

No Wrong Door System Listening Sessions Findings Final Report

HEALTHCARE AND HUMAN SERVICES POLICY, RESEARCH, AND CONSULTING—WITH REAL-WORLD PERSPECTIVE.



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I. Introduction

A. Background on the No Wrong Door System

Both nationally and in Illinois, long-term services and supports (LTSS) for older adults, people with disabilities, people with behavioral health needs, and people with other chronic conditions, are provided by many organizations, through various programs and applications with different rules and funding streams.

To streamline and improve access to LTSS for all populations, the U.S. Administration for Community Living (ACL), the Centers for

Medicare & Medicaid Services (CMS), and the Veterans Health Administration (VHA) developed a shared vision in which every state will have a single, coordinated, statewide No Wrong Door (NWD) System. The NWD System is designed to make it easier for everyone, regardless of a person's age, income level, type of disability, or behavioral health need, to find information about and access LTSS. In Illinois, the NWD System will build upon the progress made by Aging and Disability Resource Networks (ADRN) around the state to coordinate across multiple organizations and streamline how people access LTSS.

The NWD System vision calls for many organizations with different areas of expertise and resources to partner and coordinate to raise visibility in the community, make it easier for people to find the answers they need, learn about their options, and connect with the right kind of services. In a highly developed NWD System, every organization in the network might be virtually linked through the use of shared resource directories and secure data sharing networks. Staff across organizations in the network are trained to work according to common policies and protocols and to uphold the same standards.

To further develop and strengthen the NWD System in Illinois, the state received a Planning Grant from ACL. As part of this grant, Illinois must include a detailed work plan that it can follow over the next three years to bring together all the different service networks and organizations into a single and coordinated NWD System. This effort is also supported with funding from the Illinois' Balancing Incentive Program.

B. Purpose of the Listening Sessions

A key part of the NWD planning process is to engage individuals and organizations outside of existing ADRN, new and potential partners, individuals receiving LTSS and their families to better understand the strengths and existing needs of each NWD System across the state. This ensures the meaningful involvement of consumers, families, and other stakeholders in the design, implementation, and continuous improvement of the NWD System. To support stakeholder engagement in the development of its NWD Three-Year Plan, Illinois contracted with the Lewin Group to conduct listening sessions across the state.

Four Functions of a No Wrong Door System

1. Raise awareness about where and how to access services and supports and the availability of home and community-based options
2. Provide person-centered counseling (information about public and private service options and individualized help making decisions)
3. Help people apply for and access public programs
4. Help people access privately funded services

II. Listening Session Design

A. Methodology

The listening sessions were designed to collect feedback from a broad range of stakeholders on how individuals and families in Illinois receive information about and access LTSS. Lewin helped the state to facilitate a total of six listening sessions between December 2014 and September 2015.

The first listening session was held in conjunction with the Governor’s Conference on Aging in Chicago on December 12, 2014. The session was open to any attendee of the conference and approximately 100 individuals participated. Lewin used a “World Café” style facilitation model with participants moving from one small group to another to discuss different discussion questions. **Exhibit 1** shows the discussion questions used in the 2014 listening session.

Exhibit 1: No Wrong Door 2014 Listening Session Discussion Questions

<p>The NWD Vision</p> <p>What are your thoughts regarding the NWD vision and what it could do for the IL ADRN?</p> <ul style="list-style-type: none"> Does it seem realistic? Are there elements of the vision that you would modify? How can we (Illinois/Lewin) help advance the vision? What is IL doing already that fulfills the vision?
<p>Realizing the NWD Vision</p> <p>How can we realize the NWD vision?</p> <ul style="list-style-type: none"> What will you or your organization offer to help bring this vision to reality? How can we ensure everyone is included (and stays included) in making the vision a reality?
<p>Barriers</p> <p>What are some barriers that your organization and/or stakeholder group might face?</p> <ul style="list-style-type: none"> What needs to be done to overcome potential barriers? What assistance is needed? How can other stakeholders in the room help mitigate these barriers? How can your organization/stakeholder group help others overcome barriers they are facing? How can efforts to overcome these barriers strengthen the IL ADRN and the NWD vision?
<p>Leaving in Action</p> <p>What can you do now to realize the NWD vision?</p> <ul style="list-style-type: none"> What action steps will your organization offer? How would you like to stay engaged with other stakeholders? What new partnerships could help further the NWD vision?

The themes that emerged from this listening session are presented in aggregate with the summary findings from all six listening sessions later in this report. However, as noted in the findings tables, this session was open to all attendees of the conference and we are not able to identify the different populations each attendee represented.

Between July and September 2015, Lewin facilitated five more listening sessions (four in-person and one virtual meeting) using a similar but updated format. Participants in these later listening sessions were asked to share their insights on current outreach and marketing practices, strengths that exist in the current system of accessing LTSS, identify challenges and discuss ways the system could be improved. Each listening session lasted for 90 minutes and followed the same agenda, displayed in **Exhibit 2**.

Exhibit 2: 2015 Listening Session Agenda

Agenda Item	Time
Introduction and NWD System Presentation	15 minutes
Small Group Discussion Purpose, Format and Ground Rules	10 minutes
Small Group Discussion Topic 1: Marketing and Outreach Current Practices	10-15 minutes
Small Group Discussion Topic 2: NWD System Strengths	10-15 minutes
Small Group Discussion Topic 3: NWD System Challenges and Areas for Improvement	10-15 minutes
Closing	10 minutes

These later listening sessions followed a quasi-focus group format, with all participants beginning the session together for a presentation from Illinois and Lewin staff and then dividing into breakout groups of 8-14 participants each. Participants were divided into these small groups to facilitate conversation and ensure that everyone would have the opportunity to answer each question. The specific questions that participants were asked to discuss are presented in **Exhibit 3**.

Exhibit 3: No Wrong Door 2015 Listening Session Discussion Questions

<p>Marketing and Outreach Current Practices How can Illinois make people more aware of their service options and how to access information and assistance?</p> <ul style="list-style-type: none"> • How do people get information about where to go and what type of long term services and supports are available now? • How are services and supports currently advertised and marketed? • What kinds of marketing and communication strategies are most effective? • What could be done to help raise visibility?
<p>NWD System Strengths What strengths does Illinois have that should be part of a statewide No Wrong Door System to help people of all ages and with all types of disabilities get information, make decisions about and access long term services and supports?</p> <ul style="list-style-type: none"> • What do you think is currently working well, for me, for the people I work with or for all populations? • What do I or what does my organization already do to help people make decisions and help people apply for or access services? • What are we already doing really well to help people make decisions and get connected to long term services and supports? In other words, what do we have in place to build on?
<p>NWD System Challenges and Areas for Improvement What are some challenges to building a statewide No Wrong Door System in Illinois?</p> <ul style="list-style-type: none"> • What is not currently working well for some or all populations? What barriers stand in the way of people trying to access information and assistance? • What could be done to remove barriers and improve coordination across networks? • What can I/we/my organization do to help coordinate better across networks?

B. Site Selection

In consultation with Illinois, Lewin selected three cities in Illinois to host the regional listening sessions:

- Peoria (Peoria Public Library) on July 21, 2015
- Mt. Vernon (Rolland Lewis Community Building) on July 22, 2015
- Chicago (Access Living Center for Independent Living) on August 6, 2015

These cities were selected to ensure geographic diversity in the listening sessions and to allow individuals across the state to be able to attend at least one in-person listening session. The in-person listening session

meeting locations were chosen because they offered accessible meeting space in central locations in the community.

In response to high interest in and registration for the in-person listening sessions, Lewin convened one online listening session on September 22, 2015. The format and agenda were identical to the in-person events. Lewin held the event through Webex, its teleconferencing platform.

C. Participant Outreach and Recruitment

For each of the identified sites, Lewin developed partnerships with local community-based organizations (e.g., area agencies on aging, centers for independent living) to conduct outreach to potential participants. Lewin and its partner agencies used existing contact lists to reach individuals receiving LTSS, their family members and provider agency staff. State government agencies also posted information about the meetings on state websites and emailed their contact lists to elicit participation across populations.

For the online listening session, Lewin sent emails to more than 300 individuals, including registrants for the in-person listening sessions, its in-person listening session partner agencies, state agency staff workgroups and contacts from Illinois' Nursing Home Deflection Pilot. State government agencies also emailed their contact lists to elicit participation across populations.

D. Participation

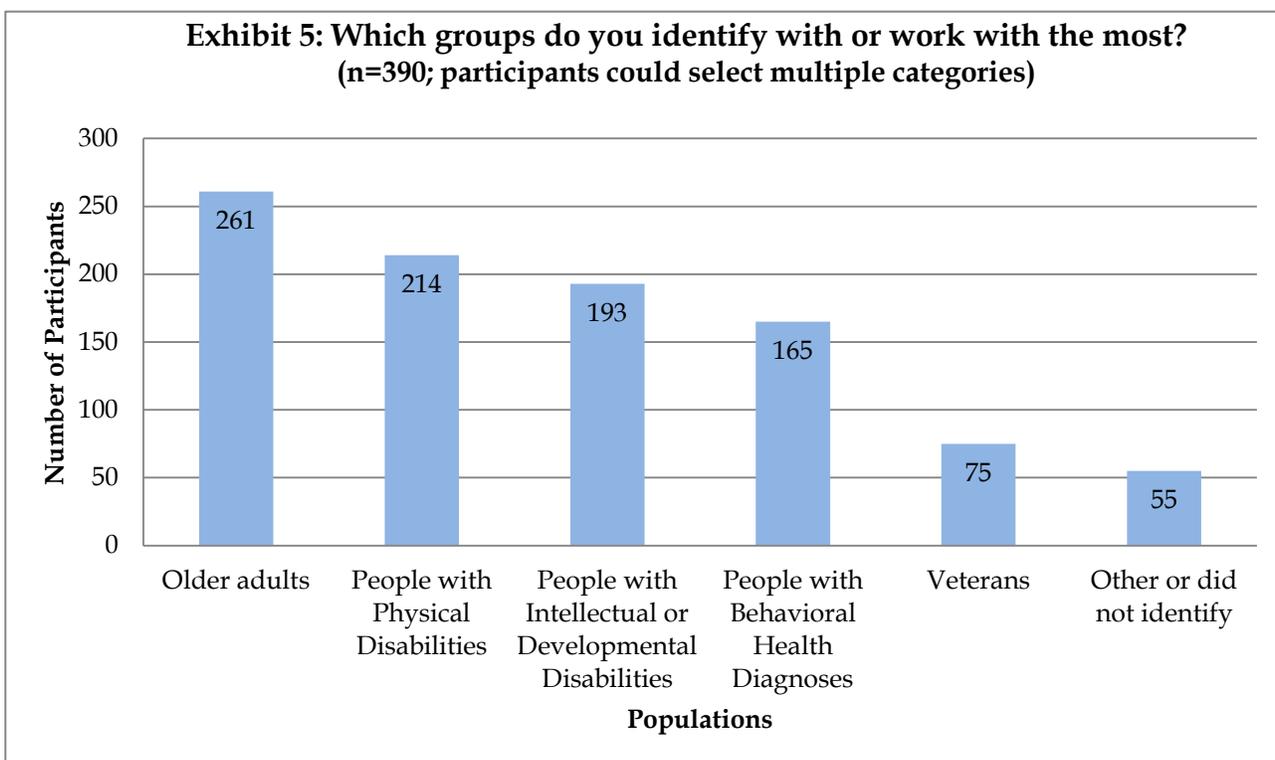
Approximately 490 individuals participated in the listening sessions across all six sessions. Each listening session was well attended, as shown in **Exhibit 4**. Lewin does not have an exact registration count from the 2014 Listening Session, but facilitators estimate 100 individuals participated in the event.

Exhibit 4: Listening Session Attendance by Location

Listening Session Location	Date and Time	Number of Attendees
Chicago (at statewide Governor's Conference on Aging)	December 12, 2014	100 (approximate)
Peoria	July 21, 2015 2:30-4:00 PM	54
Mt. Vernon	July 22, 2015 11:00-12:30 PM	62
Chicago	August 6, 2015 12:30-2:00 PM	49
Chicago	August 6, 2015 2:30-4:00 PM	67
Online	September 22, 2015 10:00-11:30 AM	158
Total		490

Individuals across populations participated in the listening sessions. Upon registration for the listening sessions, individuals were asked to indicate the population(s) with which they identify and/or work. Populations include older adults, individuals with physical disabilities, individuals with intellectual/developmental disabilities (I/DD) and individuals with behavioral health diagnoses. There was also participation from other key populations including veterans and individuals with traumatic brain injury. **Exhibit 5** shows the by-population participation across five 2015 listening sessions.¹

¹ **Exhibit 5** includes attendees at the 2015 Listening Sessions. Participants at the 2014 session in Chicago did not provide this information.

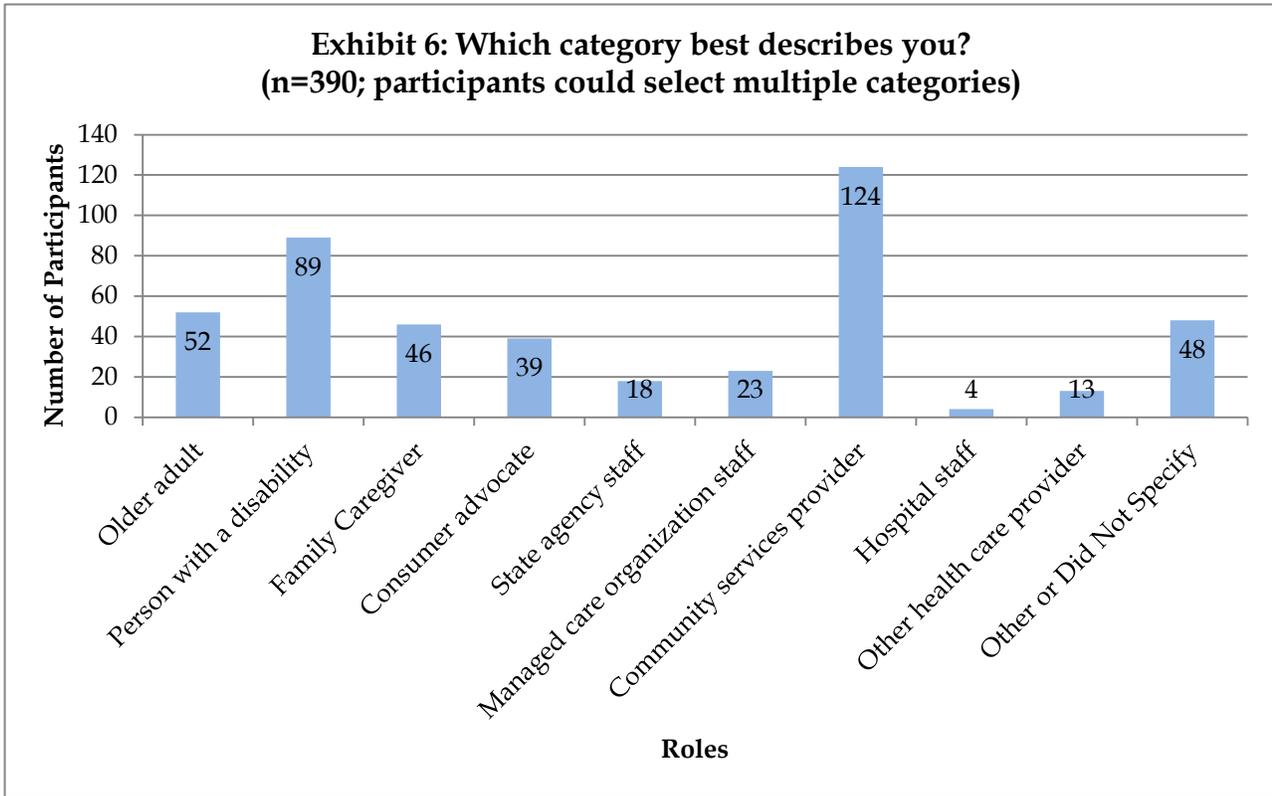


In addition to a broad range of populations, listening session participants were diverse in the roles they play in LTSS. Individuals who receive LTSS, their family members, service provider staff², state agency staff, hospital staff, Managed Care Organization staff, advocates and other individuals involved in LTSS were represented at the listening sessions. **Exhibit 6** shows the participation across the listening sessions by role.³

A list of organizations that were represented at the 2015 listening sessions is shown in **Appendix A**.

² Provider staff includes employees and/or administrators of agencies that provide NWD System functions (e.g., information and referral, one-on-one counseling and assistance) as well as employees and/or administrators of organizations that provide direct services (e.g., home health, personal assistance, adult day services) and health care providers.

³ **Exhibit 6** includes attendees at the 2015 Listening Sessions. Participants at the 2014 session in Chicago did not provide this information.



E. Analysis Framework

Lewin developed a tool to record and analyze the comments that participants made during the listening sessions. Facilitators of each small group across each listening session took detailed notes and recorded the first names of the individuals who made each comment at their table. Following the listening sessions, facilitators entered their notes into the tool, with each comment entered in its own row. In addition to entering comments, facilitators also indicated how the person who made the comment introduced themselves to the other participants in their small group. For example, the facilitator noted if the person introduced themselves as someone who receives or provides services and what populations they said they identified with or had experience working with. Participants were also asked to provide this information ahead of time through the registration process for each listening session and the registration information was used to help fill in gaps and serve as a cross-reference for the facilitator’s notes.

Lewin’s team reviewed all the comments one by one and sorted each comment into groups with comments similar to them to see how often the same or a very similar idea was shared. The team also looked to see which ideas appear to be most important to different groups of stakeholders. Across the six listening sessions, the Lewin team recorded and reviewed 1,137 separate comments and sorted them into 94 response categories (groups of similar ideas). A complete list of the response categories that the comments fell into and the number of individuals who expressed the same or similar comment is presented in **Appendix B**. The team completed internal quality assurance throughout the analysis process, including interrater reliability tests and peer reviews.

III. Listening Session Findings

A. Introduction

This section presents summary findings of major themes that emerged across all participants and within specific populations and roles organized into areas of strength and areas for improvement. We include analysis of both cross-population and cross-role trends as well as frequent themes by participants self-identifying with just one or two populations or roles. There were no significant differences or variation in the types of comments or the frequency of comments made in the different areas of the state, so all findings are presented using data from across all six sessions.

For the purpose of this analysis, we counted as “providers” employees of organizations that provide NWD System function services (e.g., information and referral, one-on-one counseling and assistance) as well as employees of organizations that provide direct services (e.g., home health agencies, personal attendant assistance, adult day services services) and health care providers.

Lewin identified several common ideas that listening session participants representing all populations and roles raised with the high frequency. These are shown in **Exhibits 7 and 8** and discussed in greater depth below in Section IIIB.

Exhibit 7: Strengths Identified with High Frequency across All Populations and Roles

Response Categories- Strengths	Comment Frequency
Community Level Collaboration and Networking	56
Referrals between Providers	47
Person Centered Counseling and Options Counseling	17

Exhibit 8: Areas for Improvement Identified with High Frequency across All Populations and Roles

Response Categories- Areas for Improvement	Comment Frequency
Training and Education	51
Awareness, Marketing and Outreach for LTSS Options ⁴	48
Medicaid Eligibility Determination/Navigation Issues ⁵	42
Collaboration among State Agencies	36
Suggestions for a Statewide Resource Database	36

In addition, Lewin identified themes that were raised frequently by representatives of only one or two populations and/or roles. These are shown in **Exhibits 9 and 10** and discussed in greater depth below in Section IIIC.

Exhibit 9: Strengths Identified with High Frequency by Some Populations and Roles

Response Category	Populations and Roles
Independent Service Coordinators	Intellectual/Developmental Disability
Aging and Disability Resource Networks and Area Agencies on Aging	Older Adults Providers State Agency Staff

⁴ Includes multiple response categories related to issues with advertising, marketing and outreach.

⁵ Includes multiple response categories related to issues with Medicaid.

Exhibit 10: Areas for Improvement Identified with High Frequency by Some Populations and Roles

Response Category	Populations and Roles
Issues with State Agency Websites and 1-800 Numbers	Older Adults
Supporting Independence	Consumers and Family Members Physical Disabilities
Access to Behavioral Health Services	Behavioral Health

Before the beginning of the small group discussions, participants were asked to focus their comments as much as possible on NWD System core functions. State staff acknowledged that there are many other things going on in the state related to LTSS and many issues of concern to stakeholders, such as the impact of the state budget situation on services, the Balancing Incentive Program, and the development of a Universal Assessment Tool. They asked that these topics be addressed in other meetings and venues and/or that participants submit written comments for review and consideration. However, the small group facilitators recorded all the comments made during the discussions, including comments about issues not directly within the scope of the NWD System. A high-level summary of these comments are presented in **Appendix C**. In **Appendix D** is a summary of comments that were submitted by listening session participants in writing during and after the events.

B. Themes Emerging across All Populations and Roles

1. Strengths

a. Community Level Collaboration and Networking

The most frequently identified strength identified by listening session participants across all populations is the connections between agencies and network capacity at the local level. This was identified as an existing strength by more than 50 individual participants. Among providers, many noted that building personal relationships with staff across service agencies facilitates referring people to and from those organizations. Participants also mentioned meetings, networking events and other in-person networking opportunities as key strategies currently used to connect agencies. In addition, providers of NWD system functions and providers of direct services each discussed connections to one another.

“We developed a collaboration in the Chicago/Rockford area with six other agencies and are working on a website, trying to make it a one stop and bring everyone together.”

“Building personal relationships with people in other agencies and helping each other facilitate other ideas and use as a referral system [has been helpful].”

“Community network meetings are good, too. Interagency meetings are phenomenal way to coordinate, help reach people before it’s a crisis. For example, one client needed a ramp to help their mom get into a van and the local CIL helped us with that.”

b. Referrals between Providers

Another major strength identified is the capacity of providers to provide and receive appropriate referrals from other agencies. This includes cross-population referrals (e.g., an aging services provider referring an individual to community-based mental health services) as well as referrals between providers of NWD system functions and providers of direct services. 47 individuals mentioned that referrals between agencies work well and help connect people to services.

“We’ve built rapport and it pays off now. We get a response when we call our partners.”

“Providers in the community and their programs/supports are very good at what they do. We feel good about referring to these agencies.”

“Referral process works well. We’re not just handing a piece of paper, we make sure someone gets access.”

c. Person Centered Planning and Options Counseling

17 participants highlighted person-centered planning and options counseling (PCP/OC) services as an existing strength or a foundation on which to build. People that cited this strength were enthusiastic, emphasizing the importance of PCC/OP in providing comprehensive, high quality personalized assistance to consumers.

“We provide options counseling at our CIL, and it's good because we talk about all the aspects of their lives - not just their challenges.”

“We already provide a lot of person centered counseling and it is an essential service, helps people figure out what direction to go in, really important.”

2. Areas for Improvement

a. Training and Education

A major theme that emerged from participants, especially providers across all populations and people that identified with the physical disabilities population, is the importance of increasing and improving training and education for staff who work with people with disabilities. More than 50 participants provided comments addressing training and education needs related to LTSS.

In addition, participants mentioned the need to train provider and state agency staff in how to work with anyone needing LTSS rather than one specific population, cultural competency towards disability and how to navigate Medicaid, including eligibility and application systems. Participants also mentioned the need to increase training opportunities for specific services, including personal assistance. Many participants in the 2014 Listening Session in particular noted a general need for training.

“With limited staff and time, there’s a lot of throwing new staff into the fire, with no training.”

“Cross-train staff on the different service networks and populations, and have staff “shadow” their counterparts who work in different service networks to better understand their programs and populations.”

“Who you get changes the answer to a question. Provide more education on what is available. Families want to help.”

“Training has to be valued, viewed as worth having. It would encourage breaking down barriers, a dedicated curriculum for social service staff on what’s available. So when someone asks about it, they’ll have a basic answer.”

b. Medicaid Eligibility Determination/Navigation Issues

More than 40 participants identified areas for improvement related to applying for and navigating Medicaid services. Participants across populations, especially consumers and family members, spoke to problems navigating both the Medicaid eligibility determination process as well as accessing services once enrolled. People also commented on the complexity of Medicaid eligibility.

“It’s hard to for people to apply for DD services. Some people aren’t even applying because of the hardness and the pointlessness of applying.”

“People don’t understand Medicaid eligibility.”

“It’s difficult to navigate geographic boundaries and who can serve who based on where they live.”

“Navigating through Medicaid is a nightmare. Payment needs to be quicker, especially when auditor generals are investigating. Facilities are out of money, waiting for the results. If they find fraud did occur then the senior owes the money and they can’t afford it.”

“There is a long waiting period for even being assessed for a waiver. MCOs could help with this by administering the DON [themselves].”

c. Suggestions for a Statewide Resource Database

Before the listening session discussions began, representatives from Illinois gave a brief presentation to the participants on upcoming developments to the NWD System, including a website with a statewide resource database providing information about resources and services and LTSS service providers for all populations throughout the state. Participants were very supportive of the idea of such a database, and 27 participants provided specific ideas on how to best capitalize on the database. Many individuals noted that currently not all information is in one place, which makes it difficult to use the existing resource listings. Additionally, participants noted that current resource databases may be outdated.

“We need one database and not four.”

“There needs to be a comprehensive list of state and private funding service providers. Enter zip code and get list of all providers, the services they provide and the populations they serve.”

“Private services should be included in database.”

“We need real time information about available housing and other services.”

“Providers should be able to update their own information on database.”

d. Awareness, Marketing and Outreach for LTSS Options

Another notable area for improvement relates to awareness of LTSS available to people who might need services. More than 40 participants said that they or the people they serve often came into LTSS with almost no knowledge of what services and supports were available to them. These participants also referenced low visibility of LTSS across the general population.

“Surprised at how many seniors don’t know about home-based services at all.”

“People have no idea what services are available when I meet with them.”

“People gravitate to the institutionalized setting because there is signage. Home services and smaller services are not visible.”

“People are unaware of what’s out there for them.”

There were 33 participants that commented on outreach and marketing for LTSS is performed, adding that this area could improve as the NWD System develops.

Providers in particular expressed concern over funding for marketing, with many saying they simply cannot afford to advertise their services. These providers frequently cited no-cost or low-cost approaches to outreach, such as word-of-mouth and health fairs. In general, providers characterized these avenues as less effective than higher-cost marketing and outreach approaches.

“There is not enough funding for ads.”

“We’ve tried to get information about HCBS out through health fairs, attending meetings with community programs, sometimes at senior centers.”

“We rely on word of mouth mostly.”

Individuals receiving services mentioned other issues with marketing, including a lack consumer input into advertising and outreach materials, and the lack of information available outside of urban areas. Select comments on this topic include:

“There is not enough consumer input in marketing”

“Marketing efforts are only as good as what people understand from them.”

Improving outreach for and boosting the visibility of LTSS options are two linked areas for improvement the state could consider emphasizing as it develops its NWD System.

e. Collaboration between State Agencies

36 participants noted that improved collaboration across and leadership from state agencies would strengthen the development of the NWD System. Participants across roles and populations suggested that state agencies do not regularly work in collaboration or share resources. Many participants noted that continuing this trend could jeopardize the development of Illinois’ NWD System.

“We need unified leadership from state government agencies for a top down approach [to NWD].”

“State agencies should share marketing resources.”

“If this is going to work, we need more buy-in from state agencies, not just Aging.”

C. Themes Emerging from Specific Populations and Different Role Categories

This section of the report identifies strengths and areas of improvement that were noted with more frequency by participants that identified with or work with a particular population or that assume a particular role in LTSS.

3. Strengths

a. Independent Service Coordinators

Seven participants who identified with the intellectual or developmental disability (I/DD) population, or who provide services to this population, identified the state’s network of Independent Service Coordinators as a strength. This was the third most frequent strength cited by those identifying or working with people

with I/DD, following referrals at the community level and community level collaboration and networking. Nine providers across all populations also noted this strength.

“I/DD services have good coverage.”

“Independent Service Coordinators [are] retraining people, [and] will work with any age range, kids in school and older”

b. ADRNs and AAAs

10 participants who identified as or work with older adults mentioned strengths related to the Illinois Aging and Disability Resource Networks and Area Agencies on Aging. Additionally, seven providers and two state staff members cited the ADRN/AAA network as an area of strength.

“People know they will get personal attention at the AAA. We’ll be straightforward on who to go to.”

“The AAAs and case coordination units outside of the Chicago area work very well for people 60 and older.”

4. Areas for Improvement

a. Issues with State Agency Websites and 1-800 Numbers

Fourteen participants that identify or work with older adults cited issues with statewide websites and the 1-800 information line, stressing the importance of developing consumer-oriented resources.

“Communicating to people about services in their hometowns is important. There is a hesitation to call a 1-800 number that is in Chicago, even though we have information about other places in the state.”

“There needs to be a central intake - a call line for people to receive information about what programs are available.”

“It’s critical that consumers be involved in the development of any website that will be used to disseminate information. The State of Illinois’ website is too confusing for consumers to use.”

b. Supporting Independence

Five consumers and family members and five people that identify or work with people with physical disabilities noted a need to help people and families to be independent.

“Young people out there today, their parents are sheltering them. We need to teach them to be independent. We age and die. When mom and dad are gone, kids end up in the care of the State. I refused to let my parents put me in a box and refused to accept living with them forever. I got my own apartment.”

c. Behavioral Health Services

Individuals that identify or work with people with behavioral health diagnoses (7) cited the need for more services for people with serious mental illness (SMI).

“I’m my brother’s guardian. I don’t know how anyone with SMI could ever get through this system on their own. Being persistent is critical... Before I became his guardian, no one would talk to me.”

It was always "it's his decision." Once I became his guardian, the process wasn't so painful, but I've heard from others it is tough...getting doctor's records, filing paperwork for organizations, telling [the] story over and over again. The paperwork that organizations require was a huge barrier."

D. Next Steps

The State of Illinois will consider the input from stakeholders described in this report. This report will also inform the development of Illinois' NWD System Three-Year Plan, which is due to ACL in 2016. Once the Three-Year Plan is finalized, it will be made publicly available.

Appendix A- Organizations Present at the Listening Sessions

The following organizations attended at least one of the listening sessions in 2015. Many organizations sent multiple representatives. Additionally, many participants attended on their own behalf and did not self-identify with any one organization. There are 166 organizations represented.

This list presents an unduplicated list of attending organizations.

Abcor Home Health Inc.	Center for Disability and Elder Law	DuPage County Senior Services
Abequa Home Care Agency, LLC	Centers for Residential Alternatives	Easter Seals Metropolitan Chicago
Access Living	Centerstone of Illinois	Effingham City/Co. Committee on Aging (ECCOA)
Access Living of Metropolitan Chicago	Central IL Service Access	Egyptian Area Agency on Aging Inc
ACM Care	Central Illinois Agency on Aging, Inc.	Egyptian Health Department
ADAPT	Chicago Department of Family Support Services/Senior Services/AAA	Elm City Center
Addus	Chicagoland Methodist Senior Services	Envision Unlimited
Addus HomeCare	Children's Habilitation Center	EPIC
Advocate BroMenn	Children's Place Association	Fox Valley Older Adult Services
Advocates for Access	Chinese American Service League	GROW in Illinois
Aetna	Clearbrook	Grundy County Health Department
Aetna Better Health	Coalition of Citizens with Disabilities in Illinois	Habilitative.org
Agency on Aging	Collinsville Faith in Action	Harmony
AIM Center for Independent Living	Community Care Systems, Inc.	Health & Medicine Policy ResearchGroup
Alternatives for You	Community Resource Center	Healthcare Consortium of Illinois
Alzheimer's Association	Comprehensive Behavioral Health Center of St. Clair County, Inc.	Healthcom
Among Friends Adult Day Care, Inc.	Comprehensive Connections	Heartland Human Services
Area Agency on Aging for Lincolnland	CRIS Healthy Aging	Help At Home
Ashley's Quality Care, Inc.	Crosspoint Human Services	Helping Hand Center
Asian Human Services	Department on Aging	Heritage Woods of Mt Vernon
Association House	Department on Aging- Senior Helpline	Heritage Woods of Plainfield
Association House of Chicago	Department of Human Services/Division of Developmental Disabilities	Hillview Healthcare Center
ASSYRIAN NATIONAL COUNCIL OF IL.	Department of Human Services/Division of Mental Health	HMPRG
Assyrian universal alliance foundation	Department of Human Services/Division of Rehabilitation Services	Home and Community Ombudsman
Austin Special Chicago	Don Moss and Associates	Human Service Center
Awakened Alternatives	DRACH	IAMC
Barbara Olson Center of Hope		IL State Board of Education
Behavioral Health Alternatives		Illinicare Health and CountyCare Health
Bridgeway Inc.		Illinois Alliance for Living
Bureau County Senior Citizens Association		Illinois Center for Autism
Bureau of Accreditation and Licensure		Illinois Council of Case Coordination Units

Illinois Guardianship Association
Illinois HomeCare & Hospice Council
Illinois Iowa Center for Independent Living
Illinois Network of Centers for Independent Living
Illinois Valley Center for Independent Living
Illinois-Iowa Center for Independent Living
IMPACT CIL
Independence Center
Independent Voices
IPMR
Jewish Child and Family Services
Journeycare
Kenneth Young Center
Lake County Center for Independent Living
LINC, Inc.
LTC Support Services, LLC
Lutheran Social Services of Illinois
Mascoutah Senior Services Program
Maximum group of companies
Memorial Hospital
Mendota Area Senior Services
Midland Area Agency on Aging
MIL
Mosaic
New Age Elder Care
New Hope Center, Inc.
Northeastern Illinois Agency on

Aging
Northeastern Illinois Area Agency on Aging
Northwestern Memorial Hospital
NSSED
Oak Park Township Senior Services
Ombudsman Program
PACE, Inc.
PACTT Learning Center
PCG Public Partnerships (PPL)
Pioneer Center for Human Services
Progressive Careers & Housing
Ray Graham Association
RDK Management
Residential Centers of Illinois
REST - Respite Education and Support Tools
RFMS - LTC Support Services
RFS
Richland County Senior Center
Rincon Family Services
Rosecrance
Sacred Creations
Search Inc.
Senior Resource Center
Senior Services Plus
Sertoma Centre
Shawnee Alliance
SICCS
South Side Office of Concern
Southwestern Illinois College,

Programs & Services for Older Persons
State of IL - Division of Developmental Disabilities
Stephenson Co SRC
Stickney Township Office on Aging
SWAN Senior Services
Taskforce for Attendant Services
The Alliance for Community Services
The Arc of Illinois
The Association for Individual Development
The Chicago Lighthouse
Therapy Services
Thrive Counseling Center
TRADE Industries
UCP Land of Lincoln
UCP Seguin of Greater Chicago
UnityPoint Health Methodist/Proctor
Universal Healthcare Management
Villa Catherine
Washington Christian Village & Leading Age
WellCare Health Plan
WellCare/Harmony
West Central IL Center for Independent Living
Western Illinois Area Agency on Aging
Will-Grundy Center for Independent Living

Appendix B- Response Categories and Frequencies

Response Categories- Strengths	Comment Frequency
Community level collaboration and networking	56
Referrals between organizations at the local level	47
Person Centered Counseling and Options Counseling	17
Aging and Disability Resource Networks (ADRNs)	13
Independent Service Coordinators	12
Specific local programs (varied by region)	12
Strong community centers/agencies	10
Primary education system	8
Care Coordination Units	7
Medicaid eligibility/navigation process	7
Electronic data exchange	6
Good training	6
Personal assistance services	6
Centers for Independent Living	5
Current databases and other statewide resources	5
Adult Protective Services/Protection and Advocacy	3
Physicians	3
Consent Decrees (helping to transition people out of institutions)	2
Transportation	2
Existing caregiver programs	2
Cultural competency	2
Department of Human Services	1
Care Transitions Program	1
Olmstead	1

Response Categories- Areas for Improvement	Comment Frequency
More training/education	51
Improve collaboration across state agencies	36
Suggestions for a statewide resource database	36
Medicaid eligibility determination process	28
Improve collaboration/communication at local level	23
Medicaid Offices/Staffing problems and complaints	17
Need more support for caregivers	16
Issues with statewide websites and 1-800 line	15
Stronger networks with providers (hospitals, NF, acute care, physicians)	15
Increase standardization of assessment across waivers/populations	15
Medicaid navigation issues	14
Need better customer service	14
Better IT/Infrastructure - update outdated computers and IT systems	13
Data exchange - need to improve individual-level sharing of data across community orgs and medical providers, at community level, with state, in general	13
Nursing home members need more awareness of services	13
Turf war issues/Silos	12
Better state websites/easier to navigate/better information (separate from resource directory information)	11
Primary education system	10
Interpretation services and language issues	10
More services for people with severe mental illness	9
Need to help people and families to be independent	9
Lack of understanding of disability	9
Division of Rehabilitation Services	8
MCO issues	7
Look at activities of other states/countries	6
Waiting list process	6
Visibility is not good	6
Access to internet/computer	6
Transportation issues	6
Improvements for rural service areas	6
Roles of local agencies	6
Veterans services	5
Division of Developmental Disabilities	5
Focus on community living	5
More housing/residential options	5
Stigma associated with disabilities	5
Medicaid reassessment process	4
People are confused about where to go	4
Better employment services are needed	4
NWD staff with specialty areas and generalists	3

Response Categories- Areas for Improvement	Comment Frequency
Should be able to apply for Medicaid outside Medicaid agency	3
Social Security application/ staff problems	2
Use staff that have been through the system	2
Expanded state toll-free number will not be able to keep up with call volume	2
More stakeholder engagement	2
Conflict of interest concerns	1
More flexibility in NWD gateway	1
Change HIPAA	1

Response Categories- Strengths and Recommendations about Marketing	Comment Frequency
Internet/websites/social media	35
Broad public advertisements, PSAs (radio, television, newspaper)	35
Marketing to providers	31
Provider-specific and other in-house resources	30
Word of Mouth	24
Community connections, liaisons	22
211	19
Resource and job fairs	16
Referrals from Case Managers	12
Religious Organizations	11

Response Categories- Areas for Improvement about Marketing	Comment Frequency
Problems with marketing (funding, other issues)	33
People do not contact until they are in a crisis	19
Hard to help people who don't want help/are afraid/suspicious of help/embarrassed	13
Does not work to rely entirely on websites and computers	11
General education/outreach	10
Market to younger people	8
Local Shoppers Pages/local newspaper	7
Should improve/unify NWD brand	6

Appendix C- Response Categories Outside the Scope of the NWD System Listening Sessions

Response Categories- Areas for Improvement within LTSS System Outside the Scope of NWD System Functions	Comment Frequency
Not enough funding for HCBS/Existence of waiting list for services	49
Improve access (general)	20
Federal funding being blocked or held up by state	9
Increase standardization of services across waivers/populations	7

Appendix D- Written Comments and Questions

Written comments received at and after the listening sessions include:

- Comments noting potential systemic issues in accessing or applying for LTSS, including personal assistance, coordination with the education system and low awareness of current practices.
- Concerns about changes to financial and functional eligibility criteria for waiver services, including the Determination of Need and the Universal Assessment Tool.
- Concerns about losing consumer- or self-directed services.
- Concerns about the state budget/financial situation and implications of that for LTSS, including PACE.
- Concerns that state and local government agency employees may be overworked and are limited in how much they can help individuals access services.
- Questions clarifying the meaning of CIL (center for independent living).
- Suggestions for additional marketing outlets (e.g., flyers, bus advertisements, radio).
- Suggestions for the statewide resource database that improve access for individuals who are deaf and/or hard of hearing.
- Suggestions of additional stakeholders to include in the NWD System development activities.