these support groups spoke of obtaining information from their peers and cited the support group as being a lifesaver in their ability to cope, manage, learn about and access HCBS services.

Older caregivers spoke of seeking information in the telephone book yellow pages. However, both the younger and older caregivers expressed concern about not obtaining clear information. There was a lack of clarity when it came to terms. For example, they too wanted HCBS services to be called by exactly what it was.

§ Internet

Caregivers that appeared to be younger than 60 years of age frequently cited the Internet as their first venue for seeking HCBS information and access. This was stated even though a frequent comment was that the information was confusing or not useful. Cited examples of confusion were trying to obtain information on local programs and the result of their searches was information about programs in distant communities from their own. There was also a frequent comment of disbelief when information was not found. In these cases, caregivers were usually searching for free or highly subsidized programs and benefits that just do not exist.

§ Confusion About Where to Access HCBS Services

On the whole and especially compared to older adult consumers, caregivers appeared to have a better definition of who they were speaking about when they used the term "Department on Aging." It was common to hear the caregivers speak of the AAA or the CCU. Again this knowledge was known due to their engagement with these organizations for help in obtaining HCBS services. They had personal experience with one of these points of access and this occurred often after their web or telephone search to find to these organizations.

§ Trust in Information Resources

Both the caregivers and consumers often expressed a high degree of mistrust of the information that was given to them. This concern surfaced in discussions related to several of the other mentioned patterns and themes. In many of the examples cited by caregivers, what appeared to be happening was that the information they received was indeed accurate. However the caregiver did not believe the message as stated previously because they were searching for something that was free, at low cost, simply does not exist, or appeared to have some mistrust of the messenger.

Themes Cited by Providers of HCBS Services

§ Networking and Engagement

Providers felt that the most effective means of engaging consumers and caregivers concerning how to access HCBS was their efforts to "Get the word out." These efforts at engagement frequently took place at health fairs, public speaking opportunities held at senior centers, houses of worship and support group meetings.

A few of the providers expressed concern about reaching the current and up-coming generation of older adults as persons not wanting to be identified as seniors. In contrast, consumers and caregivers asked that services be called what they are in order to avoid confusion.

"In Barrington, no one wants to go to a place labeled for the old."

Providers also spoke of direct mailings, but these were often done on their behalf by an outside source such as state government or a funder. Providers expressed great concern that these venues often lead to confusion and a deluge of telephone calls to the agency. It was felt that these efforts may create an interest in HCBS services, but should be more targeted or they as the provider would prefer to get message out to the public.

"People are too proud often times to say that they need help."

Providers felt that older adults had a strong desire to be independent and consequently, they may not ask for help. In addition, they may ask for help from only a few people that they felt they could trust.

Providers also validated that consumers who had limited to no experience with HCBS services knew very little about HCBS services. They felt that consumers, as well as caregivers, had beliefs that there were more resources available or that Medicare would cover long-term care costs.

"We're constantly surprised that people do not know about various government programs."

- Medicare Part D Enrollment

Many providers spoke of reaching more consumers than normal during this last year because of Medicare Part D enrollment efforts. This was seen as a separate activity from other engagement and information sessions. In general, this massive outreach effort was viewed positively, but framed with a sense of being overwhelmed by the task.

Finally, in a number of communities, providers spoke of using billboards to reach consumers. These efforts appeared to be in large measure associated with a recent elder abuse reporting campaign. Also, the efforts of postal employees, public service and utility personnel and Social Security offices were frequently cited as effective means of identification at-risk consumers in need of HCBS services.

Thoughts about Current Services

Questions for all three participant groups related to their thoughts about current services, and focused on their list of programs and services that was generated in the first set of questions relating to access to services. Participants were asked to share their impressions about these current services and to offer suggestions that would make these programs and services more responsive. Participants were also asked to think of program and service improvements under the framework of alternatives to nursing home placement. This concept was reinforced in several ways as participants were essentially asked to put themselves in situations where they would be seeking assistance to avoid nursing home placement.

In terms of a general response and as previously stated, all groups reported an array of programs and services. These lists included community lending closets to formal in-home care and senior centers. Participants were able to provide commentary about the strengths and weaknesses of these programs and services. However, there was a feeling that the greatest weakness was in disparities relating to program capacity that exists within and between communities.

Themes Cited by Older Adult Consumers

Consumers who are current users of services had a lot to say. Consumers that were in good health and perhaps attended only a senior center or ate at a congregant meal site had limited ability to share their thoughts concerning current services. A periodic statement made was that, "Oh I have heard of home delivered meals, but have never used it myself." Another example was from a few of the more rural areas, or smaller cities and towns, where consumers stated that they knew of transportation resources, but again were not users. One consumer in the Bloomington, Illinois area stated that she had seen the bus go-by, but had never been on it. However, many of the older adult consumers had been in a position of previously being a caregiver to a now deceased parent or knew of family, friends or neighbors that were current or past recipients of HCBS services.

- High Level of Satisfaction With Current Services

Consumers that participated in a HCBS service such as attendance at the senior center or ate at a congregant meal site had very positive comments. Participants expressed a high level of satisfaction and appreciation of what was offered. This seems logical, that one would not participate in something that they did not like. For example, participants in the senior centers felt that there should be more senior centers and congregant meal site participants had concern that the program was at-risk of elimination. There were a couple of participants that admitted to benefiting from Elder Abuse and Neglect services and spoke of how helpful it was to be able to move out of unhealthy situations.

In terms of government programs not provided by the IDOA or through grants from the AAA's Older Americans Act funds, consumers spoke highly of Medicare certified home health care and especially of Hospice. No one cited any negative experiences about Hospice care and consumers repeatedly gave testimonials on its behalf. There were some concerns expressed that Medicare in-home health was limited or the outcome of the care was less than hoped. Concerning Medicare Part D, consumers expressed overwhelming confusion about the program being different from traditional Medicare Parts A and B in terms of provider selection and its enrollment processes even though there was generally a high level of satisfaction with the benefits of the program.

- Array of HCBS Services

In generating their list of programs and services, consumers often cited those sponsored by community groups and faith-based organizations. In many communities they spoke of lending closets, food pantries, nursing homes, home care, counseling, lawn services, friendly visitors, benefits counseling, legal assistance and transportation. They spoke of many hospitals providing wellness programs, support groups, lectures and outpatient services. Stated by consumers in the suburban Cook County were programs provided by township offices.

"There are a lot more activities than there use to be."

In many communities, consumers expressed concern about a lack of hospitals and access to emergency care. Universally across the state, there was dissatisfaction with hospital emergency room care. In Southern Illinois, consumers reported hearing about persons sent from one emergency room to another and waiting for hours in an emergency room. A couple of consumers suggested that one should always go to a hospital in an ambulance otherwise you wait and wait for care.

Many consumers spoke of volunteer experiences and civic engagement opportunities. If the consumer was a resident of a senior building, they most often cited volunteer opportunities provided or arranged by their residence. Another very common opportunity for volunteerism was cited to be available at the hospital. A comment heard several times from consumers in Central and Southern Illinois was the mention of a parish nurse program as a wonderful resource to both volunteer and from which to receive service.

Similar to volunteer opportunities, residents of senior buildings spoke highly of the programs and services offered at or arranged for by their residence. Examples of services included on-site banking, mobile post office, and visiting doctors, particularly podiatrists. The RSC appeared to be the link to everything from finding a tailor to arranging a Power of Attorney.
Consumers felt that senior centers were under-funded and that participation was an integral part of their lives.

Consumers expressed mixed opinions about the quality of care in nursing homes. There were some positive comments, particularly in relationship to temporary stays. No one stated that they wanted to live there and a few consumers and caregivers spoke of bringing family members out of the facilities. Participants expressed concern that many times persons in the facilities are left alone.

"There are lots of things that you would curl your nose at, but some of the Certified Nurses Aides are wonderful."

Consumers residing in rural communities expressed themes of self-reliance, independence and interdependence. Rural consumers more frequently expressed an ability to manage on their own or state that they could receive help from family. Many of their comments appeared to present ambivalence about the role of government in providing care. While there was deep appreciation of the value of a congregant meal, or home care, there were also comments or perceptions of potential negatives of government interference in what was perceived to be their personal responsibility.

- Lack of Choice at Hospital Discharge

Consumers in many of the groups felt that upon discharge from the hospital they had not been informed of HCBS options. A common statement of consumers that had experienced a hospitalization stated that upon discharge they were told that they were going to a nursing home. This issue surfaced in discussions concerning access to HCBS services and in relationship to discussions about nursing homes as a current service. Consumers appeared to be seeking choice from knowledgeable personnel that would provide them with options.

§ Housing Options

"We need a 'Habitat for Humanity' for seniors to remain in their homes."

In some communities, consumers spoke about limited alternative housing options or the alternative housing options were too expensive to consider. Consumers felt that there needed to be affordable condominiums built so that if they chose to downsize from their currently owned home there would be an affordable option. Also, in regards to houses, apartments and condominiums that were being built, these developments were not being built with an aging population in mind.

"There should be something between the subsidized housing and the high end."

In a number of focus groups, consumers spoke of wanting walk-in showers and wider doors as part of new construction. One consumer spoke of having difficulty convincing the developer of new construction to change the design and make it friendlier to the physically disabled. She stated that she was successful and that a year after moving in, her husband had a stroke. If she had not insisted on these changes, they would have had to move.

"We added a ramp, and that has made a world of difference."

A similar concept regarding home and community was a satisfaction with home modification programs and housing rehabilitation. Several consumers spoke of the benefit of home modifications and that more money was needed. Consumers stated that it was due to some minor home modifications, which now allowed them to continue residing in the same residence. Consumers also spoke of needing home repairs such as new porches and railings, gutters and sidewalks.

"We live in the house that Columbus built."

§ Quality of CCP In-home Care

There were a number of issues expressed by older adult consumers who were recipients of the IDOA's Community Care Program (CCP). While there were consistent expressions of appreciation and satisfaction, this contentment appeared to develop after an initial rocky period of both experiencing a number of in-home service workers and finding the right match between the consumer and the in-home care worker. The satisfaction with the program appeared to happen after there was this period of frustration.

"I get three hours of service (in the plan of care), but they give me only one hour of work."

Across the state, older adults consumers who received CCP homemaker service were quite vocal about the quality of the service. They felt that more training was needed concerning the tasks to be done and sensitivity to aging and the older adult. Consumers spoke of inconsistencies in the skill levels of the workers. There was a feeling that higher skilled, better trained and more highly committed individuals should be employed.

A consistent comment made by older adults was their desire to be treated with respect and dignity and not as children. Consumers felt that many of the younger in-home workers came to their home with an attitude. They felt that training needed to include the impact of attitude on the consumer. They expressed a desire for the in-home care worker to do the job and to know what to do regarding how to clean, cook and provide personal care. A frequent comment was the desire to have some choice in the selection of the in-home care worker.

"It would be nice if people could screen their caregiver."

Consumers expressed a concern that once a "good" worker was found, she would be re-assigned to a different client or she left the agency. The consumer had to now find another worker and begin this process of relationship building and trust again.

Extremely passionate comments referred to a fear that the in-home care worker would steal from them. This was a more frequent common from urban Chicago, East St. Louis and Rockford and suburban Cook County consumers. One East St. Louis consumer stated:

"I prayed to the Lord to give me someone I could trust."

This woman appeared to be in her late 70's. She stated that God had answered her prayers by sending her a home care worker that was older than her, but in better health, and this relationship was working-out well.

Consumers, across the state who were not users of in-home services over and over again expressed concern about gaps in HCBS services on the weekends and evenings. There was a repeated theme of, "I wonder how she manages at night," and "I know a woman that spent the evening on the floor." Consumers felt that night care was needed.

§ Trust, Fear and Safety

Related to the quality concerns of their in-home care worker, consumers expressed feelings of being vulnerable and a wanting to feel safe. As stated, but framed a bit differently was the theme of consumers in the urban and suburban areas of trying-out several workers before there was a fit. They cited a concern about needing to watch the in-home care worker and being at-risk of theft.

Not specifically related to in-home care, but related to the issue of trust, there was a general theme amongst lower income older and urban elderly of not feeling safe in the community. One East St. Louis consumer reported she felt a need to keep a gun at her bedside because she was a frequent victim of theft. She not so humorously reported that she placed a sign in front of her house implying that she had a burglar alarm system and “They stole the sign!”

Concerning vulnerability, in most of the urban and suburban focus groups consumers expressed fear of sharing information. Most often this was cited in relationship to applying for programs and services, and more so if they had been approached by a service provider. One consumer stated, “They ask you question after question and then tell you that you do not qualify, couldn’t they have told you that at the beginning?” “How did they find me and why did I have to share so much personal information?”

- Transportation

The first choice of consumers across the state is drive their automobile. Urban consumers more frequently reported using public transportation. For those consumers that have difficulty, regardless of the community felt that transportation services were limited and not always the right service or at the right time. Several times consumers expressed a desire for a more on-demand transportation program that would be available when they wanted to go. On the other hand, many consumers who attend senior centers or congregant meal sites reported that if there was no transportation to the program, they would not have been able to attend.

Consumers stated that an at-home pick-up to a medical appointment was great, but it would be better if the service offered door-to-door verses curb-to-curb services. Assistance with escorting out of the house or apartment was desirable. They also reported having difficulty negotiating outside stairs and finding the doctor’s office once at the doorstep to the building. Many consumers reported dissatisfaction with having to call early in the morning for the curb-to-curb transportation. Similarly, consumers were asking for help with carrying the groceries into their kitchen after the ride to the grocery store.

- Nutritional Services

Across the state there were mixed reviews about the quality of home delivered meals. Consumers interviewed were for the most part temporary users of the service. They stated that it was following a short-term hospital stay. Meals were reported to have been most welcomed and appreciated. Many wished that the meal had been hot or of a better quality. A few consumers reported to “cook-over” the food to make it tastier or if they had been well enough to put a frozen meal in the oven, then they would be well enough to make something. There was a general consensus that consumers, who were in need of home delivered meals, desired the delivery of a hot meal on a daily basis over the delivery of a frozen meal two to three times per week.

§ Eligibility Thresholds and Co-Share in Government Programs

While the frequency of comments related primarily to eligibility guidelines for IDOA's Community Care Program (CCP), there were a number of comments that appeared to relate to eligibility thresholds for all programs.

"I am just $200 over the limit for most programs."

Consumers reported that they may be under the asset eligibility threshold for CCP which is currently at $17,500, but they self-selected themselves out of the program because of inadequate incomes to cover the co-payment or cost share required for incomes over the Federal Poverty Index. The current Federal Poverty Index for 2007 is currently at $10,210 per year for a one person household and $13,690 for a two person household. Older adult CCP consumers are required to make a co-payment or cost share towards the cost of the CCP service on a sliding scale based on need, hours of service and the income perceived, by rule, to be available over the Federal Poverty Index. Consumers viewed these requirements along with all of expenses of life that include food, medical costs, utilities, rent/mortgage and transportation which are theoretically included in the Federal Poverty Index.

§ Cost of HCBS Services

Regardless of the location in the state or the socio-economic status of the consumer, they felt that private pay services were too expensive. Consumers feared that existing resources would be depleted and wanted to feel assured that there was something for a rainy day. Consumers reported feeling financially squeezed by the high costs of living, and subsequently they would chose to do without a program that required them to pay or as stated to cost share. Chicago consumers spoke of a gap between their income and expenses. One stated that there should be a "living subsidy."

"Services are simply too expensive. You save and you think you have enough and then before you know it, the money is gone."

Many consumers spoke of forgoing home repairs, not using air conditioning in the summer or turning heat off in the winter as measures to cut living costs.

§ Medicare Part D Enrollment

Concern about Medicare Part D enrollment was mentioned in 100 percent of the consumer focus groups. As mentioned previously, most consumers expressed a high level of satisfaction with the quality of supportive counseling for enrollment that was provided in a number of settings to them from AAA representatives or from their key informant and for the benefits of the program. However, there was an equally high level of dissatisfaction with the enrollment process and particularly the design of the program. Consumers expressed that the program offered too many options and felt a familiarity with traditional Medicare Parts A and B and its single intermediary. Universally, consumers stated that they might not have enrolled without the assistance of family, AAA, senior center, social service provider or their identified key informant. The significant portion of the dissatisfaction appeared to be generated from consumers that had been previously been enrolled in Illinois' Senior Care Rx program and were confused about the interface between the programs. There was also concern about the varying co-payments between plans, and there were non-specific concerns expressed by consumers who had what they perceived to be a satisfactory medication program prior to enrollment.

While the purpose of the focus groups was not education of programs and services, there usually were one or two consumer participants that said they had not enrolled and it resulted in questions by the group wondering whether they should have enrolled, the penalties and uncertainty of the continuation of current benefit programs. There appears to be a need for on-going education with current insureds as well as for new enrollees.

§ Community Disparities

Consumers expressed concern about service disparities between communities. There were comments made such as, "If I lived in Boone County, I could get a ride." Similarly, there were references made by consumers in the East St. Louis area and from focus group participants that resided quite a bit east of St. Louis in rural Illinois communities. These consumers were seeking transportation programs to take them to their doctor in St. Louis, Missouri. The more mobile consumer who had social supports stated that someone was able to take them, but the more isolated consumer felt that current programs did not fully meet their needs. This disparity was identified as a gap based on the geographic location of the consumer and where they needed to go. Sometimes it was framed as the bus stop was in an inconvenient or inaccessible location.

Themes Cited by Caregivers to Older Adults

In large measure, caregivers named similar lists of HCBS services as consumers. They were most articulate about those programs and services in which they used to supplement their caregiving responsibilities. Many of their concerns were similar to those expressed in the consumer groups.

§ Eligibility Thresholds and Cost Sharing in Government Programs

Similar to consumer concerns, caregivers to older adult consumers felt that eligibility thresholds and cost-share requirements prevented access to needed services. These were more commonly reoccurring themes amongst the middle and lower middle socio-economic class focus group participants.

There were additional comments that some of the government programs and services, particularly targeting home improvements and retrofitting took into consideration the income of the caregiver in a shared housing situation, when the older adult would be the beneficiary of the program and/or service. They felt this practice to be unfair. In general, caregivers in the same way as consumers felt that costs and fees associated with government services and unrealistic eligibility thresholds were barriers to accessing home and community-based resources.

- § Compensation for Caregiving

"We only make $20,000 per year."

Caregiver focus group participants primarily from lower socio-economic representation expressed concern of the high costs they experienced being caregivers. This issue was most often cited when the older adult resided in the same home as the caregiver. There was concern that while they accepted this caregiving responsibility, they were looking for compensation. One caregiver, but echoed by others stated that "It would cost the state a lot more if my mother was in a nursing home." There were many stories shared by caregivers of relatives juggling caregiving responsibilities and stay-at-home caregivers who felt they should to be working outside of the home because of a lack of a living wage and need for benefits. However, these caregivers felt that they could not work outside of the home because of the caregiving tasks.

"I could not leave my mother alone, so I had to quit my job."

- § Increase Need for Respite and More Hours in Current Service Packages

Caregivers of older adults voiced similar concerns as the older adult consumer concerning evenings and weekend services. Caregivers repeatedly expressed needing HCBS services expanded to evenings and weekends and more respite options. Caregivers whose parent or spouse attended adult day services spoke of a high level of satisfaction with the program. Additionally, caregivers who were participants in support groups repeatedly stated that they would not be able to physically or emotionally cope without the information and support received as a participant. There was a repetition of the benefit and desire for more support groups.

"We need more support groups at various stages, not simply for the newbies."

A repeated comment by caregivers of adult day service participants was that this service gave them personal time to do everything from sitting down to pay a bill or going to the beauty shop. Weekday support group participants desired to attend support groups on the weekends, but felt they could not because of the lack of available programs that offered supervision on the weekends. The identified gap in many of these types of supportive services was again expressed in terms of services not being there on the weekends, evenings, two and three day respite, one to two week long periods of relief and emergency situations.

- § Caregivers Need Caregivers

Aligned with the need for increased respite, evening and weekend service; caregivers spoke of working a 24 hour day, seven days per week, and 365 days per year and requiring emotional support, as well as physical support. There was this general theme expressed by all caregivers that they were tired. Over and over again caregivers spoke of working during the day and coming home to work all night caring for a parent. Many stated that if it had not been for a temporary assistance from a daughter or grandson, then they would not be able to continue with their caregiving responsibilities. As previously stated, caregivers particularly in the lower socio-economic groups spoke of giving up a job or having another relative give-up a job to stay at home and provide one-on-one care. While the caregivers acknowledged that they had made a choice, there appeared to be an underlying resentment by the restrictions that caregiving made on their lives. There was this sense of wanting to feel appreciated.

"If my daughter was not available, I could not go anywhere."

Another frequent theme expressed by caregivers was that the responsibility of providing care to a parent generally rested on one child verses all of the children. Again, this responsibility appeared to be somewhat by choice, as caregiver participants spoke of having taken their mother out of the nursing home because they were dissatisfied with its care, even against the advice of siblings.

"It wears on; I am in my 70's and never thought
I would be taking care of my mother in her 90's."

In addition, many caregivers spoke of being caregivers to two or more people. The caregiving might be to a spouse, a sister or brother or adult child. There were also a number of older adult children who were caregivers to their older parents. While they did not appear to be asking for a particular program or service, they appeared to seek acknowledgement and relief.

§ Parity Across Programs

Caregivers expressed program capacity and disparities between communities in a slightly different frame. Caregivers who did not share this dual responsibility had little knowledge of programs targeting other population groups. The concern about parity between programs was expressed primarily by caregivers who were caregivers to older adult parents and to younger disabled children. These would be persons sandwiched between the generations, and who had personal experiences and an awareness of differences between the state's programs for these two populations. However, the younger disabled person was not consistently an adult child, but was cited to be a younger physically or mentally challenged sibling. In general, these caregivers appeared to appreciate the in-home care worker for under 60 year olds' availability of more hours and for personal care tasks particularly in relationship to continence issues.

"We need parity with the non-elderly disabled.
What is the difference between 59 and over 59?"

Caregivers were especially challenged by resources in the rural areas. Some of these comments were made by long distant caregivers or from persons that lived in more urban areas, but whose parent remained on the farm. While they had no specific recommendations, they were quite frustrated.

"My Dad insisted on living five miles from nowhere."

Themes Cited by Providers of HCBS to Older Adults

Providers were the most adept at naming the array of HCBS services. They added to the consumers' lists to include information and assistance, elder abuse, money management, community action agencies, personal emergency response programs, senior companion, private geriatric case management and the Retired Senior Volunteer Program.

Primary concerns of providers related to increases in the costs of living. These increases were affecting the older adult consumer, as well as the provider agencies and its personnel providing the care. A provider council group serving Lake County and representing other parts of Northeastern Illinois spoke of older adults living in Barrington, Illinois that were forced to downsize their homes due to insufficient incomes to meet living expenses. Several providers in that area speculated that some of the movement by older adults to warmer climates occurred in truth because of the need to take cost saving measures.

§ Quality of HCBS Services and Workforce Issues

In large measure, CCU providers raised concern about a lack of quality in the delivery of CCP in-home care, but all providers expressed concern about a lack of home care workers and their abilities to deliver specific services. Many of these concerns were linked with funding, home care worker turn-over and the ability of the provider to hire and retain home care workers because of their wages and lack of benefits.

"They can't get someone there on Wednesday at 2 p.m., let alone on Christmas Eve."

For example, providers cited problems with the delivery of personal care by the home care worker and trying to find someone to do tasks such as medication management, eye drops and other tasks that are performed by non-licensed people everyday. However due to regulations, the home care worker is not allowed to perform these tasks.

"Our case managers develop a beautiful care plan, but you are in luck if you get a live body in there that is not sleeping on the job."

There were other issues cited as challenges to the delivery of the plan of care. Particularly in Northwestern and Central Illinois case management representatives spoke of having too many provider agencies resulting in no one agency able to meet the needs of clients. It was their belief that the work was being spread too thinly amongst all provider agencies. Others spoke of simply getting a homemaker out to the rural communities because of a lack of transportation. Inadequate transportation was cited as being a problem for both the older adult and for his/her receipt of in-home services.

"It is devastating in the rural areas where we often tell people that we simply cannot serve you."

§ Program Funding Levels Effecting Capacity

In a somewhat similar manner to consumers and caregivers, HCBS providers who are reliant upon government funding stated that their budgets were stretched to the maximum. This was stated regardless of what service was being provided. It was also heard across the state. Repeatedly stated was whatever cost cutting measures could have been done to reduce expenses related to service delivery, had been done. It was a feeling that allocations towards HCBS needed to be increased in order to meet current needs, let alone expansion of services. Existing dollars were impacting the capacity of programs.

In many of the rural communities across the state, providers repeated sentiments that they feared continued funding was at-risk and would "go away." Providers stated that the need appears to be growing, but the local agencies were being asked more and more to fill gaps in funding due to reduced or flat revenue streams and increased costs of service delivery. A number of providers felt that it was not necessarily the system that needed more money, but money needed to be prioritized to HCBS services over nursing home care which was perceived to be more responsive to the needs and desires of older adults.

"They need everything from ramps to furnaces to roofs."

CCP providers felt that reimbursement rates for the state programs all needed to be re-evaluated and raised. This was cited a number of times by CCUs and Ombudsmen. Several largely rural case management agencies stated that we simply cannot respond as we used to do. This was attributed to few rate increases and the need to have staff assume more responsibilities.

"We have not gotten a raise since forever."

In addition to concerns expressed by CCP in-home care providers about the funding, non-home care providers raised the issue of inadequate funding of in-home care workers and its impact on service delivery. Travel costs and the need to provide a living wage were frequently cited as problems. It was reported that home care workers are finding it too expensive to drive their car to get to the home of a rural client and consequently it was perceived that they refused to accept the rural older adult client.

Representatives of CCP home care providers that crossed rural and urban settings stated that homemakers serving rural areas were often persons from dual income family situations, while the urban homemaker was more likely to be trying to live only on the salary of the home care worker. The outcome was that they simply could not make it on the wages being provided. They frequently were reported to have no health care benefits and consequently, it became a challenge to hire and retain staff.

"Many do the little extras such as driving Helen to her grand-daughter's birthday party in Timbuktu."

On the other hand, many of the HCBS providers spoke highly of the dedication of their workers and that they worked beyond the call of duty. Cited examples included home care workers that checked-in on their clients on the weekends and holidays on their own time.

§ Program Capacity and Community Disparities

Many of the provider focus group participants had contracts with their AAA and IDOA to provide HCBS services, particularly CCP. They spoke of similar disparities between locations that were cited by consumers and caregivers. There appeared to be a general tone in their comments that programs were fundamentally on-target and were making efforts to meet consumer needs. However, the home care providers and CCU representatives had similar concerns and framed the disparity concerns from their perspectives. The CCU representatives were perhaps more passionate about consumer concerns in the delivery of services and the home care providers focused on their workers.

In general, all HCBS providers spoke highly of existing services, but emphasized the need for more options in services and more dollars to offer flexible plans of care responsive to individual consumer needs. At several provider groups they singled-out the need for more public health nurses.

"Not that we have gaps, we have a capacity problem."

In particular, the Northeastern Illinois providers stated that communities offer an array of programs and services, but there was a gap of parody between communities. This related to programs capacity and the scope of services. It was stated that "No program has the amount of money it needs to adequately provide its services and meet the needs."

Similar sentiments were echoed in Northwestern, Central, Southern and Southwestern, Illinois. The Northwestern, Illinois providers added that there needed to be better efforts to integrate services suggesting more of a boundary and locality driven concern. Again, they too cited, Boone County has having a transportation program, but problematic if the older adult needed to travel to Rockford for medical treatment.

"What is frustrating is that every year the need grows and this past year we had over 175 people waiting for home delivered meals."

A number of programs were cited as having unique parity and capacity issues. The frequently cited programs and services are discussed in more detail.

- Home Delivered Meals and Transportation

  Home delivery of meals was cited as having significant service delivery boundary and funding concerns. One Northwestern, Illinois provider shared an example of saying to an older adult, "Oh, we could get you a meal if you lived in Sycamore, but since you live in Genoa, we're sorry." Southwestern, Illinois providers expressed concern that Washington County was in the process of closing its one meal program. Rural providers across the state asked that consideration be given to seven days per week hot meals. They cited the meal delivery was seen not simply meeting older adult nutritional needs, but the daily contact was important and suggested that the delivery itself reminded the older adult when it was time to eat.

  Providers felt that more home delivered meal diets were needed, but since little choice was being provided, physicians were choosing from the current list verses what might be in the best interest of the health requirements of the older adult.

Providers shared similar comments concerning transportation needs. An example that was cited was that the older adult may not simply need the ride to the grocery store, but again someone to assist with shopping for the groceries, carrying the bags and putting the groceries away upon return to the home of the older adult.

- Mental Health Services

Across the state, the availability of mental health services particularly for the homebound older adult was stated to be extremely limited or a service gap. The Gero-Psych Initiative offered in several areas was cited as a best practice model. In addition, providers who target the non-English speaking older adults spoke of a gap in mental health services and particularly the need to provide supportive counseling concerning depression to this cohort of the population.

- Senior Centers

Rural providers raised concern for the future of senior centers. A number framed the issue in terms of the functionality of the older adult. It was stated that well older adults are able to and want to go to mainstream programs offered by park districts and health clubs. The frail elderly living in the community are too impaired to attend the traditional senior center. Providers expressed concern that the community residents they were seeing were more impaired. Ideas suggested more consideration of finding ways to bring senior center programs and other HCBS programs to the consumer verses having the consumer go to a program location such as a senior center building. In response, a couple of the senior centers spoke of diversifying their service and client base and moving away from the perception of being a center for older adults.

Service Gaps

All participants were asked a series of questions that were somewhat similar to service improvements, but focused on defining services that were simply not available in their respective communities. These questions were again framed from the standpoint of alternatives to nursing home placement and asked the participants to put themselves in the position of identifying what they would need to avoid nursing home placement. Included in these questions was a discussion of what would make life better, more pleasant or enjoyable. This was often stated to be a wish list of programs and services that would help with diversion from or prevention of nursing home placement.

The responses to service gap questions were most frequently stated as areas where current services needed improvement. In general, it was felt that HCBS services need to be more consumer and caregiver friendly. As stated in the previous sections, all categories of focus group respondents felt that Illinois offers an array of services. There was a feeling that if one had available funds, you could access whatever HCBS services needed regardless of your location, but there were capacity issues related to a limited workforce and funding. However, transportation was probably the most frequently cited service that may not be available at all in rural areas. Transportation was also cited to be too limited in taking consumers to the locations where they needed to go.

Service Gaps Cited by Consumers

§ Desire to Grow Old at Home and Home Maintenance Tasks

Consumers had a repeated theme of wanting to remain in their own home. Consequently, whether the participant was low income or representative of a higher socio-economic bracket, urban or rural, the gap was trying to find assistance that could be trusted and to do the small daily tasks or home maintenance projects. Consumers reported that it would be nice if someone was around to help with "little things." These were defined in large measure as changing light bulbs, putting in a railing, snow shoveling, fixing a broken step, or fixing a screen door. People felt that it was difficult to find a handy man for home maintenance activities and equally difficult to find someone they could trust. While certain services provided by senior centers and their staff or from the individual that they identified as their key informant were identified as helpful, consumers repeatedly identified finding help with home maintenance tasks as a service gap.

This desire to grow old at home was cited in discussions about housing and what if they had to move to an independent living retirement community or assisted living.

"I do not know about you, but I do not want to put on earrings and pantyhose just to have a cup of coffee."

§ Trust, Fear and Safety

The concerns expressed primarily by older adults who were representative of lower socio-economic status and more urban dwellers often had an undertone of fear, vulnerability and uncertainty. It came up in conversation, as stated previously in a number of areas in relationship to access to service, assessment and service delivery. Their concern paralleled some of the anxiety expressed by consumers in relationship to improvements needed in HCBS services and in particular CCP. Consumers also stated this worry and feelings of being at-risk by unknown persons that came to their home. These persons could be professionals, service personnel or trades people. The consumers found it difficult to identify a specific service that would meet this gap, except through addressing the delivery of all HCBS services and in environmental design.

"You asked me about my wish list; it is to live the rest of my life without fear."

This trust, fear and safety appeared to surface in some ways as a conflict between wanting to be independent and also not wanting to be alone. There was mention of more the need for security presence in the community and as stated previously, the need for better training and sensitivity of all professionals involved in HCBS services.

There were a few specific gaps that were identified. The most commonly mentioned gaps were:

- § Medical Specialists in Rural Communities

Consumers in rural areas stated that access to medical specialties and pharmacies that were open after normal business hours was a service gap. Many consumers in Southern Illinois spoke of going to St. Louis for their all medical care and especially care from a specialist. This gap was heard significantly less where a metropolitan center was nearby or perceived to be not too far away. For example, consumers in Chicago and its suburban communities mentioned about going to some of the large medical centers and getting a ride from family or friends to get to these facilities.

- § Affordable Dental Services

Affordable dental services were a common request. A gap was identified in the area of routine dental care. This was heard more frequently in the suburban areas where people stated that the free dental clinics were too far to travel.

Service Gaps Cited by Caregivers

- § More Respite Care and Emergency Respite Care

"I have to do everything. I have to do the inside and the outside,
everything that Frank use to do and I am 81 years old."

The most frequently cited service gap by caregivers was the need for respite care. As previously stated, caregivers are tired. There were several statements made by consumers who had received respite through an Area Agency on Aging program, and they expressed deep appreciation. A model of a cash grant given by the Southeastern Illinois Area on Aging received high praise.

"The week I (a caregiver) spent in the hospital was wonderful."

However, a gap that was identified across the state and across economic groups was no formal program or service in response to a need for emergency respite. Caregivers appear to be looking for a respite care option where they could drop off their spouse or parent and know that they would be safe and well taken care of by persons that they could trust. The examples cited were caregivers that needed to go to the hospital for their own need and not knowing what to do with an impaired loved one. Others stated that not all situations can be planned. Caregivers that had tried to create a solution to this need spoke of calling the local nursing home and asking if they could drop off their spouse on very short notice.

"I wish someone would just knock on my door and say, I am here to help.
You can take a nap or go do your errands without worry."

The next two themes relate to supportive housing options connect to each other. These concerns were expressed primarily by adult children who are caregivers who supported their parents desire to grow old at home.

- § Supportive Services in Independent Senior Housing and Apartment Buildings

A number of caregivers spoke of the concern about their older adult parents that were living alone in both independent senior housing and in apartment buildings. Caregivers spoke of receiving services in the day time either from an in-home care worker or through attendance at adult day services. However, caregivers were wondering if their parents were going to need to move into a nursing home because there was no one to check-in with the older adult in the evening and to give the older adult a reminder or assistance with the administration of evening medication.

There appeared to be a desire by caregivers to create more supportive communities where their older adult parents currently resided. While not specifically defined by any term referencing the emergence of supportive communities, caregivers spoke of the need for services that would enhance the ability of their aging parents to grow old at home.

- § Housing Options

Caregivers that were seeking alternative housing situations felt that assisted living may be more appealing if there was a stronger medical component as part of the service package. Consumers and caregivers stated that you needed to be "semi-independent" and that there was a feeling that if a person received a little more help in getting to bed at night and getting up in the morning, assisted living could be more of an option.

- § Medical Specialists

The need for medical specialists in rural communities that was expressed by consumers was equally expressed by caregivers. Rural communities spoke of not having easy availability of specialty services. For example, caregivers in Southern Illinois' Parkinson's Support Group spoke of a lack of neurologists. There was also a consistent theme in the caregiver groups that general practitioners and internists practicing in rural communities were frequently not as up to date on all treatment options as compared to their experiences in the urban settings. In addition to neurology, this concern was expressed concerning access of quality psychiatric and mental health services. One caregiver reported that psychiatric care was simply absent in her Southern Illinois community.

Service Gaps Cited by HCBS Providers

Similar to consumers and caregivers, gaps identified by HCBS providers were generally cited as improvements that were needed in the current array of services. These improvements were most frequently framed as "if we only had more money." The disparities between communities were cited as gaps; waiting lists created due to limited funding and limited services in the evenings and weekends. There were a few specifically stated gaps; these are cited on the next page.

- Care Planning and Early Intervention

"We need a system that requires the physician to contact us (CCU) when surgery is being planned instead of when the person is coming-out of surgery."

HCBS providers felt that it would be helpful if programs across the board were more collaborative in their planning and willingness to cooperate with each other. Most often stated was that those attending the provider focus group "work well together." But there was this feeling that the gap was in the extended network beyond the known service providers. It was particularly problematic with collaboration between the HCBS network and medical professionals. The gap was in establishing some form of process or mechanism for enhanced collaboration. It was recommended by several CCU providers that concerning efforts to help in diverting persons from nursing home to HCBS services, better efforts were needed to collaborate on early intervention strategies that would occur at the point of hospital discharge and an improvement was needed in the willingness of nursing home staff to open their door to discharge planning by the CCU. It was stated that early and consistent intervention would also benefit older adults from losing their home and community-based supports that were mentioned as physical assistance and their community residence.

"Information gets to us in the 11th hour."

- Medication Management

Medication management surfaced with caregivers in reference to supportive services in the evening; however providers were the most vocal in speaking to the ability of older adults to maintain themselves in the community if they received help with medication management. This gap in assistance included persons who could order the medication, set-up the medication and provide reminders to the older adult to take his/her medication. There was a significant concern in not being able to find this type of assistance, regardless of any issue of affordability. The service was simply not there.

In addition, a second gap was trying to find persons able to successfully administer oral medications, eye drops and insulin injections. This gap was expressed mainly by CCU representatives that stated few could be found to do these tasks. Agencies that were to be found were cited to be too expensive. The large cost was due to the requirement that the person would perform the medication set-up and/or the administration of the medication had to be licensed. This was seen as a financial barrier to a medication management programs.

Analysis by Locations

The ability to state that a need is greater in one particular community over another community is a weakness of the methodology of this study. However, throughout the analysis section there are references to urban, suburban and rural differences and variations in areas of the state. These location differences were more identifiable relating to access to services. Thoughts of participants concerning current services and service gaps across Illinois were more alike.

Access to medical specialists was cited more frequently by participants that were further away from our large urban centers such as Chicago; Champaign/Urbana, Springfield, Peoria and St. Louis, Missouri. Issues expressed by consumers and caregivers pertaining to trust were cited with a louder voice in metropolitan Chicago and East St. Louis areas. However, issues concerning safety and trust did emerge and were heard across the state. The availability of home care workers to serve the rural elderly was heard across the state, but perhaps with a louder voice by participants north of Interstate 80.

There did not appear to be much difference in the knowledge of participants based on location, again with a few exceptions cited pertaining to provider outreach efforts. The knowledge of consumers and caregivers appeared to be based on personal experiences.

Recommendations and Summary

Every one of the themes identified should be considered as areas that are worthy of programmatic consideration for improvement and systems change. It is hoped that the report will be carefully read by the Older Adult Services Committee and all of its workgroups who are charged with transforming Illinois' comprehensive system of older adult services as defined by Public Act 093-1031. In addition, this report should be helpful to all AAAs in Illinois as they develop their plans and contracts for upcoming fiscal years.

Number one, regardless of the type of focus group, participants are looking for ease, clarity, quality, and the ability to trust information pertaining to accessing HCBS services. These thoughts were underlying concerns when speaking about how one finds out about services and expressed when speaking from personal experience engaging private, federal and state programs. Illinois citizens are looking to have questions answered from knowledgeable, caring and compassionate personnel. This means we need to:

- Identify resources in their community that are the best sources for information,
- Provide comprehensive information, assistance and assessment,
- Offer information that enables consumers and caregivers to appreciate HCBS options,
- Educate current consumers, caregivers and consumers of the future about long-term care options and planning.

It is hoped that the Coordinated Point of Entry workgroup will consider these thoughts.

Secondly, regardless of the category, older adults desire to grow old at home and desire supportive services which will enable this to happen. This means we need to:

- Enhance or expand the current array of services and focus our improvements with expanded hours of service delivery in the evenings and weekends,
- Fully fund current programs and services to reduce disparities between communities and reduce waiting lists where they exist,
- Improve the training and sensitivity of direct care workers and professionals.

It is hoped that the Services workgroup will consider these thoughts.

Related to the second point, there is a feeling that the funding of HCBS has a systemic effect which impacts the older adults' health, safety, well-being and ability to remain in the community. Inadequate funds also impacted paid and family caregivers' abilities to be caregivers, and it impacts the stability and quality of the workforce. This includes the direct care worker who lacks a living wage and health care benefits, the family member that quits his/her job to be a caregiver and to the stability of case managers. This means we need to:

- Enhance reimbursement rates to enable living wages and benefits for home care workers and case managers,
- Enable family members to be employed as paid caregivers and support all efforts of family caregivers in their role as caregivers.

It is hoped that the Services, Workforce and Finance workgroups will consider these thoughts.

In addition to funding, assurances are needed of quality HCBS services. This was expressed by all focus participant groups and across the state. The older adults framed it more of feeling vulnerable and afraid. Providers expressed the quality issue more in terms of a workforce issue of finding qualified workers, again referencing poor salaries and lack of benefits. The issue was also framed as the workforce would benefit from more training. Participants consistently spoke of a caring and compassionate workforce, but older adult consumers experienced a process of going through a number of workers before the right match was made.
This means we need to:

- Enhance efforts to stabilize the workforce,
- Explore and adopt efforts at creating elder friendly communities that promote safety and security,
- Improve the training and sensitivity of direct care workers.

It is hoped that the Services, Workforce and Finance workgroups will consider these thoughts.

Another across the participant groups' common theme was the need for expanded affordable housing options and communities conducive in which to grow old. Regardless of the specific theme that emerged, it centered on the maintenance of a physically or cognitively impaired older adult in community settings. This included the service delivery of HCBS services either by the housing community or by outside provider agencies, more home modifications and the conceptualization that new housing should be built with the likelihood that one might become disabled as one aged. This means we need to:

- Explore and adopt efforts at creating elder friendly communities that promote affordable housing conducive to aging in place and enhance safety and security,
- Enhance home modification programs and assist in resource development of individuals and entities to perform minor home repair tasks,
- Expand programs and services that support access to affordable housing.

It is hoped that the Services and Finance workgroups will consider these thoughts and work with state agencies beyond IDOA to consider these needs.

There were actually few new services identified. We need to consider emergency services and expanding respite. We also need to examine our medical services. This means we need to:

- Provide emergency assistance and a service that offers the ability to drop-off an impaired older adult on very short notice. This program would assure a caregiver that a safe and secure environment was provided during the emergency need of the caregiver,
- Increase the availability of medical specialists in rural communities,

- Examine current programs in relationship to their ability to support persons providing care,
- Development of realistic, affordable and consumer friendly medication management programs.

Both of these options should be considered by the Services workgroup and state agencies beyond IDOA.

Finally, it should be noted that the focus group research was conducted prior full implementation of comprehensive care coordination, the passage of PA 95-0565 and amendments to the Illinois Act on Aging. Some of the consumer and caregiver concerns regarding knowledge of options in HCBS services might be getting addressed with the comprehensive assessment. Provisions in PA 95-0565 are expected to impact the CCP programs' service delivery concerning evenings and weekends. It should also enable in-home workers to offer expanded personal care and provider agencies to more easily employ family members. In addition, the Cash and Counseling demonstration program of IDOA has now enrolled participants in a few selected communities in the state. This too allows more flexibility regarding family as paid caregivers, as well as options for consumers to hire direct care workers. The concepts in these legislative changes and demonstration projects should appeal to consumers and caregivers across Illinois. They reflect thoughts obtained in the focus groups conducted on behalf of the Systems Change grant.

Appendix A

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University of Illinois at Chicago
Consent for Participation in Research
“Systems Change”

Why am I being asked?

You are being asked to be a participant in a research study to identify your awareness, thoughts and preferences concerning home and community based; housing and nursing home services to:

- persons over the age of 60 years old,
- caregivers of persons over the age of 60 years old,
- providers of services to these same two groups

that are available, possibly improved or should be available in your community. This study is being conducted by Alan Factor Ph.D. and Paul H. Bennett, MSW of the University of Illinois at Chicago, Disability and Human Development of the College of Applied Health Sciences. This study is part of a larger projected funded by the Illinois Department on Aging.

We ask that you read this form and ask any questions you may have before agreeing to be in the research.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or the Illinois Department on Aging. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Summary

The goal of this study is to develop a computerized resource inventory or guide of all the services in the state of Illinois and to also identify what services are needed, improved or missing throughout Illinois. Additionally, the plan is to use the information learned in the study to make recommendations to the Illinois Department on Aging and to other governmental officials regarding services. While there is no direct benefit or reward for your participation in these focus group meetings at this time, the benefit is to possibly help you at this time and all Illinois citizens in the future become aware of home and community based; housing and nursing home resources in our state.

What procedures are involved?

The study will consist of you voluntarily agreeing to participate in a focus group meeting discussion. A focus group is a small group discussion where participants are asked to share ideas with others. Participants will also be asked to complete a demographic survey. This demographic survey will have no individual identifying information on it.

There will be no experimental activities. It will simply be a group of adults consisting of 8 to 10 participants meeting together. The group meeting should last no longer than 1 hour and 30 minutes. It is hoped that an atmosphere will be created where all participants in the meeting feel comfortable sharing their awareness, thoughts and preferences concerning home and community based, housing and nursing home services in your community.

The focus group meeting will be audio-taped in order for the researcher/group leader to capture the discussion. These tapes will have no individual identifying or personal information on it and will be used strictly to supplement the researcher/group leader's notes and for no other purpose. Once it is decided that all information by the research/group leader is learned, the tapes will be destroyed. During the period of time the researcher/group leader needs to listen to the tapes, they will be safeguarded in a locked filing cabinet. All tapes will be destroyed, no later than 12 months following the conclusion of the research which is to occur by September 2007.

What are the potential risks and discomforts?

There have been minimal risks identified in your participation. If at anytime you become tired or need to leave the meeting either briefly or early, you may do so. If you feel the topics of the discussion become too painful or sensitive, please express your concerns to the group or to the researcher/group leader. Also, the researcher/group leader will monitor participants' emotional state and health and offer supportive assistance if needed.

Again, it should also be noted that no identifying information specific to the participant in the study will be asked for or used. Researcher/group leader is interested in your awareness, thoughts and preferences and not in your identity.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. The audiotape recordings of you will be used for educational purposes; your identity will be protected.

What about privacy and confidentiality?

Participants are not required to share any personal information about themselves or regarding persons to whom they are providing care. Anything said in the group will be kept strictly confidential by the research/group leaders. Participants in the group will be asked to also keep all discussions strictly confidential. However, it should be understood that the researcher/group leader has no control over keeping information heard by fellow participants confidential.

It should also be noted that no identifying information specific to the participant in the study will be asked for or used. Researcher/group leader is interested in your awareness, thoughts and preferences and not in your identity.

The small group discussion will be tape recorded in order for the researcher/group leader to obtain everything that is said in the meeting and to be able to spend time listening and leading the discussion during the meeting. These tapes will be used at a later date and in a private setting to analyze the participants' awareness, thoughts and preferences. Again, these tapes, as well as~~,~~ all notes regarding the meetings will be kept in a locked filing cabinet until the analysis is completed. Once that analysis has occurred, the tapes will be destroyed. No tapes will be kept longer than 12 months following the completion of the study which is expected to end no later than September 30, 2007.

What are the costs and re-imbursement for participation in this research?

All costs associated with this research are covered by a grant from the Illinois Department on Aging to the University of Illinois at Chicago.

There is no financial reward or compensation for your participation in these focus group meetings.

Who should I contact if I have questions?

If you have any questions at any time about this study or the procedures, you may contact the researcher/group leader, Paul H. Bennett at the University of Illinois at Chicago, Department of Disability and Human Development, 1640 W. Roosevelt Road, Chicago, Illinois 60608, and/or by calling 312-413-1294.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty.

What are my rights as a research subject?

If you have any questions about your rights as a research subject, you may call the Office for Protection of Research Subjects at 312-996-1711.

Remember: Your participation in this research is voluntary; you may decline to participate without penalty. Your decision whether or not to participate will not affect your current or future relations with the University, the Illinois Department on Aging or the program site where this focus group meeting is taking place. If you decide to participate, you are free to leave at any time without affecting these relationships.

You will be given a copy of this form for your information and to keep for your records.

Signature of participant

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I have been given a copy of this form.

______________________________ Signature	____________ Date
______________________________ Printed Name	
______________________________ Signature of Researcher	____________ Date (must be same as subject's)

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Appendix B

Demographic Worksheet

To the best of your ability, please answer the following questions. This information will be helpful

- In knowing where in state of Illinois, services are being provided and where services are needed or need to be improved.
- To ensure that the information we receive comes from individuals representing diverse ethnic groups, cultures and economic levels.

The zip code of where you live: _________

Please circle your gender:

Male	Female

Which category best describes your race? Please circle.

White	Japanese
Black, African American	Korean
Spanish/Hispanic/Latino	Vietnamese
American Indian, Alaska Native, First Nation	Other Asian: Print race
Asian Indian	Native Hawaiian
Chinese	Guamanian or Charnorro
Filipino	Samoan
	Other Pacific Islander:

Please indicate which best fits your total household income:

Under $9,570 (1 person) or $12,830 (2 people)	Between $60,000 to $79,000
Between $9,570/$12,830 and $19,000	Between $80,000 to $99,000
Between $20,000 to $39,000	$100,000 and over
Between $40,000 to $59,000	

Appendix C

Focus Group Questions

Access to Services

1. What services are there in your community to help older adults? Can you name them?
2. How do you know about these services?
3. If you needed help, how would you get the help you needed?
4. Of the services you mentioned, do you currently use any of these services? If so, how did you first get started using these services?

Thoughts about Current Services

5. What is your impression of each of these services? What, if anything, would make them better?
6. If you had a condition that resulted in your doctor saying you had to go to a nursing home, what current services might you think about using instead of or help (you, your mother, aunt) avoid going to the nursing home?
7. If you are a caregiver to a (your spouse, mother, aunt, friend), which of these services do you use or have you used to help (your spouse, mother, aunt, friend) avoid going to the nursing home?
8. Again, what can think would make these services better and avoid going to the nursing home?

Gaps in Services

9. What services do you believe are missing from your community? "We really need . . . . and that would help (me, my wife/husband, mother, aunt) from going to a nursing until it is absolutely necessary."
10. What services do you believe are missing from your community that would make life better, more pleasant or enjoyable?
11. If you are a caregiver for someone currently living in a nursing home, have you given any thought about having this person again living in the community outside of the nursing home? If so, what services and/or programs do you think might help achieve this goal of again living in the community outside of the nursing home?
12. If you feel you cannot possibly consider having (your husband/wife, mother, aunt or friend) leave the nursing home, why?
13. Which of the new and/or improved services we have discussed today, do you feel would be the most beneficial and why?

Identification of Consumers’ Long-Term Care Needs in Illinois

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February 2008

Illinois Department on Aging
421 East Capitol Ave., #100
Springfield, Illinois 62701-1789
217-785-3356
Fax: 217-785-4477

Senior HelpLine:
1-800-252-8966
1-888-206-1327 (TTY)
8:30 a.m. to 5:00 p.m.
Monday through Friday

To report elder abuse:
1-866-800-1409
1-888-206-1327 (TTY)

www.state.il.us/aging/

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