

# Indiana's Long Term Services & Supports

## Summary Report

### No Wrong Door Community Engagement

September 28, 2015

## Acknowledgements

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## Introduction

In 2015, Indiana’s Family Social Services Agency (FSSA) began preparation of a three-year plan for implementation of a No Wrong Door system for all populations and payers. This report provides a summary of input gained from all community engagement activities undertaken by the Center for Aging & Community (CAC) team to inform Indiana’s No Wrong Door (NWD) System plan.

To inform the planning process, the CAC team undertook different activities to engage stakeholders in an analysis of the strengths and weaknesses of the current Long-Term Services and Supports (LTSS) system, and in defining what a No Wrong Door system should look like. How might this system best serve the range of consumers served by the LTSS system? Three distinct activities were used to engage community stakeholders in this discussion: 1) focus groups; 2) regional information gathering sessions; and 3) consumer surveys. These activities were designed to incorporate perspectives at the system, organization and individual levels.

## Methodology

A summary of the data collection methods is provided here. See the sections of the report for more details and the appendices for data collection protocols.

### Focus Groups

Between July 16 and July 23, 2015 the CAC team conducted three focus groups with representatives of state agencies and state-level organizations. The purpose of the focus groups was to include the views of those with knowledge and experience with system development, and those representing statewide organizations, such as those engaged in advocacy, planning, and/or service. FSSA staff assisted in this process by identifying representatives and extending the invitations to participate. A total of 25 individuals participated in the focus group discussions.

### Information Gathering Sessions

The purpose of the information gathering sessions was to gain insights from providers, advocates and others on the issues facing the current system of long term services and supports, opportunities and challenges in developing a NWD system, attributes of an “ideal” NWD system, and supports needed at the state, regional and local level to

implement a successful NWD system. The CAC team conducted ten regional events throughout the state between July 24 and Sept. 10, 2015. FSSA staff assisted at each event by providing an overview of NWD and the importance of community member engagement in planning its implementation in Indiana.

### Consumer Surveys

An electronic survey was made available to consumers, family members, care providers, advocates and other interested parties. A total of 393 surveys were collected from across the state between July 10 and August 28, 2015.

### Limitations

In this process, working with FSSA, we made every effort to identify representative stakeholders, it is likely that we did not reach all who need and use LTSS. The information in this report thus represents a broad range of stakeholders, but is not comprehensive. Hard to reach groups, such as those who live alone, in care settings, or who may not have access to public meetings or web-based technology are not well-represented through this engagement effort.

### Acronyms and Definitions

Term	Definition
AAA	Area Agency on Aging
ADRC	Aging and Disability Resource Center
LTSS	Long Term Services and Supports
NWD	No Wrong Door
“door”	The “doors” of NWD are access points that consumers use to get information about services (public and private), providers and Medicaid or other payer eligibility requirements.
PCC	Person Centered Counseling
HCBS	Home and Community Based Services

## Summary of Findings

As part of the community engagement discussions, each set of stakeholders was asked to identify positive or successful aspects of the current system of LTSS, as well as existing consumer issues and needs. The first part of this summary includes analysis of themes emerging in response to these questions.

The planning framework for No Wrong Door includes four major components. These include: public outreach; personal centered counseling; streamlined access; and governance and administration (including an assessment of the current system and continuous quality improvement). Some of the stakeholder input relates to underlying changes which must be addressed if NWD is to be successful.

The remainder of this summary is organized by the four major components of the framework, but each also includes input gathered on related system issues/changes. We have included this additional input where we believe it best fits the intent of NWD and the changes stakeholders think are necessary to improve access to LTSS.

## Themes

### Positive Aspects of Current System

Participants in focus groups and regional events easily identified positive changes seen in the state's LTSS system over the past few years. Survey respondents identified aspects of the LTSS system that currently work "best" in their communities. Common themes emerged regarding positive aspects of the current system. Among these themes were:

- **Increased awareness** of issues in the system has occurred among state level stakeholders. Approaches to care reflect these changes.
- **Delays have been reduced and eligibility expanded.** Waiver programs have reduced wait times, those with higher income levels (higher than Federal poverty level) are being served), and streamlined applications have improved agency response time.
- **AAAs/ADRCs** are perceived as strong and are seen as knowledgeable and effective resources in the community. AAAs were the most frequently cited

source survey respondents noted when asked how they learn about supportive services in their communities.

- **Options for care have expanded** and there is evidence of increased collaboration and coordination among programs and providers. More and different types of providers have entered the system. Programs offered, once accessed, provide many with the assistance they need, and many respondents reported high quality experiences and help.

## Consumer Needs & System Issues

Focus group and regional event participants, along with survey respondents, identified consistent challenges consumers face in accessing and using LTSS. Common themes emerged including the following:

- **There is no central source of “neutral” information on LTSS.** Information is not available, not current, and not available through one objective source.
- **A deep lack of education/information about services** and the choices available in LTSS exists. This is a problem for both consumers and providers. Not only are consumers and providers not aware of existing services, but there is not enough information available about what the organizations/facilities provide and who they serve. Information is not only unavailable, but if provided, is often not relevant to the need presented at the time of inquiry. At the same time, it is difficult to filter through existing information to find what is relevant. Existing entry ways, such as the Area Agencies on Aging/Aging and Disability Resource Centers, are not well known or easily identifiable by name (most have a different name) and or population served. There is also the perception that “services” are only for those with low incomes.
- **An extensive but disconnected service system exists,** but it is often focused on program eligibility. There are many services available, but they are fragmented. Systems are fragmented by age, and the focus of the systems is on determining eligibility. There is a focus on “how to pay,” rather than on accurate assessment

*“It’s just not knowing all the services available. Medicaid system is complicated and not easy to understand. Not many people seem to comprehend it and we do not know those who do. “*

of current and underlying needs of the consumer. Linkages are not made between aging and non-aging services and organizations.

- **More skilled “navigators”** are needed, and they need to be easily accessible. Whether at the time of hospital discharge, or in a health or other crisis situation, or just needing a service to remain safely and successfully in one’s current residence, finding a skilled person to assist with assessment and securing the most appropriate service(s), is very challenging. This issue is exacerbated by the lack of coordination between organizations that may be providing services to one individual. Because there is not central coordination, service gaps or redundancies occur.
- **Skilled and consistent staff is lacking across the LTSS system.** Consumers receive inconsistent information from the same and different staff in the same agencies. Even if someone gets to the “door,” they cannot consistently obtain accurate information. Some staff are seen as lacking in respect or compassion for those served, and/or do not fully understand the goals of service/programs. Key staff guiding transitions lack needed information or expertise.
- **Communication about services is in language** not easily understood by consumers, and their friends and families. This can be attributed a lack of health literacy on the part of consumers, but also to the fact that providers use language that makes it difficult for consumers to understand the choices offered. Consumers do not know what to ask, and thus cannot find the services they need.
- **Consumers at the “wrong door” are not given information on where to find what they need.** Often referrals are not made when consumers are refused; they are not told of other “doors” to visit where service might be appropriate to their needs.
- **Limited services and regional differences** limits those identified and referred, and those receiving service. Delays are common and eligibility policies are unpredictable and limit coverage. It is more difficult to inform residents in smaller communities about existing service options. Service options in smaller towns and rural areas are fewer, making them more difficult to find. There is a

*“You can tell a person “no,” but that should not be the end. We may tell them “no,” but we have to add, “there is this [other option]...”*

need to standardize information and processes at “like” agencies/organizations across the state.

- **Many barriers to agencies working together.** From the lack of a standard initial assessment, to barriers to sharing client data (HIPAA, other), to lack of a common technology platform on which to share information, even agencies who want to collaborate find it challenging.

## Public Outreach

For a NWD system to be successful, extensive education and awareness efforts are needed. Recommendations for improving awareness and knowledge are provided below.

- **Simplify information and make it easily accessible.** Information should be readily available, comprehensive, understandable, accurate, fully accessible, and consistent. Information should also reflect and respond to cultural and language difference.
- **Branding of system is critical.** System name must not be about aging, but go beyond to communicate to the public what the system is, why it is there, and what it does.
- **Consistently promote and create awareness;** NWD cannot be just a one-time campaign. The need to educate and inform the public, and providers, especially as changes occur constantly, must remain a priority. The message of the campaign should include the “why” of NWD and its importance. The message should also help educate the public on the reasons for using the system to plan for future needs, as well as how to access information about what is needed now.
- **Outreach is not just about “information.”** Outreach also involves connecting consumers to skilled navigators and/or a system that helps them find what they need, and what is most relevant to them.
- **Work to ensure the broadest possible means of communication** so everyone is informed. This means using technology (websites, social media), other media (TV, radio, print), mail, and providers at all of the “doors.” It also means going to where

*“Consider public kiosks placed in places where people congregate. This might be the library, transit areas, or even have public walk-in centers.”*

people with need congregate. Explore other **options for information sharing**, such as family to family, caregiver to caregiver, information and referral. This may mean moving beyond the “they come to us” model to one of ensuring delivery where consumers typically access information.

## Person Centered Counseling

Many of the issues identified regarding options and choice, assessment, eligibility, and staff capacity relate to person centered counseling (PCC). That is, it is difficult to achieve the goal without well trained staff, available resources, reduced delays, and follow-up. Consumer choice involves not only knowing what is available but that the service or care option can be accessed. Therefore, the recommendations summarized below reflect that person-centered counseling is not just about providing information about choices, but that services must be available and of good quality so that person centered counseling is not a “hollow” goal of a NWD system.

- **Ensure consumers only have to “tell their story”** one time. Information sharing is supported by the system.
- **Work aggressively to address issues of staff availability and training.** While increasing staff at all “doors,” and enhancing pay and benefits to reduce turnover, may be well beyond the NWD initiative, it makes little sense to invest in good information and referrals if only a few across the system are able to provide it and turnover among them is high. Training of existing and new staff is critical. Properly trained and adequate staff with access to the most up to date information is essential for NWD to succeed, and to achieve other system improvements such as:
  - reduced “handoffs”
  - more successful care transitions (right care at the right time)
  - effective options counseling
  - focus on need rather than eligibility

*“We need to have personnel to help clients through any system. For example, now that we have Navigators on site to help people apply for health insurance, many more have applied. On the other hand, when someone is dropped from food stamps or other government assistance, they frequently give up because they just don't understand...”*

- enhanced collaboration
- **Work aggressively to address Build incentives for follow-up into all forms of referral.** Whether referrals occur at the staff level, or through any technology supported system of information and decision-making, incentives and processes must be in place to ensure appropriate information and services were accessed. Many consumers surveyed agreed they were provided choices, but accessing the service was difficult. In addition, person centered counseling includes monitoring to be sure service and care options are presented when change requires re-assessment.

### Streamlined Access

Focus group and regional event participants identified important attributes of a streamlined system of access to LTSS. There are many ways that streamlined access can contribute to a successful NWD system. Recommendations for planning follows:

- **Build on existing models rather than inventing an entirely new system.** Carefully and extensively review existing models of how to increase awareness and access. These include aspects of the 2-1-1 call center, programs like First Steps and Systems of Care in child services, Google SNAP, Elder Locator, screening instruments, models for engaging doctors and other health providers, navigator programs, and others.
- **Review program policies and tools, and focus on minimizing the “hoops” to jump through.** This can seem an obvious fix, but it is among the most challenging. Barriers to information, service and coordination, cited by consumers, providers and staff, lie at the center of the issues to be addressed by NWD. A common intake tool was often recommended by community engagement participants, however, some states have approached this not by having a common form, but rather by requiring partners to assess across common domains. In addition, policies which inhibit the sharing of information may also hinder streamlined access and need consideration. Certification of staff is another area for review across agencies and programs. Finally, including a range of stakeholders in this review can help to create buy-in and draw on ideas which everyone may find of benefit.

- **Build a NWD system that is easy to use and is accessible to all.** NWD is intended to serve all payers, all ages, all abilities, and all providers, and all consumers. Any system serving such a broad audience must be simple, use language that is easily understandable, and make information and assistance available through multiple venues and formats.
- **Use technology effectively to streamline intake, assessment and referral.** An effective web-based information and decision-making portal is strongly and consistently supported by the stakeholder community. The technology should support the NWD system, but not be the exclusive point of entry. Rather the technology should support the system of trained staff, consumers, friends and family, and providers who can use it to find information and make guided decisions. An effective web-based system would:
  - Be fully functional, from day of launch.
  - Be consistently updated to reflect state and regional information and resources, as well as changes in technology.
  - Incorporate self-guided tools (similar to gaming programs, or the interactive survey for insurance under the Affordable Car Act) which navigate the user from assessment through service access or referral.
  - Facilitate a “warm hand off” where staff in the first contact organization can push out referrals and receive reminders to follow-up.
  - Include state-of-the-art, data driven, searches based on common keywords. Utilize keywords that are in the language of the consumer. Keywords should be need- or issue-based not names of programs. Results should also be displayed by location.
  - Be fully accessible (language, ability, non-readers), function 24/7, and be available through multiple venues, e.g., call centers and possibly physical hubs, for consumers who prefer this option, have language barriers, or lack computer access.
- **Work aggressively to improve staff capacity.** As in achieving improvements in PCC, streamlined access requires not only a supportive technology platform, but also demand staff who are well-trained in its use, in the goals and outcomes of a

*“Make it a ‘smart system and one which is accessible on mobile devices... But also have a human follow-up.”*

customer-driven, person-centered, needs-based system of information and referral. Here, too, the NWD system can build on existing models, including the high quality of service provided by the AAAs/ADRCS noted by surveyed consumers, and on partner systems as well. Certification and other mechanisms of ensuring adequate training should be reviewed, as well as incentives and mechanisms of accountability for staff performance.

## Governance & Administration

“Governance and administration” was examined in the stakeholder events largely through questions related to what would be needed at the state, regional and local levels to ensure successful implementation. Recommendations based on stakeholder feedback are presented for consideration below.

- **Ensure buy in and involvement of all players.** State level stakeholders (governor’s office, legislature, divisions), as well as regional players (agencies, providers) must be committed to systems change. Advocates and consumers must be included in planning and implementation of the NWD system to ensure support from those who the system serves.
- **Ensure effective and accountable leadership.** There should be clear ownership of and accountability for NWD efforts. Ethics and oversight should be built in to the system. A “transparent system,” from the policy level to local implementation, is needed to ensure ongoing commitment and support. NWD will likely be achieved through phased implementation. A clear plan for managing expectations of stakeholders during each phase will help to deflect detractors who may focus on “unrealized” outcomes in the early stages.
- **Focus on sustainable development.** Funding is needed to ensure adequate marketing, a state-of-the-art information and referral system, enhanced capacity, training, evaluation and quality improvement. A plan for ongoing support for infrastructure maintenance, training, updating service and program information, and other aspects of the system must be included in the planning process. A legislative option to ensure sustainability should be considered.
- **Review impacts on existing policies, processes and programs.** For example, the organization of regional divisions varies by FSSA division (i.e., the Division of Aging’s sixteen AAAs serve different geographic areas than the Division of Family

Resources ten regions). In considering outreach plans, location-specific service information, training, and other components of NWD, it may be useful to review the various ways in which “regions” are defined by system partners. Differing regional boundaries across systems will impact system implementation and should be considered early in the planning process.

- **Efforts should be made to ensure that existing programs, such as options counseling offered through the AAAs and ADRCs, will not be diluted.** Specialized expertise may not be reflected in a large scale system. Any change should incorporate successful and well-developed approaches.
- **Acknowledge the gaps in services and focus on strategies to address them.** As discussed previously, system capacity issues, including availability of adequate numbers of case managers, service coordinators, and information specialists is essential to service access. Where service gaps exist, NWD planning should incorporate strategies to address them.
- **Establish advisory processes to inform ongoing NWD planning and implementation.** A panel of consumers, representative of the served by population, could function long-term to provide feedback on the early stages of the system and provide input on revisions as implementation progresses. An advisory group of regional stakeholders (providers, agencies, advocates) could function in a similar fashion, but also provide input regarding policy, process and market issues.
- **Consider options for incorporating incentives and sanctions** to ensure buy-in, collaboration and information sharing at state, regional and local levels of service provision and among system partners. Given issues with staff quality identified by stakeholders through all stakeholder engagement modes (focus groups, regional events, survey), exploring options for all systems to encourage the NWD culture could provide strong support for effective implementation of systems change.
- **Develop a robust system of ongoing community engagement.** Initial stakeholder engagement activities generated high interest and also raised expectations of ongoing dialogue. Using e-mail blasts, website alerts, periodic community events, and other means of communication will assist in building ongoing support while increasing awareness of system improvements across the state.

## Continuous Quality Improvement

Continuous quality improvement is an integral part of all of the components of NWD. As such, those quality-related recommendations made in previous sections, e.g., ensuring updated information in a web-based system, are not repeated here. Rather a few additional recommendations building on stakeholder feedback are offered as guidance.

- **Use long term data analysis and research** to inform the system. Include in this effort, a using “big” or “smart data” technologies as well as consumer research. The latter might include research on user & provider experience and tests to ensure information on resources is correct and current.

## Conclusion

In addition to the key themes which emerged related to the key NWD planning components, stakeholders identified significant opportunities for system change and thus consumer outcomes if NWD is successful. Among the opportunities noted were increased collaboration, early intervention to reduce health and social crises, reduced system costs, and more educated and self-directed consumers. NWD is viewed as a unique opportunity to shift how public and private partners work together and serve the stakeholder population.

## I. Summary of Focus Groups

The purpose of the focus groups was to gather information from state agency staff as well as representatives of organizations representing statewide constituencies on the system of Long-Term Services and Supports (LTSS). The discussions were designed to elicit stakeholders' views of past efforts to improve the system, current system issues, and ideas for how NWD implementation could improve LTSS.

### 1.a Focus Group Methods

FSSA staff assisted the CAC team in identifying participants drawn from both state agency staff and representative advocacy or provider organizations. FSSA extended the invitations to the focus groups participants. One group was conducted with state agency staff and two were conducted for the organizations. Each focus group began with a brief overview of the purpose of NWD, a description of the planning process and an explanation of the role of the focus groups in the community engagement effort. Each focus group lasted about two hours.

Participant Expertise/Affiliation	Date	Number of Participants (n=25)
FSSA Strategic	July 16, 2015	3
State Department of Health (ISDH)	July 16, 2015	2
Health Care Quality (HQCIS)	July 16, 2015	1
Division of Disability & Recovery Services (DDRS)	July 16, 2015	1
Department of Child Services (DCS)	July 16, 2015	2
Division of Family Resources (DFR)	July 16, 2015	1
Association of Service Agencies	July 21, 2015	1
Provider	July 21, 2015	1
Family Advocacy Organization	July 23, 2015	4
Provider Organization	July 21, 2015	3
	July 23, 2015	3

Indiana Office of Technology (IOT)	July 23, 2015	1
Disease Specific Organization	July 23, 2015	2

## I.b Focus Group Results

The focus group facilitator asked a set of 16 questions developed to elicit stakeholders' views on the strengths and weaknesses of the current system of LTSS and to identify crucial areas to be addressed in implementation of a NWD system. Input received from focus group participants is summarized below by major topic of discussion.

### Consumer Needs

Focus group participants were asked what they identify as the most significant challenges or needs facing people who are trying to use or need LTSS?, and whether any of the challenges faced are particularly pronounced in distinct geographic areas of the state.

Participants most often cited the following needs or challenges facing consumers:

- **Information**
  - General lack of information and education about services available
  - No central source of information on services
  - Health language is not well-understood
  - Lack of inter-agency knowledge and coordination
- **Geographic Inconsistency**
  - Rural areas lack providers, and thus services are harder to find
  - Takes longer for information to spread in smaller communities

*“There so much variability. You receive radically different responses from different offices.”*

*“Case management can mean something different depending on what your problem is and where you are in the process.”*

- Transportation to access services is difficult in all parts of the state
- Lack of standardized information and process around the state
- **Professional Services**
  - Difficult to find skilled navigators or persons skilled in assessment
  - Fragmented services and few staff knowledgeable about all possible options
  - Key staff, e.g., discharge planners, lack needed information or expertise

### Consumer Awareness and Access

The facilitator asked the group participants to identify the “doors” through which consumers currently access LTSS and the means by which outreach and awareness of these services and supports are achieved. Then, participants were asked to assess these current systems of information and access and to provide suggestions for improvement.

Key themes in the discussion of the “doors” currently used to access LTSS include:

- **Extensive but disconnected**
  - There are formal doors: Agencies, hospitals, health providers, legal system professionals, 2-1-1, social service organizations, schools, public safety providers, state offices, county and state representatives, advocacy organizations
  - Informal doors are also important: Churches, friends, family and the internet
- **Navigation**
  - Consumers lack “language” to find needed services
  - Websites, offices, and other entry points are not user-friendly
- **Point of entry**
  - Entry point is critical as “as this determines everything that comes after”

Participant’s most often cited the following as the means by which outreach and awareness of LTSS are conducted:

- **Internet**
  - Google searches, websites and social media
- **Area specific marketing** and advertising

- Pamphlets and other written materials available in the community
- Speeches to community groups
- **Public events** (health fairs, expos)
- **Professional education**
- **211**
  - Phone and website
- **Word of mouth**
  - Providers to clients and clients to clients

*“I find out from other parents. When I need information they are the ones who know.”*

*“Now? Pull out that phone; do a search with a few words. That’s what people do now.”*

Participants were asked to share their recommendations for improving consumer awareness of and access to LTSS. Among the most commonly cited recommendations were:

- **Education and training**
  - Trained staff at the “doors” need better information to effectively assist consumers
  - Effective and well-trained staff navigators are needed for assessment and guidance
- **Consumer-driven**
  - Assessment should be focused on the needs or problems of the consumer, followed by the determination of eligibility for services
  - Easy to understand and consistent language used throughout the system; includes consistent naming of similar services and programs
  - System messaging that “connects” with consumers
  - System response for people with language barriers or who lack technology skills or access
  - Minimum number of transitions
- **Web-based resources**
  - Enhancement of existing websites, including for 2-1-1 and state websites; language is difficult to understand and search functions are not effective
  - Facilitated technology (helps consumer navigate) with strong electronic connection points between programs and services
  - One central electronic information center

- Systems accessible on mobile devices
- **Incentives for Collaboration and Sharing**
  - Tools and incentives needed for sharing information and to support buy-in to a more effective system

### Partnerships/Coordination of Efforts

In this section of the discussion, focus group participants were asked to assess the current state of coordination and collaboration in the LTSS system, and to identify barriers to developing and maintaining services so a coordinated system would work effectively. They were also asked to provide ideas for improving coordination efforts.

Among the barriers to developing and maintaining services in a coordinated system, those most commonly cited by participants were:

- **Lack of communication, understanding and commitment**
  - State FSSA divisions and service providers function in silos; they operate in “their own worlds”
  - No incentives to make connections across divisions, programs, and providers
  - Lack of tools and systems to support information sharing
- **Regional differences**
  - Difficult to provide uniform information with no difference by region

Participants’ key recommendations for improving coordination clustered in response to the barriers identified.

- **Collaborative environment**
  - Create environment of collaboration from state agencies to local providers; message that working together is better and expected
  - Create incentives for coordination, reduced “handoffs,” and other indicators of coordinated service

## NWD Implementation

The final area of discussion focused participants on describing opportunities a NWD system could provide for change, as well as what critical issues must be addressed for a successful NWD system to be implemented.

Participants were positive about the opportunities a NWD system could provide, but were concerned about the design and implementation process. The most cited opportunities in having a NWD system were as follows:

- **State Divisions and external organizations work together**
  - NWD is opportunity to show the benefits of working together
- **Consumer benefits**
  - Creation of useful consumer website
  - Consumers get matched with correct services the first time
  - Decreased wait times for services
  - Closing gaps in service
  - Prevention of health and social crises
- **System benefits**
  - Reduced layers with a “one-source” system
  - Reduced cost of long term care
  - Efficient use of available funds to allow service to more people in need

While participants were hopeful these opportunities for change would be realized, they also expressed concerns that only with effective implementation of NWD would this occur. Integrated into these concerns were their responses to the policy and practical, i.e. day-to-day, level changes needed to ensure such as system is successful.

Focus group participants’ concerns about implementation of a NWD system and the policy and practical level changes identified clustered around key themes, including:

- **Effective leadership**
  - Evidence of commitment by state leaders (Divisions, legislature)
  - Effective public case made to gain support for the required investment
  - Open and transparent planning and implementation process
  - Possible legislative mandate for assurance of long-term support of the system

- **Manage expectations**
  - Fully functioning system at beginning crucial for long term buy-in
  - Long term system change requires management of expectations along the way to ensure continued engagement and commitment to moving forward
- **Build on Strengths**
  - Integrate current and successful options counseling done by AAAs and ADRCS
  - Model current expertise from across the service spectrum in any large scale system
- **Adequate and sustained funding**
  - Initial and ongoing funding must be sufficient to build and maintain a fully functional system
  - Funding for ongoing maintenance and continuous improvement

## II. Summary of Information Gathering Sessions

The purpose of these events was to engage a broad range of local consumers, providers, advocates, family and friends, and other key participants in a discussion of LTSS and to engage them in crafting the “ideal” NWD system for Indiana.

### II.a Methods

FSSA staff assisted in identifying 10 regional sites to hold public information gathering sessions around the state. The Area Agencies on Aging (AAAs) were enlisted to act as hosts for these events (e.g., secure a location; identify time and date), to assist in identifying regional stakeholders, and to extend invitations and send reminders to stakeholders. With their help we held 10 successful events in eight weeks.

Location	Date	Total Participants	Provider	Advocate	Other*	No Affiliation Noted
Muncie	July 24,2015	14	10	2	2	na
Richmond	July 28,2015	7	3	3	1	na
Lafayette	July 30, 2015	20	6	7	-	7
Indianapolis	July 31, 2015	29	7	9	7	6
Fort Wayne	August 4, 2015	31	18	3	7	3
Evansville	August 5, 2015	47	20	11	6	-
Greenwood	August 7, 2015	14	nc**	nc	nc	nc
Hammond	August 11, 2015	16***	6	-	8	2
Columbus	August 20, 2015	44	17	7	17	3
Vincennes	September 10, 2015	16	5	1	10	-

\*Includes those who checked multiple categories.

\*\*Data was not captured by project staff before event sign-in sheets were deleted. Project staff in attendance identified a strong group of advocates at this event, a few providers, and others (e.g., attorney, educator) in attendance.

\*\*\*Discrepancy between recorders may underestimate attendance; one scribe noted 19 participants.

## Limitations

While the NWD system is intended to bring together those needing and using LTSS across the life span, a majority of attendees at the regional events represented providers and advocates for older adults and for persons with disabilities (of all ages). Fewer attendees represented LTSS for youth and their families, schools and other providers serving populations and representing programs from the wide range of potential stakeholders in the LTSS system. Hard to reach populations without access to transportation or who are not on lists of stakeholders were not reached through this effort.

Event facilitators also asked attendees to identify themselves as a provider, advocates, consumer or “other” when signing in at the event. The categories used did not always accurately identify all participants. Many noted they fell into more than one category (e.g., providers, consumer and advocate), or did not identify with any category. Another category of attendees, staff members of state legislators’ and township trustees’ offices, was not adequately captured in these categories. Thus, these data on type of provider should be viewed with caution.

## II.b Results

After an introduction of the NWD initiative by an FSSA staff member, the event facilitator asked participants a set of 10 questions to elicit their views on the current system of LTSS, suggestions for improvement through NWD, needed resources to implement a NWD system, priorities for action, and ideas for sustaining stakeholder engagement as the system is developed and implemented. During the three-hour events, large and small group discussions allowed for interactive consideration of the questions. Input received from event participants is summarized below by major topic of discussion.

### Current System of LTSS

To begin the discussion, the facilitator asked participants to identify positive changes they have observed in LTSS over the past five years. Responses converged around common themes. Among the themes regarding recent system improvements were:

- **Awareness of Need for Change**
  - State level actors aware of issues
  - Shift in thinking among stakeholders about serving consumers
  - Conversation shift to healthy aging, aging in place, person centered counseling, engagement in one’s own care, preventive services
- **Reduced waiting lists and expanded eligibility**
  - Waiver programs have no wait times or reduced wait times for services
  - Waivers cover higher income levels
  - Electronic application process led to improved Medicaid response time
- **Stronger AAAs/ADRCs**
  - Increased communication between FSSA Divisions and regions
  - Certification of staff improved information provided
- **Expanded options**
  - Money follows the Person
  - More in-home service options
- **More providers**
  - General increase in number and type of providers
- **Better coordination and collaboration**
  - Increased interagency collaboration (state divisions, local agencies)
  - Improved collaboration between hospitals, providers and care facilities
- **Access to information**
  - Media coverage
  - Technology access
  - 2-1-1

Discussion of these improvements set the stage for identifying changes still needed to ensure effective LTSS. Some of the “changes needed” participants’ reported build on continuing improvement where positive change has already occurred, e.g., access to information, focus on community-based care, while other suggestions moved beyond existing improvements. Among the system aspects commonly cited as needing improvement were:

- **Access to information**
  - Information readily available, comprehensive, understandable, accurate, and consistent

- Education and outreach with focus on early planning
- Increased awareness of AAAs and other sources as available to all
- Guidance and navigation in filtering to relevant information
- Improve access for those with vision and hearing impairments
- **Ensuring options**
  - Consistent waiver services
  - Enhance nursing home discharge policies and planning
  - Reduce system bias toward the use of institutional settings; sustained efforts to rebalance between institutional and home and community based services
- **Referrals and follow-up**
  - Shared assessments and other forms
  - Support with technology interacting across systems
- **Resources for mental health**
  - Integrate mental health and social services
  - Formal guardianship program
- **Linkages across age-span and payers**
  - Connect aging and non-aging services and organizations
  - Support for multi-generational caregiving
  - Better integrate services and supports for those under age 18 and non-elderly adults
  - Expand awareness for public and private payers
- **Cultural needs and differences**
  - Reflect in language of information, staff training, availability of translators
  - Reflect in options for care
- **Expanded Services**
  - More services for rural areas, for homeless, those with traumatic brain injuries, criminal history, or behavioral issues
  - Expand transportation and reduce fragmentation in transit services
  - Increase adult protective services
  - More emergency and/or temporary placement options
  - Expanded night and weekend options
- **Streamlined system**
  - Reduce fragmentation

- Simplify information
- Common forms and shared information
- **Fragile system**
  - Reimbursement rates and available waivers fluctuate; reliability is needed
  - Hiring and training of staff needs to focus on viable and sustainable workforce

### “Best” NWD System

The facilitator asked small groups of participants to identify what a “best” NWD system of LTSS would look like, with their ideas to be shared with the larger group and merged into a set of ideal components. Many of the ideas proposed grew from the discussion of needed system improvements, but many of the ideas for a “best” system were much more concrete and detailed. Participants were encouraged to envision an ideal system, rather than one constrained by the current environment (policies, funding, historical relationships). After small group ideas were combined, participants were asked to identify their priorities among the many suggested components of an ideal system.

Strong common themes emerged around the following priority components for a NWD system:

- **Centralized, web-based system with the following characteristics:**
  - User friendly with a simple search function available 24/7
  - Employs “scenario builders” like those used by hospitals, insurance companies
  - Algorithm driven
  - Incorporates triage to rate urgency of care or information need
  - Uses pictures and visual cues; consider chat function
  - Uses language of the consumer
  - Fully accessible, in language, literacy and ability
  - May include public and professional portals
  - Automatic follow-up by a human to assist in choice where services are indicated and tracking of outcomes (i.e., system navigators, coaches or transitions managers)

- Quality control, including fully functional from day one, consistently updated and checked for accuracy
- **Provides multiple access points for consumers who do not use technology**
  - Consider public kiosks (library, transit areas), walk-in centers
- **Uses a road-based, continuing ad campaign**
  - Ensure community is aware and remains aware of the system
  - System name indicates it is a system for all ages and all payers
  - Utilize all media, social media, and community communication methods, including print (e.g., ads with utility bills, community newspapers and newsletters, flyers)
  - Identify and targets market segments
- **Includes screening and extensive and ongoing training for common procedures and information/referral**
  - Ensure intensive screening and training for system employees
  - Expand training and cross-training at all “doors”
  - Use consistent intake and assessment processes; certification of intake staff is needed to ensure quality
  - Remove barriers to information sharing
- **Includes these underlying assumptions:**
  - Utilizes and builds on existing systems and resources(2-1-1, Elder Locator, Food Bank, others)
  - One-call, one person to gain access; information follows the person
  - Assessment focused on need not eligibility
  - State access with regional focus
  - Accountable to consumers
  - Sufficient start-up and sustained funding to ensure highest quality system

*“Every ‘door’ could have an information specialist who receives training and knows how to navigate the basic system”*

*“We need to focus more on putting the doors where the needs are; go where the people with needs congregate.”*

## Supports Needed for Implementation

The facilitator asked event participants to identify the types and levels of support needed to ensure success of a NWD system in Indiana. These supports were focused at the state, regional and local levels and on technology supports.

### State Level Support

Participants most frequently identified the following supports as needed at the state level to ensure local NWD system success.

- **All players involved**

- State level stakeholders (divisions, legislature, and administration) share a common goal, and are committed to long term systems change.

*“There must be a vision for change that is robust against changes in administration.”*

- **Effective leadership**

- Clear ownership and accountability
- Transparency in policy, planning and implementation
- Ethics and oversight integrated into system
- Manage staged implementation
- Review/rethink regional boundaries across systems
- Incentivizes NWD engagement, including through program funding opportunities

- **Adequate initial and long-term funding**

- Combination of public and private, and shared between state, regional and local communities/entities
- Flexible funding for strategic, results based implementation

- **System quality**

- Adequate staffing
- Training
- Statewide consistency
- Accurate and timely updates
- Security

- **Marketing and education**
  - Public and agency campaign
  - Conveys importance – “the why” of NWD has to be communicated
  - Conveys awareness of the importance of planning, and knowing how to access information, prior to a crisis
- **Consumer engagement**
  - Ongoing opportunities to “listen” and incorporate consumers’ needs

### *Regional Level Support*

When asked to identify what is needed at the regional level to ensure local success, participants most frequently cited the following:

- **Regional players involved**
  - Buy-in from all agencies, providers, advocates
- **Leadership**
  - Communication path between state and local levels
  - Collaboration hub the norm at the regional level
  - Engagement of all regional leaders
- **System quality**
  - Responsive to stakeholders (consumers, providers, advocates)
  - Adequate capacity (staffing, training)
  - Regionally consistent
  - Up-to-date regional information
- **Funding**
  - Advocacy for adequate and sustained (and increased if needed) funding

### *Local Support*

When asked to identify what is needed at the local to ensure NWD success, participants most frequently cited the following:

- **Marketing and education**
  - Convey importance of “keeping residents in the community” and link to NWD; convey who it services, what it is and why it is needed

- Ensure message is connecting to unique communities
- **Leadership**
  - Local agencies and provider communication/collaboration; build a “hub” of collaborative service at the local level
- **System quality**
  - Identify and update local resource information
- **Engagement**
  - Grassroots communication

### *Technology Support*

The facilitator asked event participants to identify the key functions of technology in supporting a NWD system. Participant responses mirrored the components of technology recommended in their “vision” of a best NWD system. That is, rather than focusing on the functions of such a system, the participants cited essential attributes. Among the most frequently cited attributes of a technology system in supporting NWD were:

- Web-based
- Easy to use; clear navigation; access to multiple services from single entry
- Multiple portals and multiple modes of entry
- Integrated
- Smart/algorithm driven
- Universal access
- Consumer tested
- Ensures privacy and security
- Maintained
- Builds on existing effective systems (local, other states)

### *Keeping Stakeholders Engaged*

To wrap up the sessions, the facilitator asked event participants for their suggestions for ensuring consumers, advocates, providers, caregivers and others are engaged in implementation and assessment of Indiana’s NWD system. Frequently reported suggestions include:

- Distribution of draft NWD plan for review and comment
- Electronic and in-person opportunities
  - Continue regional events
  - Consider webinars and streaming of statewide meetings/trainings
  - E-mail updates with latest NWD information, including progress reports, and opportunity for comment/suggestions
  - Updates posted on all relevant websites
- Establish consumer advisory group or panel that continues development of the system by providing regular input
  - Representative of local population
  - Expands as process expands

### III. Summary of Consumer Survey

Consumer surveys were used to allow consumers, providers, family and friends, and advocates to provide input on the current LTSS system, and to provide suggestions for improving the system under a NWD process.

#### III.a Methods

The CAC team developed questions to collect information on a range of topics related to respondent's use and perceptions of the long term services and supports.<sup>1</sup> The survey was designed in Qualtrics and made available electronically to anyone with an interest in sharing their views.

The survey was made available on July 10, 2015 and closed on August 28, 2015. Efforts to broadcast the survey included:

- **FSSA No Wrong Door website.** The link to the survey was included on FSSA's No Wrong Door website, with announcements made of survey launch, two mid-survey reminders of closing dates, and a final reminder of one week remaining prior to close. FSSA asked all state agency partners in the NWD process to broadcast the survey and share the link through their venues (e.g., social media, listserv, mailing lists).
- **FSSA Contacts.** FSSA's Division of Aging sent an invitation to participate to the 1100 contacts on the Division's listserv. The link and language inviting participation was also sent to the AAAs and ADRCS, asking that they share the link widely through their networks of consumers, providers, family members, advocates, and other stakeholders.
- **Project Stakeholder List.** The CAC team developed, with FSSA, a list of 215 stakeholders, and all were sent notice of the survey and of the regional events. These stakeholders were asked to share the link and information with their respective audiences via all means available.
- **Focus Groups and Regional Events.** The CAC team shared the purpose of the survey and the link to it at all focus groups and regional events. Regional event

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<sup>1</sup> The CAC team appreciates the prior work of Social Entrepreneurs, Inc., who developed and implemented Nevada's No Wrong Door community outreach effort. We adapted their excellent survey tool and clear reporting process to guide our own work.

participants also received the event Power Point presentation containing the link to the survey and were asked to share the link with their networks.

The lists noted above were not exclusive, but using all of them provided the best chance of reaching the widest possible audience. A total of 393 completed surveys were included in the analysis.

Quantitative analysis of closed-ended survey items included descriptive statistics. The CAC team analyzed the qualitative data using a grounded theory approach, coding comments based on emerging themes, noting similarities and differences, along with outliers or strong consensus of respondent statements. These data analyses guide the survey data presentation in this section.

### *Limitations*

To encourage survey response and limit risk related to participation, the survey was anonymous. No information was gathered on respondents and no ISP addresses were retained to ensure anonymity. A few stakeholders expressed concern that respondents could complete the survey more than once.

While we worked through the venues made available to us, consumers are under-represented in the survey. Since the survey was only made available in English, we believe non-English speaking populations, and those for whom English is not their primary language, are under-represented, as are African-Americans and Asians. More women than men participated.

## Respondent Profile

### *Geographic Representation*

Respondents were asked to identify their county of residence. Five counties account for 35% of responses. The percentage of total survey respondents represented by Marion, Lake and Allen counties are comparable to the state percentages accounted for by each. A slightly lower percentage of respondents identifying as consumers were Marion County residents than the percentage of the total state population represented. Participation from rural communities was lower than from urban areas.

Geography	Indiana Population Statistics		Survey Respondents (n=393)		Consumers (n=71)	
	#	%	#	%	#	%
Marion	903,393	14%	60	15%	7	10%
Lake	496,005	8%	37	9%	6	9%
Allen	355,329	6%	25	6%	4	6%
Knox	38,440	1%	18	5%	4	6%
Vanderburgh	179,703	3%	16	4%	3	4%
Vigo	107,848	2%	15	4%	1	1%
Hamilton	274,569	4%	14	4%	1	1%
Delaware	117,671	2%	13	3%	6	9%
Porter	164,343	3%	10	3%	4	6%
Tippecanoe	172,780	3%	10	3%	0	0%
Balance of State	3,673,721	57%	175	44%	35	48%

\*Indiana population statistics from 2010 U.S. Census

\*\*While numbers may differ, rounding will indicate the same percentage of the population.

\*\*Balance of Counties: Adams, Bartholomew, Benton, Blackford, Boone, Brown, Carroll, Cass, Clark, Clay, Clinton, Crawford, Daviess, Dearborn, Decatur, DeKalb, Dubois, Elkhart, Fayette, Floyd, Fountain, Franklin, Fulton, Gibson, Grant, Greene, Hancock, Harrison, Hendricks, Henry, Howard, Huntington, Jackson, Jasper, Jay, Jefferson, Jennings, Johnson, Kosciusko, LaGrange, LaPorte, Lawrence, Madison, Marshall, Martin, Miami, Monroe, Montgomery, Morgan, Newton, Noble, Ohio, Orange, Owen, Parke, Perry, Pike, Posey, Pulaski, Putnam, Randolph, Ripley, Rush, Scott, Shelby, Spencer, St. Joseph, Starke, Steuben, Sullivan, Switzerland, Tipton, Union, Vermillion, Wabash, Warren, Warrick, Washington, Wayne, Wells, White, & Whitley.

### *Type of Respondent*

The survey asked respondents to identify a category best describing their profile. Friends and or family members of consumers and advocates comprise more than half of those responding. Consumers, former and current, comprise 18%.

Of the total responding, almost one fourth (24%) indicated they were completing the survey on behalf of someone who was unable to complete it independently.

Respondent Identification (n=393)	#	%
Friend/Family member of consumer	110	28%
Advocate for consumers	93	24%
Consumer (Current and Former)	71	18%
Provider	64	16%
Non-paid caregiver	16	4%
Someone in need of services but not currently receiving them	13	3%
Paid caregiver	4	1%
Other	23	6%

Among those identifying as some other type of respondent, frequent responses included:

- Social worker
- Case or care manager
- Multiple identities (e.g., caregiver, advocate, family member and professional in the field; older person helping another elder)

### *Demographics*

While males and females are almost evenly represented in Indiana, more than three-quarters (81%) of survey respondents were female. In terms of race, African-Americans, Hispanics and Asians had lower representation when compared to state population statistics.

Fewer young persons and those over the age of 75 are represented. Persons aged 45-74 account for more than two thirds (65%) of survey respondents, while those 25-44 represent almost one quarter of those completing the survey.

<b>Gender</b>	Indiana Population Statistics*		Survey Respondents (n=393)		Consumers (71)	
	#	%	#	%	#	%
Female	3,364,396	51%	381	81%	50	70
Male	3,232,459	49%	74	19%	21	30
Other	0	0%	1	<1%	0	0%
<b>Race</b>			Survey Respondents** (n=381)		Consumer (n=70)	
	#	%	#	%	#	%
White	5,302,565	81%	351	89%	64	90%
Black/African American	624,217	10%	13	3%	3	4%
Hispanic	420,525	6%	4	1%	1	2%
Asian	124,843	2%	0	0%	0	0%
Mixed Race	118,272	2%	6	2%	0	0%
American Indian/Alaska n	26,282	<1%	1	<1%	0	0%
Pacific Islander	6,570	<1%	1	<1%	0	0%
Other	n/a	n/a	5	1%	2	3%

\*Indiana Population Statistics from 2013 Census Data

\*\*12 Respondents did not identify by race

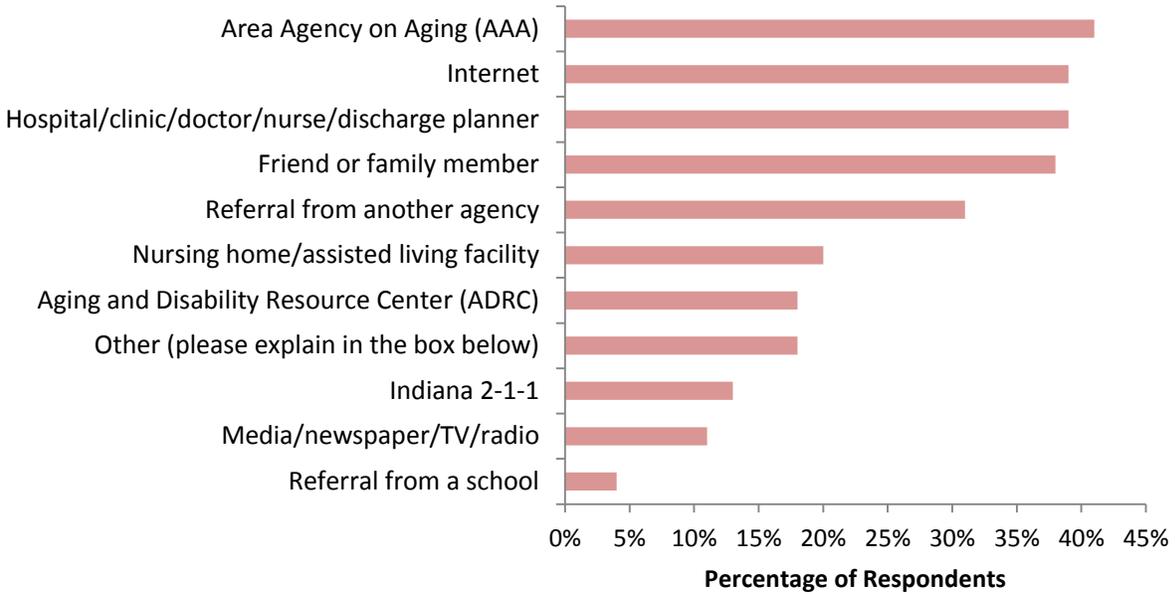
AGE	Total (n=393)		Friends/Family members of consumer (n = 110)		Consumers Only (n= 71)	
	#	%	#	%	#	%
0-20	1	0%	1	1%	0	0
21-24	3	1%	0	0%	1	2%
25-44	109	28%	21	19%	17	24%
45-64	198	50%	61	56%	25	35%
65-74	65	17%	22	20%	21	30%
75-84	13	3%	4	4%	5	7%
85+	4	1%	1	1%	2	3%

### Service Use and Perceptions

**Survey respondents were asked to identify how they learn about supportive services in their communities and they could cite multiple sources of information.**

The most frequently cited source of information was the Area Agency on Aging (AAA) with almost 45% of respondents listing the AAA as one way in which they learn about services. The Internet and medical providers such as a hospital, doctor, nurse or discharge planner were cited by almost 40% of respondents, followed by friends and family members.

## Learning about Services



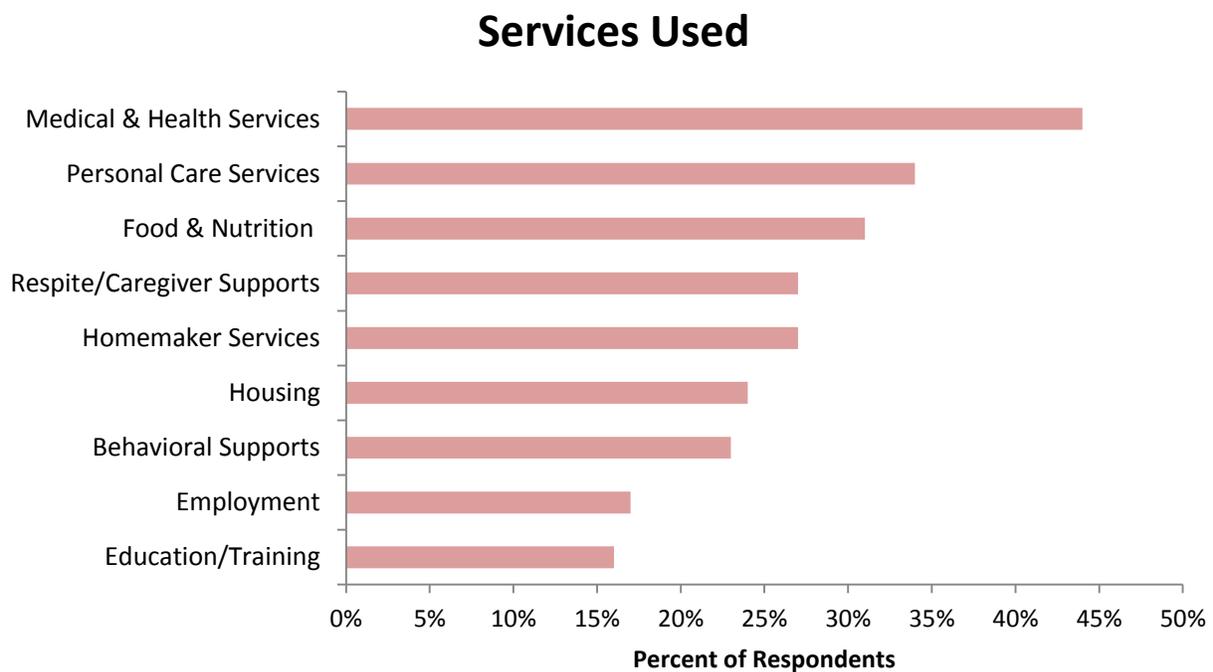
Among the most frequently cited “other” ways in which respondents mentioned they learned about services were:

- Senior centers
- Independent Living Centers
- Vocational Rehab
- Churches
- Mental health centers
- Professional networking
- Volunteer connections
- Support groups
- Fairs/workshops/seminars for self-advocates
- Advocacy organizations (e.g., ARC, Family Voices, About Special Kids, AARP)

**Survey respondents were asked to identify which of the information sources cited they found most helpful.**

Among the sources most frequently cited as “very helpful” or “helpful” were advocacy organizations (Family Voices, ASK, AARP), providers (service agencies, social workers), and personal contacts. Among the sources most frequently cited as “somewhat helpful” were state programs.

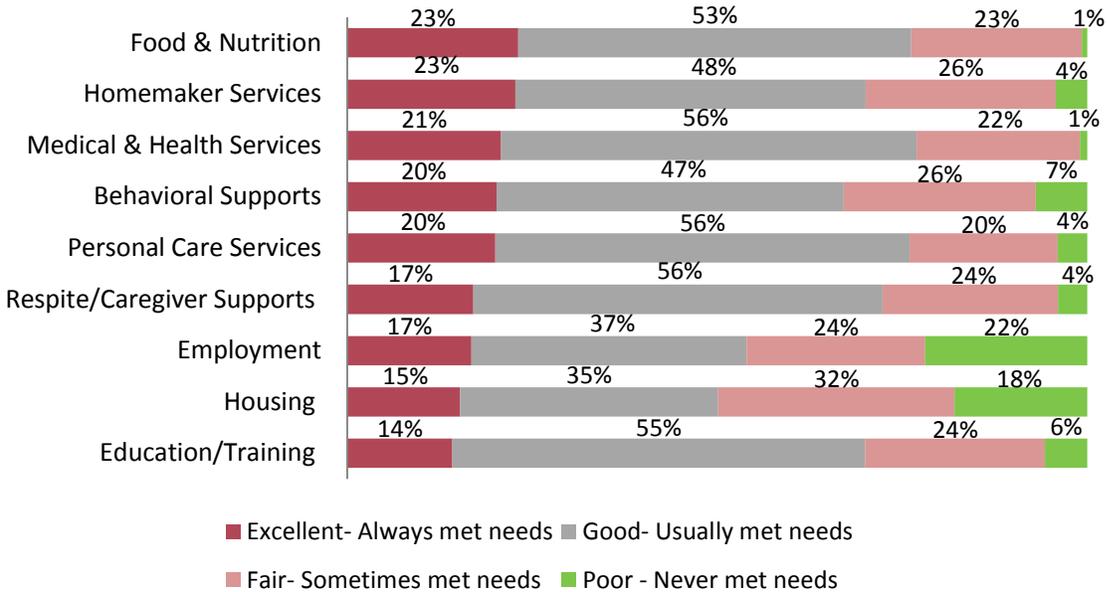
From a list of services, survey respondents were asked to identify those which they have used. Of those responding, 286 (73%) reported having used one or more of the following services. As shown, the services respondents most frequently reported as used were medical and health and personal care services.



**For each of the services used, respondents were asked to rate the extent to which the service met their need.**

The services most often rated as “excellent; always met needs” (23%) were Food and Nutrition and Homemaker Services, followed by Medical and Health Services (21%). Medical and Health Services, Personal Care Services and Respite/Caregiver Supports were also rated as “good; usually met needs” by more than half of those using these services.

## Evaluation of Services Used



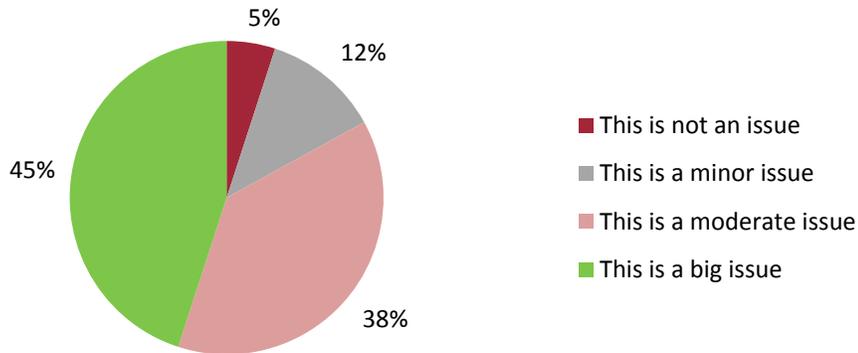
### Barriers to Service

Respondents were asked two questions focused on their views of barriers to accessing services.

**The survey first posed a general question about the degree to which gaining access to services is an issue in their community.**

Almost half (45%) rated access to services as a big issue, with more than one-third (38%) reporting this is a “moderate” issue.

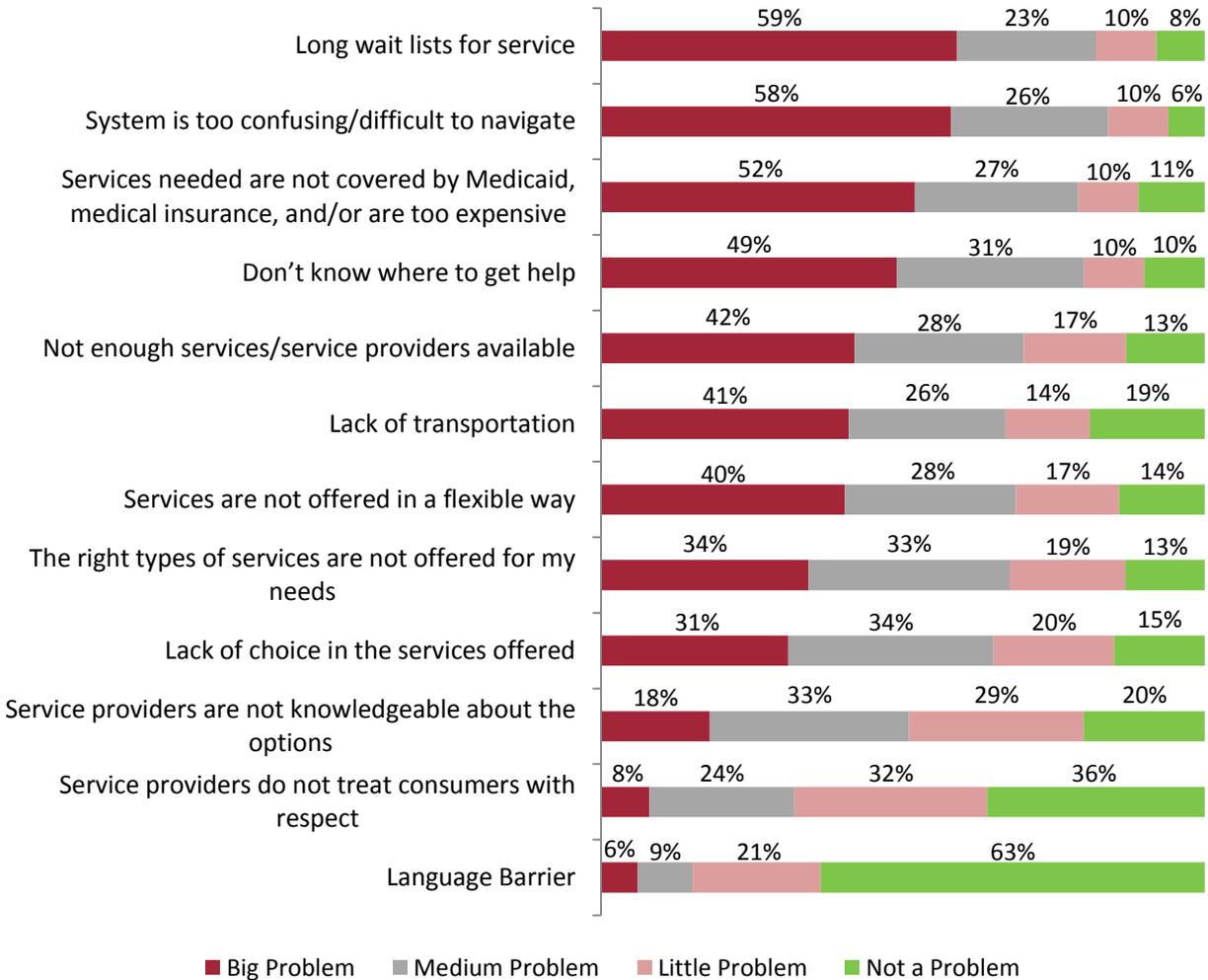
## Accessibility of Services in Community



**Respondents were then provided a list of possible barriers to service and asked to assess the degree to which each is a problem for them or someone they know in getting services needed.**

The issues survey respondents most often rated most often as being a “big problem” were long waits for services (59%) and a confusing system that is difficult to navigate (58%). More than half (52%) of those responding also rated services needed are not covered or are too expensive as a “big problem,” while (49%) of respondents rated not knowing where to get help at nearly this same problem level.

## Magnitude of Issues



Respondents were also asked to describe their number one frustration with getting the help they or someone they know need. An analysis of the open-ended responses revealed respondents' most frequently cited frustrations centered on what were coded as the following:

- System capacity.** As the most frequently noted frustration, capacity included the lack of providers in general, and specific providers, such as physicians. Specific services noted as lacking were transportation, addiction and/or mental health services, residential options, home health service for dually eligible, services for younger developmentally disabled, housekeeping, along with lack of access to

needed equipment. The lack of services available for those not meeting low-income requirements was also noted.

System capacity also is used to describe the numerous reports of frustration respondents reported with agency staff. Respondents expressed frustration with the lack of providers (physicians, nurses, etc.), high turnover rates, and lack of both enough staff and knowledgeable staff in agencies.

- **Program policies.** Comments on this theme identified Medicare and Medicaid policies that limit coverage, limit options (with focus on long term facility placement), and confusion regarding waivers as well as overall coverage for medical and non-medical expenses. Others noted difficulty in getting guardianship in order to ensure needed medical procedures would be covered.
- **Eligibility.** Closely related to overall program policies were comments our team coded as frustrations with access services due to eligibility restrictions. From young to old, issues of eligibility for residential placement, for in-home services, for equipment, and for non-medical related assistance were frequently noted.
- **Service delays/waiting lists.** Along with overall system capacity and program policies, delays in receiving services, along with the combined time to complete the application(s) process and receive service, was another of the most frequently cited respondent frustrations. Delays and long waiting times were noted in obtaining information, receiving assessments, obtaining service approval, and finding a provider from a limited pool. Some

*“I have a 7-year old wheelchair and a 12-year old hospital bed and cannot get them replaced. They are being held together with tape – literally.”*

*“People at the upper edge of the 80% low- moderate income can’t get assistance, which is not helpful in the aging environment. Aging people in this category have or will drain their resources they have worked so hard to accumulate only to pay medical bills or other unforeseen expenses. Go a leaky roof ...sorry can't help you because you're over income by 2% etc.”*

*“There are many complex factors that make people eligible or ineligible for services. Once you complete applications it often takes a long time to hear back from agencies and often there is no follow-up regarding whether or not people are approved for services.”*

respondents noted that a person's status declines (or the person may die) while waiting for a residential placement or needed services.

Following these major categories of "frustration," respondents also cited obtaining information (timely, sufficient, correct, consistent), and the lack of training among providers and agency staff to sufficiently and effectively serve those who come to them for assistance. The issue of the lack of "compassion" or respect shown to consumers, including not listening, was also coded in this category of training, but is an issue as well of overall service quality. Service quality, including responses from doctors, other providers, and agency staff was seen as a frequent frustration, as were providers who do not show up or who did not follow-up as promised.

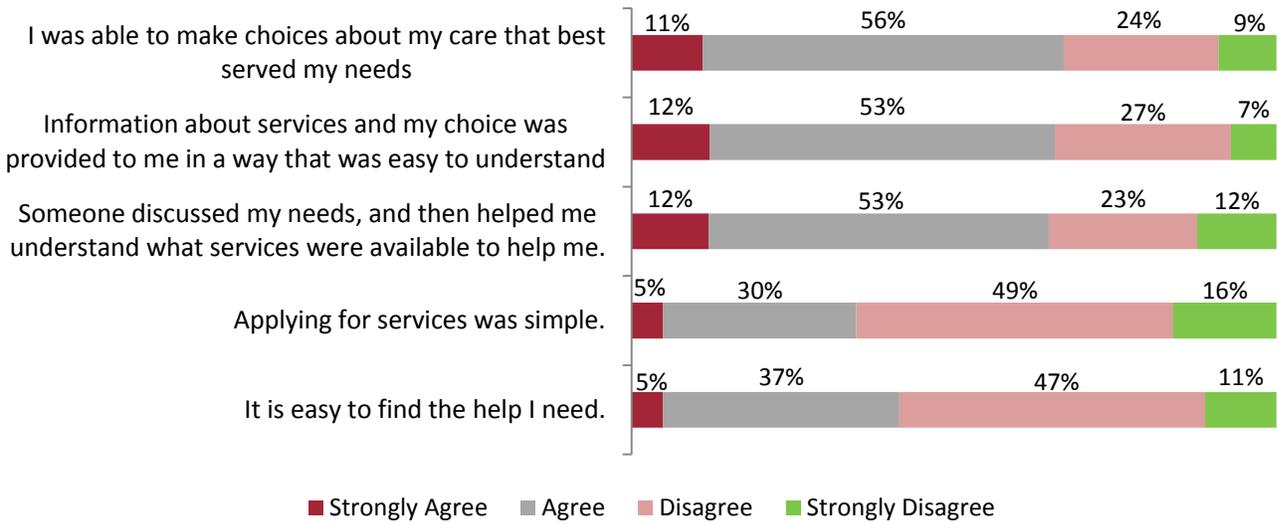
### Perceptions of Choice

Respondents were asked a series of questions to assess ease of finding services and the degree to which they were offered choice in their services.

**Respondents were first asked to rate the degree to which they agreed with a series of three items describing the way in which choice was integrated into their service experience. Then, respondents were asked to rate the degree to which they agreed with two items describing the ease of obtaining services and finding help needed.**

While about two-thirds of respondents indicated either strong agreement or agreement with the statements related to choice, fewer did so in rating the ease of finding help or applying for services. Sixteen percent strongly disagreed with the statement, "Applying for services was simple."

## Perceptions of Choice



### Assessment of What Works in the Current System

As part of a closing set of questions related to the overall system of LTSS, respondents were asked to reflect on what works in the current system.

**Respondents were asked what one thing works best in the current system of long term services and supports in their community.**

By a large margin over other responses, respondents identified three key components of the current system that work best. Among the most frequently cited things which work best in the current system – all to do with system capacity - were the following.

- Resources.** Available services, and the relative ease of accessing them once the consumer is connected, were cited as strengths in the respondents' current communities. Citing information and referral services, meal programs, housing, nutrition support, home health, medical transport, personal services, and community specific agencies, respondents

*“Once someone is connected (after an extensive wait) services are readily available and supportive.”*

*“We have plenty of places to go for help as long as you know they are there and what they are for.”*

noted that many can get the services they need. Yet, even with all of these resources, a few respondents mentioned that despite services available, consumers' are still challenged by too short time frames in which to make care transition decisions, service delays and a general lack of awareness that makes using available resources difficult.

- **Staff.** Specific examples of effective case managers, discharge planners, home nurses, attendant care aides, medical equipment providers, Ombudsmen, SHIP providers, and generally helpful agencies to assist and provide good service were cited. The quality of the staff service was sometimes described as in-person, as “tenacious advocacy,” knowledgeable, and easy to talk to about issues.
- **AAAs/ADRCs.** Among the three most frequent responses about what works best in their communities, respondents frequently cited the AAAs/ADRCs specifically. These resources were seen as being accessible, helpful, having knowledgeable staff, offering choices, assisting in navigating the system, providing easy referrals.

*“The Area Agencies and ADRCs are the most helpful resources.”*

*“Having an Area Agency on Aging worker to be your advocate is best.”*

Among the less frequently cited aspects of the system that work “best,” respondents noted collaboration between agencies, options for care, and the level of community support for people needing services.

### Priority Recommendations to Improve Access

**Respondents were asked what one change would make the most difference in improving access to services in their community.**

In order of frequency, the most commonly cited recommendations clustered in the following areas:

- **Improve Information.** Recommendations associated with improving access to information were the most frequent ones given by respondents (followed closely by improving availability of services). Recommended improvements in information ranged widely. Some focused on general education of the public about resources. Others were specific to information on location of navigators or providers. Others noted that education is also about helping the public understand the need for future planning, i.e., being aware now so when services are needed you know where to go and who can help. Among the themes emerging in the recommendations regarding improving information were the following:

- Simplify information
- Advertise services/Educate the community
  - Improve knowledge of services available and where/how to access them
  - Inform public of how to find and use existing navigators
  - Improve health literacy in the community
  - Use television, media, print, internet, direct mail and inserts; publicity must meet needs of all
  - Use informational meetings; distribute notices via schools, medical providers, churches, media – places where people get information
- Enhance websites
  - One website that is up to date

*“Using simple language to explain services rather than government policy lingo. More information on what is available to individuals who fall in the middle class section. More information on intensive services. More information on services available and who you can contact to get help with services.”*

*“Make sure that everyone knows the same thing so that they are all treated the same way. Give everybody the access to all services and make sure they know what is needed when they leave so they are ready for whatever comes up.”*

*“All service providers sharing their resources and programs for all individuals to be informed.”*

- Establish one central service agency; one-stop service
- Information should include realistic expectations for services (current waiting lists, costs, options)
- Provide information about which providers will accept reimbursement
- Family to family models of information and referral
- **Increase Availability of Services.** Recommendations associated with increasing the availability of services were the next most frequent ones given by respondents. Recommendations associated with increasing available services ranged widely, from just “more services” generally to very specific types of service. Among the recommendations were the following:
  - More services in rural areas
  - Improved transportation
  - Childcare
  - Continuum of care for persons with brain injury and/or mental illness
  - Expanded services after “office hours”
  - Expanded home and community based services
  - Programs and services for those not qualifying for Medicaid and other low-income based assistance
  - Increased number of day care service providers (for special needs youth)
  - More services for teens (social activities; wrap around services for those with disabilities and their families)
  - Advocacy centers
  - Affordable housing
  - Enhanced transition services
  - Home maintenance
- **Increase Capacity: Staff.** Recommendations associated with increasing the availability of staff were the next most frequent ones given by respondents. Among the common themes in these recommendations were ranged from generally increasing available personnel to changing policies that would attract quality staff and reduce turnover.

*“If there is a competent Case Manager involved, it is easier to comprehend all that needs to be done and understand who provides which services, and what each service provides. Without a good Case Manager, this process is very confusing.”*

Among the specific recommendations were:

- Provide staff to make home visits versus phone consultations
  - Have a specific family advocate versus automated system of response
  - Hire more case managers
  - Hire case managers to assist navigation of complex systems
  - Reduce caseloads of case managers
  - Increase wages for providers
  - Need enough night shift staff
  - More specialized medical providers (geriatrics; dementia care)
  - Hire Adult Protective Service case managers
- **Increase Capacity: Training.** Closely following increasing staff in respondent recommendations were recommendations related to the quality of the staff and to ensuring adequately trained staff are available. There was emphasis on ensuring that agency staff are aware of services and have the best, most up to date information in order to assist consumers. A few respondents acknowledged that quality staff and reduced turnover is related to “informed staff.” But direct care staff training was also noted, while others mentioned the need for generally more informed and well educated providers at all levels. Among specific recommendations related to staff training were:
    - Properly trained State and Federal employees who serve with kindness and respect and available on weekends and holidays
    - Train agency staff uniformly across the state on the goals for accessing and providing care
    - Train staff to be knowledgeable about medical terms and explain them in laymen’s terms to consumers
    - Train community workers to have knowledge of everything available

*“Train people in the positions to help so they have the knowledge about what is available and actually seem to care about the people looking for assistance.”*

*“We need better training for direct service staff.”*

*“We need to have easy access and contact to well trained personnel that are competent and compassionate in guiding a person through the process.”*

- Train long term care facility staff on treating co-morbid behavioral health issues
- Train staff to educate consumers about all service options

Among other recommendations frequently offered by respondents were ones related to streamlining service, improving communication/collaboration and coordination among agencies, increasing funding for programs and services, and changes in program policies to improve quality and provide coverage for to more consumers.



## Appendix A

### Focus Group Discussion Guide

#### State Level Stakeholders

##### 1.0 Welcome & Introduction

Thank you for coming today. My name is \_\_\_\_\_, with \_\_\_\_\_, and I'll be guiding today's discussion for FSSA. We should not be more than two hours and usually, once everyone is talking, this time goes very quickly.

FSSA is in the process of preparing a 3-year plan for implementing a No Wrong Door system. *[NWD Framework/Explanation]*

The purpose of this focus group is to hear from key stakeholders at the state level regarding how consumers – users of services and their families, friends and caregivers - learn about options for, and gain access to Long Term Services and Support (LTSS), how that system can be improved, and pressing issues/concerns regarding implementation of a No Wrong Door (NWD) system for LTSS. This information is essential to FSSA and to Indiana to help prepare for NWD implementation. You were invited to attend because you represent state level organizations, and thus bring your statewide perspective to this conversation.

I would like to go over a few ground rules before we get started. First, if there is no objection, I am tape recording this session. The recording is only to make sure that your comments are accurately reflected, and to assist me in writing the report of today's discussion. With only a minimal number of stakeholders in these discussions, it is not possible to guarantee complete confidentiality. However, only the netlogx staff assisting in these groups and I will access the taped sessions and, in reporting, I will not identify specific speakers. Still the content of the responses may indicate, by tone or word choice, who said what. After the report is prepared, all tape files will be destroyed.

To encourage dialogue, please be respectful of others' views and comments. You will all have an opportunity to share, so please take turns and speak one at a time. I also ask that we avoid side discussions out of respect for each other, to make it easier for all to hear and to focus. This makes the taping much more successful. Speak freely and with one another. That is, do not feel that you need to direct all your responses towards me; I am here only to facilitate.



Are there any questions or objection to taping?

- If objection; Scribe only
- If none; proceed
- You may know one another, but if not, and for my benefit, would you each, briefly, tell us your name and how you engage with or represent those who access the LTSS system (i.e., the perspective you bring).
- And, remember, our focus today is not on the delivery of service, but on OUTREACH and CONSUMER ACCESS TO INFORMATION about their service choices.

## 2.0 Consumer Needs

- 2.1 What are the most significant needs or challenges facing people who are trying to use or need/use LTSS services? (While finances might be an issue, we are asking about needs or challenges beyond economic ones).
- 2.2 Are there any challenges that are particularly pronounced based on region/geographic barriers?

## 3.0 Consumer Awareness/Access

- 3.1 What are the current “doors” by which consumers access LTSS?
- 3.2 How well do individuals and those who care for them know about LTSS services that are available?
- 3.3 What kinds of outreach are used to increase awareness about LTSS?
  - Are specific populations targeted in outreach efforts?
- 3.4 How accessible and effective are the current systems of information and access for consumers? (i.e. how well do current “doors” work?)
  - Are they comprehensive, up to date, user-friendly?
  - What are they key issues with the current “doors?”
- 3.5 Are you aware of Aging and Disability Resource Centers (ADRCs) in Indiana?
  - 3.5a If aware: What is your perception of the role of the ADRCs?



- 3.6 What sorts of things are available from the ADRCs to guide consumers to appropriate services?
- 3.7 Overall, what could improve awareness and access to information on services?

#### **4.0 Partnerships/Coordination of Efforts**

- 4.1 How well are programs and services coordinated across systems?
- 4.2 What are key barriers to developing and maintaining partnerships and coordinating services?
- 4.3 What could improve coordination efforts?

#### **5.0 NWD Implementation (briefly revisit NWD description)**

- 5.1 What opportunities do you see in regards to implementing a No Wrong Door System in Indiana?
- 5.2 What concerns do you have in regards to implementing a No Wrong Door System in Indiana?
- 5.3 What are the most critical issues that Indiana needs to address to prepare for implementation of a No Wrong Door strategy to service?
  - 5.3a What practical level changes are needed?
  - 5.3b What policy level changes are needed?
- 5.4 What resources do you think are needed for implementation of No Wrong Door?

#### **6.0 Concluding Questions**

- 6.1 I would like to summarize the key points in our discussion. Does this summary accurately reflect what was shared today?
- 6.2 Is there anything else you would have liked to discuss?

Thanks for participating today. Your views will be very useful to FSSA as staff work to draft the No Wrong Door 3 –year implementation plan.



If you have further thoughts you would like to share with me, and did not have time today or you think about something later, please feel free to follow up by phone or e-mail. (Hand out card).

## **Appendix B**

### **No Wrong Door Regional Event Agenda**

#### **Introductions & Logistics**

##### **Where We've Been & Where We're Going (FSSA Representative)**

- How does NWD different from other initiatives?

##### **Building Local Structures to Support a NWD System**

- What have been the key improvements in improving consumer access to LTSS in the past 3-5 years?
- What still needs improvement? (Key issues, challenges; probe: can we examine these in terms of staff (numbers, training); organizational characteristics (commitment to choice; collaboration/coordination; partnerships; referral systems); infrastructure (technology)

[Or: by service process – initial call; basic information, unexpressed needs, urgent needs and future needs; comprehensive assessment; eligibility determination – functional and financial; service access; ongoing monitoring]

##### **Measuring Success**

- What does the “Best” NWD system of LTSS look like?

##### **Levels of Support**

- What state-level support is required to ensure local success?
- What is needed at the regional level?
- What is needed at the local level?
- What key functions would information technology systems look like in this best system? What key functions should this technology support to ensure a “best” system?

##### **Top Priorities**

- What three changes should be priorities for NWD planning?

##### **Ensuring Broadest Possible Stakeholder Engagement over the Long Term**

- How do we ensure consumers, advocates, providers, caregivers, and others are engaged in measuring the success of NWD?

## Appendix C

### Consumer Survey

#### *Service Use & Perceptions*

##### **1.) Which of the following services have you used?**

- Medical & Health Services (for example, skilled nursing, wound care, home nursing)
- Food & Nutrition (for example, meal delivery, attending a meal site, help in getting food)
- Employment (for example, job training, looking for employment)
- Personal Care Services (for example, assistance with bathing, dressing)
- Homemaker Services (for example, help with shopping, doing laundry, managing finances)
- Respite/Caregiver Supports (for example, providing help or a break for caregivers)
- Behavioral Supports (for example counseling, behavior modification or autism treatment)
- Education/Training (for example, help in managing a chronic disease, weight/diet)
- Housing (for example, help finding housing, exploring options for living arrangements, home modifications)
- Have never used these services

##### **2.) For each of the services that you have used, to what extent did that service meet your needs? (Please click the button to represent how well those services met your needs.)**

- Excellent – Always met my needs
- Good – Usually met my needs
- Fair – Sometimes met my needs

Poor – Never met my needs

### ***Barriers to Service***

**3.) People find out about services they need in a variety of ways. Would you share how you learn about the supportive services in your community?**

- Area Agency on Aging (AAA)
- Aging and Disability Resource Center (ADRC)
- Indiana 2-1-1
- Internet
- Referral from another agency
- Referral from a school
- Hospital/clinic/doctor/nurse/discharge planner
- Friend or family member
- Nursing home/assisted living facility
- Media/newspaper/TV/radio
- Other (please explain in the box below)

**4.) For those information sources you used, rate how helpful each were in providing you with the information you needed.**

- Very Helpful
- Helpful
- Somewhat Helpful
- Not Helpful

### ***Magnitude of Issues in Accessing Service***

**5.) There are a number of reasons people may not receive the assistance they need. We want to know why people who need services may not be able to access the care they need. Please indicate how much of a problem each of the following is/has been for you or someone you know getting the services needed.**

- Don't know where to get help
- System is too confusing/difficult to navigate
- Long wait lists for service
- The right types of services are not offered for my needs
- Lack in choice of services offered
- Services are not offered in a flexible way
- Language Barriers
- Services needed are not covered by Medicaid, medical insurance, and/or are too expensive
- Not enough services/service providers available
- Lack of transportation (for example, unable to get to a provider's office to discuss services or complete needed forms)
- Service providers are not knowledgeable about the options
- Service providers do not treat consumers with respect
- Other Problem

***Perceptions of Choice***

**6.) We would like to know more about how easy it has been for you to find the help you needed. (For every statement: Please click the button that best indicates how much you agree with each of the statements below.)**

- It is easy to find the help I need.

- Applying for services was simple.
- Someone discussed my needs, and then helped me understand what services were available to help me.

**7.) We would like to know more about information you received about choices for your care and the extent to which you were given the option to choose the services that best fit your needs.**

- Information about services and my choices was provided to me in a way that was easy to understand.
- I was able to make choices about my care that best served my needs.

***Overall Community Assessment***

**8.) How big an issue is it to gain access to services in your community?**

- This is a big issue (lots of barriers, hard to understand what is available, can seem overwhelming to get what is needed)
- This is a moderate issue (some barriers, as it can be very time consuming and frustrating, but eventually you can get what is needed)
- This is a minor issue (there are some barriers, but the system is improving)
- This is not an issue (people can get the services they need)

**9. Please describe in the box below the one thing that works best in the current system of long term supports and services in your community**

**10. Please describe in the box below your number one frustration with getting the help you or someone you know needs.**

**11. What one change do you think would make the most difference in improving access to services in your community?**

**12. Which of the following best describes you?**

- Current consumer of services
- Former consumer of services
- Friend/family member of consumer
- Advocate for consumers
- Someone in need of services but not currently receiving them
- Paid caregiver
- Non-paid caregiver
- Provider
- Other

**13. Are you completing this survey on behalf of someone who is unable to complete it independently?**

- Yes
- No

**14. What is your gender?**

- Male
- Female
- Other

**15. What is your age?**

- 0-12
- 13-17
- 18-20
- 1-24
- 25-44
- 45-64
- 65-74
- 75-84
- 85+

**16. What is your race/ethnicity?**

- White
- Hispanic
- Black/African American
- American Indian/Alaskan
- Pacific Islander
- Asian
- Mixed Race
- Other (please explain in the box below)
- Prefer not to say

**17. In which county do you live?**

- Adams
- Allen
- Bartholomew
- Benton
- Blackford
- Boone
- Brown
- Carroll
- Cass
- Clark
- Clay
- Clinton
- Crawford
- Daviess

- Dearborn
- Decatur
- DeKalb
- Delaware
- Dubois
- Elkhart
- Fayette
- Floyd
- Fountain
- Franklin
- Fulton
- Gibson
- Grant
- Greene
- Hamilton
- Hancock
- Harrison
- Hendricks
- Henry
- Howard
- Huntington
- Jackson
- Jasper
- Jay
- Jefferson
- Jennings

- Johnson
- Knox
- Kosciusko
- LaGrange
- Lake
- LaPorte
- Lawrence
- Madison
- Marion
- Marshall
- Martin
- Miami
- Monroe
- Montgomery
- Morgan
- Newton
- Noble
- Ohio
- Orange
- Owen
- Parke
- Perry
- Pike
- Porter
- Posey
- Pulaski

- Putnam
- Randolph
- Ripley
- Rush
- St. Joseph
- Scott
- Shelby
- Spencer
- Starke
- Steuben
- Sullivan
- Switzerland
- Tippecanoe
- Tipton
- Union
- Vanderburgh
- Vermillion
- Vigo
- Wabash
- Washington
- Warren
- Warrick
- Wayne
- Wells
- White
- Whitley

