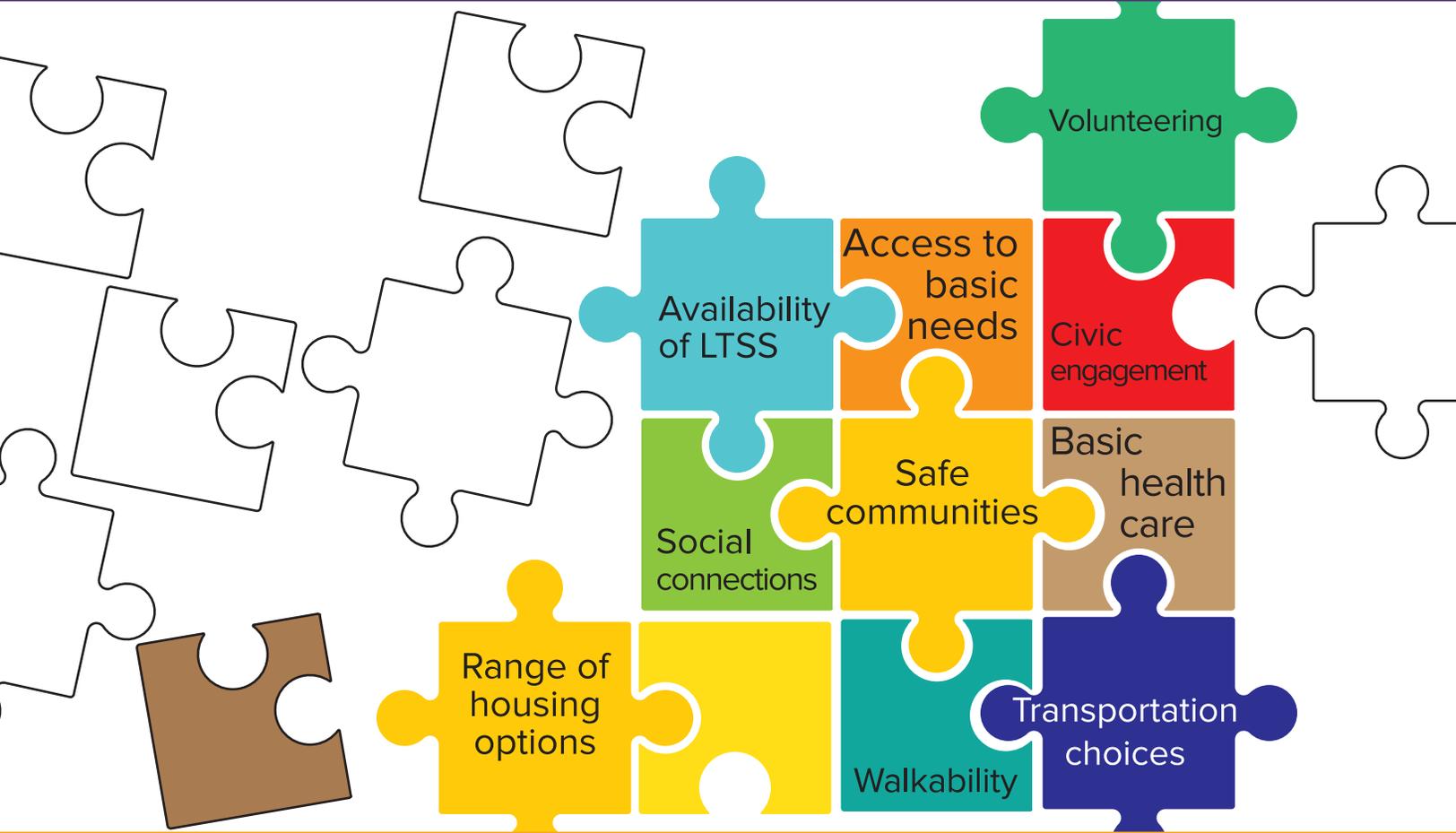




# Office for the Aging



## Office of Community Living Feasibility Study 2015



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### I. Executive Summary

The New York State Office for the Aging (NYSOFA), through Part N of Chapter 57 of the Laws of 2015 (Health and Mental Hygiene; S2007-B/A3007-B), was charged with seeking “public input about the creation of an office of community living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities.” Part N defines the areas of focus and includes:

1. Furthering the goals of New York’s Olmstead plan.
2. Strengthening the No Wrong Door approach to accessing information and services.
3. Reinforcing initiatives in New York’s Balancing Incentive Program.
4. Creating opportunities to better leverage resources.
5. Evaluating methods for service delivery improvements.
6. Analyzing the fiscal impact of creating such an office on services, individuals, and providers.

To assist NYSOFA in meeting the goals and intent of Part N, NYSOFA selected the Center for Aging and Disability Education and Research (CADER) at Boston University’s School of Social Work to assist with examining the feasibility of creating a new administrative structure and gathering public input.

To meet the goals and intent of the legislative imperative, NYSOFA surveyed consumers and providers; hosted regional listening forums; and developed a report and recommendations based on the information collected. A 21-member steering committee provided input and assisted with disseminating information about the survey and public forums. The partnership and engagement with key service providers and advocacy groups in both the aging and disabilities communities were critical in reaching more than 1,600 providers and consumers and an additional 500+ participants in the regional listening forums.

Although feedback from the public indicates that more information is needed regarding the potential of creating an Office of Community Living, valuable information was gathered on service delivery and program outcomes that would result from the expansion of coordinated services for older adults and persons of all ages with disabilities.

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### II. Introduction

#### A. Office of Community Living Authorizing Statute and Areas of Focus

The New York State Office for the Aging (NYSOFA), through Part N of Chapter 57 of the Laws of 2015 (Health and Mental Hygiene; S2007-B/A3007-B), was charged with seeking “public input about the creation of an office of community living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities.” Part N defines the areas of focus and includes:

##### **1. Furthering the goals of New York’s Olmstead plan**

In November 2012, Governor Andrew M. Cuomo issued Executive Order Number 84 to create the Olmstead Development and Implementation Cabinet (Olmstead Cabinet). The Olmstead Cabinet was charged with developing a plan consistent with New York’s obligations under the United States Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) (Olmstead). Olmstead held that the state’s services, programs, and activities for people with disabilities must be administered in the most integrated setting appropriate to a person’s needs.

To examine New York’s compliance with Olmstead, the Olmstead Cabinet employed a broad and inclusive process. The results of the Olmstead Cabinet’s work are contained in the “Report and Recommendations of the Olmstead Cabinet – A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Setting”

([https://www.ny.gov/sites/ny.gov/files/atoms/files/Olmstead\\_Final\\_Report\\_2013.pdf](https://www.ny.gov/sites/ny.gov/files/atoms/files/Olmstead_Final_Report_2013.pdf)).

The report identifies specific actions state agencies responsible for providing services to people with disabilities will take to serve people with disabilities in the most integrated setting. Four areas of focus emerged:

- The need for strategies to address specific populations in unnecessarily segregated settings, including:
  - People with intellectual and developmental disabilities in developmental centers, intermediate care facilities (ICFs), and sheltered workshops;
  - People with serious mental illness in psychiatric centers, nursing homes, adult homes, and sheltered workshops; and
  - People in nursing homes.
- The need to increase opportunities for people with disabilities to live integrated lives in the community;
- The need to develop consistent cross-systems assessments and outcomes measurements regarding how New York meets the needs and choices of people with disabilities in the most integrated setting;

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- The need for strong Olmstead accountability measures.

### **2. Strengthening the No Wrong Door approach to accessing information and services**

Finding and accessing the right long-term services and supports (LTSS) presents a daunting task for many individuals and their families. The current LTSS system involves numerous funding streams administered by multiple federal, state, and local agencies. Consequently, individuals trying to access LTSS frequently find themselves confronted with a maze of organizations and bureaucratic requirements at a time of vulnerability or crisis, which can result in people making decisions based on incomplete, and sometimes inaccurate, information about their options.

No Wrong Door (NWD) systems are intended to enhance consumer choice and control and help states create more consumer-driven, more efficient, and more cost-effective LTSS systems. The four primary functions of a NWD system include:

1. State governance and administration;
2. Public outreach and coordination with key referral sources;
3. Person-centered counseling (PCC); and
4. Streamlined eligibility for public programs.

NWD structural requirements in New York State:

- All individuals receive standardized information and experience the same eligibility process;
- A coordinated process that guides the individual through the functional and financial eligibility determination process; and
- Functional and financial assessment data are accessible to NWD staff so that eligibility determination and access to services can occur efficiently.

NWD requirements:

- Deliver standardized information about LTSS options whether an individual seeks information:
  - From an 800 number;
  - A website; or
  - A local office that is part of the state's NWD network.
- Provide individuals with assistance in accessing Medicaid or non-Medicaid LTSS services.

The state's 2013 BIP workplan identified the need to:

- Expand NYSOFA's NY Connects system statewide;
- Add an interactive online tool to allow individuals to help identify their LTSS needs;
- Develop tools and training to provide consistent information about the LTSS available in communities across New York;

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- Standardize information so that individuals experience the same eligibility determination; and
- Establish the NWD system as the gateway system for LTSS.

### 3. Reinforcing initiatives in New York's Balancing Incentive Program

The Balancing Incentive Program (BIP) authorized grants to states to increase access to non-institutional LTSS. BIP requires states to implement structural changes, including a no wrong door/single entry point system (NWD/SEP), conflict-free case management services, and core standardized assessment instruments.

BIP is helping states transform their long-term care systems by:

- Lowering costs through improved systems performance and efficiency.
- Creating tools to help consumers with care planning and assessment.
- Improving quality measurement and oversight.

BIP also provides new ways to serve more people in home and community-based settings, in keeping with the integration mandate of the Americans with Disabilities Act (ADA), as required by the *Olmstead* decision. The Balancing Incentive Program was created by the Affordable Care Act of 2010 (Section 10202).

In New York State, participation in BIP will reinforce the state's ongoing efforts to improve access to home and community-based long-term services and supports for those with physical, behavioral health needs and/or intellectual disabilities. Through improved access to information and assistance, individuals will be able to make informed choices regarding services, settings, and related issues.

To achieve these goals, New York will work to implement the three structural changes required under BIP, which will provide additional tools to streamline the state's LTSS eligibility and assessment process. To meet these requirements, specifically, the state will:

- **No Wrong Door/Single Entry Point (NWD/SEP):** Enhance the existing NY Connects network, which is currently operational in 54 counties and serves as an information and assistance system for long-term care services.
- **Core Standardized Assessment Instrument:** Continue implementation of the Uniform Assessment System (UAS-NY) and align with other agencies to ensure compliance with the core data set.
- **Conflict-Free Case Management Services:** Remediate any case management arrangements that do not align with the principles of BIP.

4. Creating opportunities to better leverage resources
5. Evaluating methods for service delivery improvements
6. Analyzing the fiscal impact of creating such an office on services, individuals, and providers.

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### B. Project Timelines and Actions

To ensure objectivity and transparency in the process, NYSOFA solicited consultants outside of New York State that had the expertise and experience to assist with the project. NYSOFA selected the Center for Aging and Disability Education and Research (CADER) at Boston University's School of Social Work (<http://www.bu.edu/cader/>) to conduct the following activities:

1. Examine recent federal initiatives creating an Administration on Community Living (ACL).
2. Examine other states' efforts to expand services supporting community living integration and local and/or regional coordination efforts within New York.
3. Lead the design and implementation of two statewide stakeholder surveys as well as conduct analysis from the survey results.
4. Facilitate steering committee meeting to gather input on the feasibility of creating an Office of Community Living.
5. Hold regional public meetings statewide to ensure maximum opportunity for stakeholders to participate.
6. Organize information and findings into a written report to be submitted to NYSOFA.

NYSOFA developed a three-phase process to meet the goals and intent of Part N.

- Phase I was the collection of data via survey instrument for consumers and providers of services that collected quantitative and qualitative information related to Part N focus areas.
- Phase II included nine regional listening forums where the initial quantitative data was shared for comment, feedback, reaction and discussion.
- Phase III included developing the report and recommendations based on Phase I and II.

The timelines and actions NYSOFA took to meet the intent and requirements of the law include:

#### **April – May 2015**

- Development of project timeline.
- Solicited to hire a consultant to assist with the data collection, analysis of data collected, other state models and structure of the federal ACL.
- Consultant secured weekly meetings to discuss scope of work began.
- Intern solicited and received from SUNY Albany to assist with project.
- Initial discussion on creation of steering committee begins.
- Consultant studies ACL structure and several state structures in preparation for kickoff webinar.

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- Kickoff webinar held on May 20 included outlining the scope of work based on the law; a brief report on federal ACL and state structures; the process for developing the steering committee and request for steering committee members; the process to collect information from the public; the ability to access a survey to weigh in on the process; timelines for the process; and ways stakeholder could help.

### June – July 2015

- Received recommendations for steering committee members and selected 21 members. 21 members represented: 10 aging, 9 disabilities, 2 aging and disabilities.
- Initiated development of surveys to capture required data as prescribed by Part N.
- Initiated development of outreach plan, expectations of steering committee members and tentative locations of regional forums.
- Held steering committee kickoff meeting explaining scope of work, project plan with timelines and deliverables, and expectations of steering committee members.
- Worked with steering committee to develop and finalize survey instrument.
- Worked with steering committee on distribution plan for survey, including commitment of steering committee members to distribute the survey among their networks and to assist consumers in filling out the survey and submitting surveys to CADER for analysis.
- Worked with 22 state agencies to disseminate survey to their networks.
- NYSOFA distributed survey to 59 area agencies on aging (AAA) directors and to internal provider and consumer lists.

### August – October 2015

- Survey open to public.
- CADER begins analysis of data, focusing on quantitative data to present preliminary findings at regional forums.
- Steering committee holds two conference calls to discuss regional forums, expectations at regional forums, assistance needed from members to identify accessible locations, and to develop the forum public announcement.
- NYSOFA works with steering committee members and AAAs to secure locations, assure appropriate technology and space capacity, and secure American Sign Language Interpreters and Communication Access Real Time Translation (CART) for each event.
- NYSOFA, CADER and several steering committee members travel 2,646 miles to attend nine regional forums in two weeks to present preliminary data and to receive initial reaction from the public.
- Web-based survey is developed and open for regional forum participants to provide additional written reactions under any of the themes presented.
- CADER analyzing the qualitative data from the survey and including regional forum feedback into its analysis.

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This report describes the findings from this work and includes: 1) a summary of three states who have experience with state-level coordination of aging and disabilities services; 2) a description of the NYSOFA feasibility study steering committee and its members; 3) the development and dissemination of a statewide survey whose purpose was to gather public input about the creation of an Office of Community Living with the goals and focus outlined in Part N of the authorizing legislation; and 4) a report on the findings from stakeholder information gathering process.

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### III. Background

#### A. Summary of Changes in Creating the Federal Administration for Community Living (ACL)

In 2012, a new federal administration, the Administration for Community Living (ACL), was created that combined the efforts and goals of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the Office of Disability, Aging, and Long-Term Care Policy. ACL is focused on streamlining access to non-medical long-term services and supports. Supporting this focus is ACL efforts to create a national no wrong door/single point of entry program for people of all ages, incomes, and ability levels to obtain information and assistance about what services are available and what options they have in accessing them. On July 22, 2014, President Obama signed the Workforce Innovation and Opportunity Act (WIOA), which further combined and transferred other governmental agencies/programs with similar missions and focus into ACL. The following entities were transferred from the US Department of Education and are now under the umbrella of ACL: 1) the Independent Living Services and Centers for Independent Living programs; 2) the Assistive Technology Act programs; and 3) the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The impetus of this transition was to bring additional programs that have a similar alignment and philosophy with ACL together under one organizational entity that shares the mission “maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers” (Administration for Community Living, 2013).

There are two key components of this evolution in federal policy. First, ACL, along with the Centers for Medicare and Medicaid Services (CMS) and the Veterans Health Administration (VHA) are working to develop a No Wrong Door (NWD) system to create “a person-centered, community-based environment that promotes independence and dignity for individuals.” Second, the federal vision for aging and disabilities services under the NWD system is one that coordinates aging and disabilities programs. Recent funding announcements (June 2014 and May 2015) exemplify this policy and program shift. The announcements stated that to receive the awards, the following state agencies must be included as full partners in co-leading the planning process to create a No Wrong Door system:

- State Medicaid agency
- State unit on aging
- State agencies that serve or represent the interests of individuals with physical disabilities and individuals with intellectual and developmental disabilities
- State authorities administering mental health services.

The federal vision for aging and disabilities services supports and encourages the coordination of aging and disabilities programs. While ACL has been leading the federal

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initiative, many states have been experimenting with organizational changes and they have learned critical lessons on best practices along the way. The following section will describe three states which have experience in combining their aging and disabilities state offices under one umbrella and can serve as examples for New York as it explores the feasibility of creating an Office for Community Living.

### B. Summary of State Organizational Changes: Case Studies: Three States' Experiences with Coordinating Aging and Disabilities Agencies

In 2015, the National Association of States United for Aging and Disability (NASUAD) released a report that found that state agency restructuring was happening across the country. The report, "*State of the States in Aging and Disability: 2014 Survey of State Agencies*," is based on NASUAD distributed questionnaires to state leaders. One of the key findings is that many states are re-envisioning how they deliver services to older adults and people with disabilities and are reorganizing based on this vision. For example, in 2014, 40% of states reported that they have combined aging and disabilities state offices, up from 20% in 2012. Based on NASUAD's report, CADER chose three states to interview about their experiences in coordinating aging and disabilities state offices. Interviews conducted with staff from these states explored their experiences with integration, the perceived benefits and challenges of coordinating aging and disabilities services at the local level, and the impact on consumers. The three states profiled are Massachusetts, Pennsylvania, and Texas.

#### **Massachusetts: Benefits and Challenges to Combining Aging and Disabilities Services and Lessons Learned**

Massachusetts was profiled for this report because aging and disabilities service agencies are under a combined health and human services umbrella agency and it was an earlier adopter of a coordinated model. Massachusetts received funding from ACL to develop and implement the No Wrong Door system, and receives funding from CMS under the Balancing Incentive Program (BIP).

Officials interviewed in Massachusetts stated that the most important lesson learned was recognizing that culture change within Massachusetts' government agencies was needed. It was important to have institutional commitment during this time of change. Massachusetts reports that the reorganization of state offices was successful because they had good public managers who supported it. Those interviewed in Massachusetts stated that one of the most important realizations was that "it is critical to look at the way government is organized and be willing to change that blueprint" and without internal support and willingness to change, it would make a challenging effort more difficult. Officials in Massachusetts also believe that the willingness to provide new authority to agencies that are combining under one umbrella is vitally important. They also stated that

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one of the concerns they see in the ACL model is that there has been no authority given to AoA, and that should have been addressed prior to the federal integration.

Officials in Massachusetts reported that the benefits to coordinating aging and disabilities services and other state offices were to decrease bureaucracy, reorganize Medicaid, and promote organizational change by breaking down the silos in the state agencies. There have also been challenges in doing this, and officials noted that it “has not been easy.” It required skilled leadership, collaborative planning, and open communication. Further, some challenges were also evident in the overall management of the agencies as exemplified by the fact that during this time, the secretary of the state unit on aging went from managing a \$300 million budget to managing a \$2.5 billion budget. This was an incredible expansion of resources that required additional management, program, and policy skills.

### **Pennsylvania: Benefits and Challenges to Combining Aging and Disabilities Services and Lessons Learned**

Pennsylvania was profiled because it has experience in combining aging and disabilities services at the state level, but recently reverted back to stand-alone agencies. Pennsylvania was awarded a grant from ACL in July 2014 under the funding title “Transforming State LTSS Access Functions into a No Wrong Door System for All Populations and Payers: Statewide Implementation”, and is also a BIP state.

One key lesson that came from Pennsylvania’s experience was the importance of being inclusive and transparent. Many state officials felt that the decision to merge aging and disabilities state offices was made without consultation from the legislature, state or local offices, or stakeholders. This seemed to set the stage for distrust among the agencies. Some of the distrust was further amplified by the variance in the size of the agencies merging and in the people they serve. For example, at the time of the consolidation, the Department of Aging had 100 employees and the Department of Public Welfare had 6,000 employees, and many felt that there was not enough planning on how these employees would work together. Further, there was great concern that the issues facing the aging population would be superseded by the needs of the population served by the Public Welfare Department. Some of the challenges were that the data and payment systems were not able to communicate with one another, which led to a further lack of coordination and frustration when trying to merge agencies.

Another lesson learned from Pennsylvania was that the process needs to be transparent and needs to include internal (state office employees) and external (stakeholders, local level agencies, consumers) representation in the process from beginning to end. Officials also learned that when staff from different agencies merge, they need to be re-trained and oriented around a core set of knowledge and skills. It is critical to allow for adequate time and planning if combining agencies and to find ample opportunities for stakeholder

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involvement. It is also important to have advocacy group input from both aging and disabilities groups because even though these groups are coming together, they need to feel independent and be able to openly address fears of being “overtaken” by the other.

### **Texas: Benefits and Challenges to Combining Aging and Disabilities Services and Lessons Learned**

Texas was profiled as an example of a large state that has all aging and disabilities service agencies under a combined health and human services umbrella agency. Texas was awarded a grant from ACL in July 2014 under the funding title “Transforming State LTSS Access Functions into a No Wrong Door System for All Populations and Payers: Statewide Implementation.” It is also a BIP state.

In 2004, the Texas legislature consolidated 13 agencies into five agencies through the Sunset Commission review (whose task is to review government agencies every 12 years before they “sunset” or expire). Because the decision to merge was decided by the Sunset Commission, there was a general lack of input from the local level agencies and consumers; however, there was input from all levels of staff at the state agencies. If appropriate or possible, interviewees from Texas believe that it is important to include input from all levels of agencies and staff at both the state and local level, along with stakeholder input.

Officials in Texas reorganized in 2004 with two guiding principles: 1) “don’t fix what isn’t broken”; and 2) “consumers need to be served during this transition and the public needs to be protected”—don’t lose sight of this while these changes are occurring. Further, there needs to be strong internal support during this transition—all levels of staff (including IT systems) need to be operating cohesively. It is critical to continually look forward and ask “what would be the best way to organize and improve services” throughout. Texas, like New York, is a large state with many rural areas and it is a challenge to find ways to get input across the state. They have found that videoconferencing works the best, as it allows for a much greater number of people to be involved in the process, especially those in remote areas or those who have concerns with mobility or transportation.

Texas believes that having an integrated state agency has provided better visibility to the issues facing older adults and people with disabilities and has increased their ability to influence decision making. An important challenge to consider is the concern that by merging agencies, something will be lost by one agency or both. It was evident that many of the concerns about what might be lost were replaced with some significant gains in partnership. For example, prior to 2004, the Texas Department of Aging had only 35 employees. After the consolidation, this department became an agency with 17,000 employees and a budget of \$6.5 billion and is now the biggest agency under the Department of Health and Human Services.

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Based on the case studies and review of other sources, the following points stand out as important to consider as New York explores the feasibility of creating of an Office of Community Living:

- Seek input from state, local, and other key stakeholders throughout the process.
- Be transparent and inclusive.
- Strong leadership is critical.
- Careful planning and consideration of structural changes is essential.

### C. Survey Development and Sampling

One of the main requirements from the authorizing legislation was to seek the broadest possible public input on the feasibility of creating an Office of Community Living that would lead to improved service delivery and program outcomes in New York State. To reach this goal, NYSOFA, CADER, and the steering committee used a three-pronged approach: 1) Information was gathered via two widely distributed surveys; 2) information gathering forums were held in all regions across the state; and 3) interested parties were afforded the opportunity to comment throughout the process online via the NYSOFA OCL webpage. Interested parties were also provided the opportunity to submit written comments/feedback. The survey, created in partnership among NYSOFA, CADER, and the steering committee, was widely distributed to consumers and providers via members of the steering committee; 22 state agencies and 59 local area agencies on aging. The partnership and engagement with key service providers and advocacy groups in both aging and disabilities was critical in reaching provider and consumer groups. To reach key stakeholder groups, CADER relied on guidance from steering committee members to both ensure that the appropriate questions were asked in the survey and also to assist in reaching key stakeholder groups.

The survey is one of several sources of information that NYSOFA used to develop recommendations; the others include the nine regional public forums conducted across the state of New York, the background brief prepared by CADER, and other sources of feedback that were received throughout the project. The analysis includes all responses from consumers and service providers received by October 21, 2015.

### D. Creation of the Steering Committee

To assist NYSOFA in the feasibility study, key advocacy and provider groups representing a broad spectrum of older adults and persons with disabilities of all ages who require or utilize long-term services and supports in New York State were solicited. As authorized by Section 2 of Part N of Chapter 57 of the Laws of 2015, NYSOFA was directed to include stakeholders to assist in the feasibility study. Section 2 states “1) The director of the state office for the aging, in collaboration with other state agencies, will consult with stakeholders, providers, individuals, and their families to gather data and

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information on the creation of an Office for Community Living.” Committee members were selected based on their experience and expertise in aging and/or disabilities. The 21-member steering committee members were asked to commit to the following:

- Participate in committee meetings (two in person, two remote)
- Assist in survey development
- Identify key consumer and provider stakeholders to complete the survey
- Assist in distributing the Office of Community Living Feasibility Study survey
- Assist in gathering the data. This may include having staff administer the survey and entering the data for those consumers who are unable to do so, but wish to participate
- Participate in Regional Informational Meetings (Post-Survey Preliminary Analysis)

The first meeting of the steering committee took place on July 10, 2015 in Albany, New York. NYSOFA provided an overview of the project, along with goals and objectives. CADER presented the results of the scan of federal efforts to develop the ACL, as well as results of three state case studies summarized previously. CADER led a discussion with the steering committee on the development of a survey, eliciting feedback and suggestions on the appropriate terminology and questions to ask and key consumer and provider stakeholders. CADER then developed the initial draft surveys that were distributed to committee members for review on July 17. Committee members submitted extensive comments and revisions to the draft surveys, which were reviewed with committee members in a phone meeting on July 31. The final versions of the surveys incorporated committee revisions and suggestions and were distributed to committee members to disseminate to their networks on August 6, 2015.

## IV. Survey Respondents

This section describes the consumer and provider respondents who participated in the survey. A total of 1,624 surveys were completed and analyzed in this report. Surveys completed between August 6, 2015, when the survey first went ‘live’ and was disseminated widely, and October 21, 2015 are included in the analysis. Surveys were largely completed online and those that were not were completed by hand and then entered electronically. The survey was disseminated through an online survey tool called Qualtrics. Data were analyzed using both Qualtrics and SPSS statistical software, and are reported below.

### A. Demographic Information on Consumers

A total of 1,019 consumers participated in the survey. Of these, 859 consumers completed the survey and are included in the report, a completion rate of 84%. Two of the target goals of the survey were to include both older consumers as well as younger consumers who self-identify as being a person with a disability. Table 1 indicates that 69% of the sample was 60 years of age. Table 2 shows that 53% of the consumers in the sample indicated that they are living with a disability.

**Table 1. Age of Consumer Respondents**

#	Answer	Response	%
1	Under 18	9	1%
2	18-35	79	9%
3	36-50	79	9%
4	51-59	101	12%
5	60-74	285	33%
6	75-84	172	20%
7	85+	134	16%
	Total	859	100%

**Table 2. Do you have a disability?**

#	Answer	Response	%
1	Yes	449	53%
2	No	393	47%
	Total	842	100%

Further analyses of the consumer sample examined the relationship between age and disability. Overall, 47% of the consumers 60 years of age and older self-reported that they have a disability. Among younger adult respondents, 68% indicated they had a disability. The relatively large proportion of older adults with a self-reported disability suggests the sample of consumers in the survey included more older adults with disabilities than is common statewide.

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As shown in Table 3, 55% of consumer respondents indicated they received assistance from informal sources of support such as family members or friends or from public or private service providers.

**Table 3. Are you receiving any assistance now from family members, friend(s), a paid worker, or from an agency to help you live independently in the community? Again, when thinking about services or assistance, please think of any government sponsored (local, state or federal) service or assistance you receive.**

#	Answer	Response	%
1	Yes	455	55%
2	No	379	45%
	Total	834	100%

Additional analyses showed that persons receiving services or assistance were much more likely to self-identify as having a disability than not (72% versus 28%).

Other demographic characteristics of consumer respondents who participated in the survey indicate that respondents were largely female (66%); white (90%, 4% black or African-American, and 3% Latino); recipients of Medicare, Medicaid or both (81%), and covered by some kind of private insurance (60%).

**Table 4. What is your gender?**

#	Answer	Response	%
1	Male	272	33%
2	Female	541	66%
3	Transgender	1	0%
	Total	814	100%

**Table 5. Race/Ethnicity**

#	Answer	Response	%
1	American Indian or Alaska Native	8	1%
2	Black or African American	34	4%
3	Asian	10	1%
4	Native American or Pacific Islander	3	0%
5	White	720	90%
6	Prefer not to answer	39	5%

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**Table 6. Do you consider yourself Latino/Hispanic?**

#	Answer	Response	%
1	Yes	27	3%
2	No	730	93%
3	Prefer not to answer	29	4%
	Total	786	100%

**Table 7. Medicare and Medicaid**

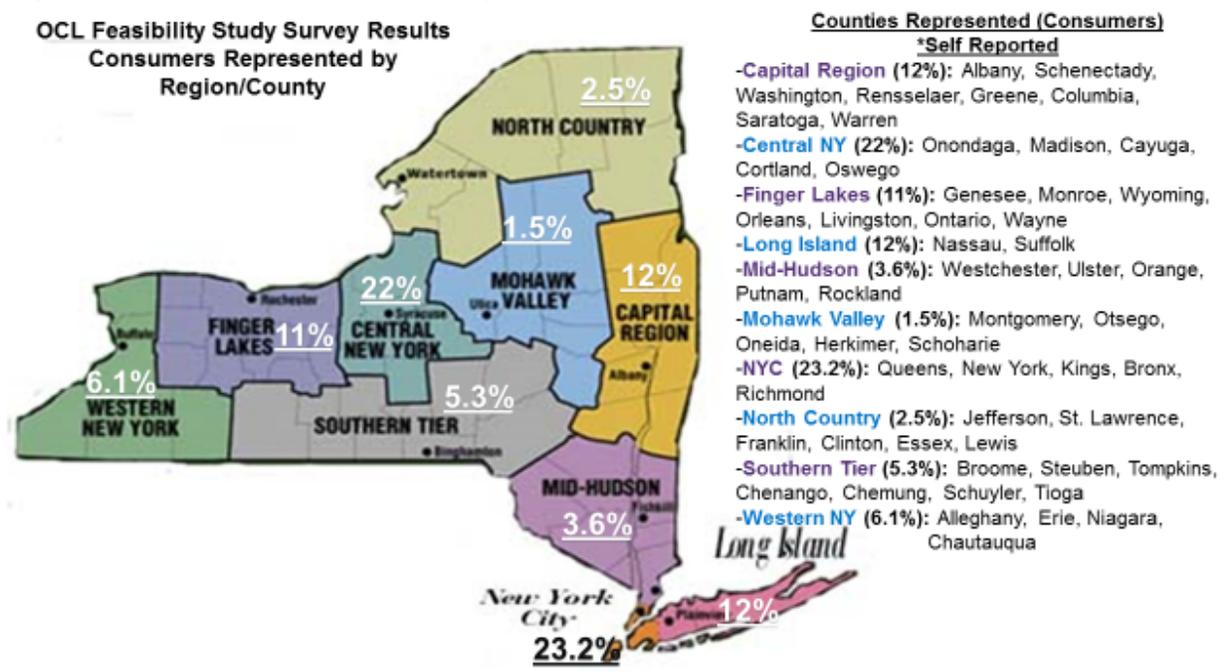
#	Answer	Response	%
1	Medicare	362	44%
2	Medicaid	107	13%
3	Both	198	24%
4	Neither	147	18%
	Total	814	100%

**Table 8. Are you covered by private insurance of any kind?**

#	Answer	Response	%
1	Yes	483	60%
2	No	325	40%
	Total	808	100%

Figure 1 indicates the distribution of consumer responses by county and region.

**Figure 1. Counties Represented by Consumer Responses**



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### B. Demographic Information Providers

A total of 873 providers participated in the survey. Of these, 765 providers completed the survey and are included in the report, a completion rate of 88%. One of the principal objectives of the provider survey was to obtain roughly equal numbers of providers that self-identified as an aging organization with those that self-identified as a disabilities organization. Table 9 shows the results of the provider survey question that asked respondents to describe the agency where they work. Approximately equal numbers of aging and disabilities organizations were included in survey (27% and 24% respectively); 33% identified as an agency serving both older adults and consumers with disabilities, and 16% identified as “Other”.

**Table 9. Can you describe the type of agency where you work?**

#	Answer	Response	%
1	Aging	208	27%
2	Disability	182	24%
3	Combine aging/disabilities	252	33%
4	Other	123	16%
	Total	765	100%

Table 10 shows the percent of time the respondent’s agency works with people with disabilities, and Table 11 shows the percent of time the respondent’s agency works with older adults.

**Table 10. What percent of your job involves working with or for people with disabilities of all ages and their families?**

#	Answer	Response	%
1	25% or less	270	36%
2	26 to 50%	109	15%
3	51 to 75%	65	9%
4	76% or more	302	40%
	Total	746	100%

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**Table 11. What percent of your job involves working with or for older adults (that is, persons 60 years of age or older) and their families?**

#	Answer	Response	%
1	25% or less	186	25%
2	26 to 50%	89	12%
3	51 to 75%	98	13%
4	76% or more	372	50%
	Total	745	100%

The analyses showed that aging organizations served more older adult consumers, and disabilities organizations served more consumers with disabilities.

Other characteristics of provider respondents are shown in tables 12-14. A large majority of provider respondents were female (81%), white (84%, 4% black or African-American, 3% Latino).

**Table 12. Gender of Providers**

#	Answer	Response	%
1	Male	139	19%
2	Female	593	81%
3	Transgender	1	0%
	Total	733	100%

**Table 13. Race/Ethnicity of Providers**

#	Answer	Response	%
1	American Indian or Alaska Native	11	1%
2	Black or African American	29	4%
3	Asian	9	1%
4	Native American or Pacific Islander	5	1%
5	White	622	84%
6	Prefer not to answer	71	10%

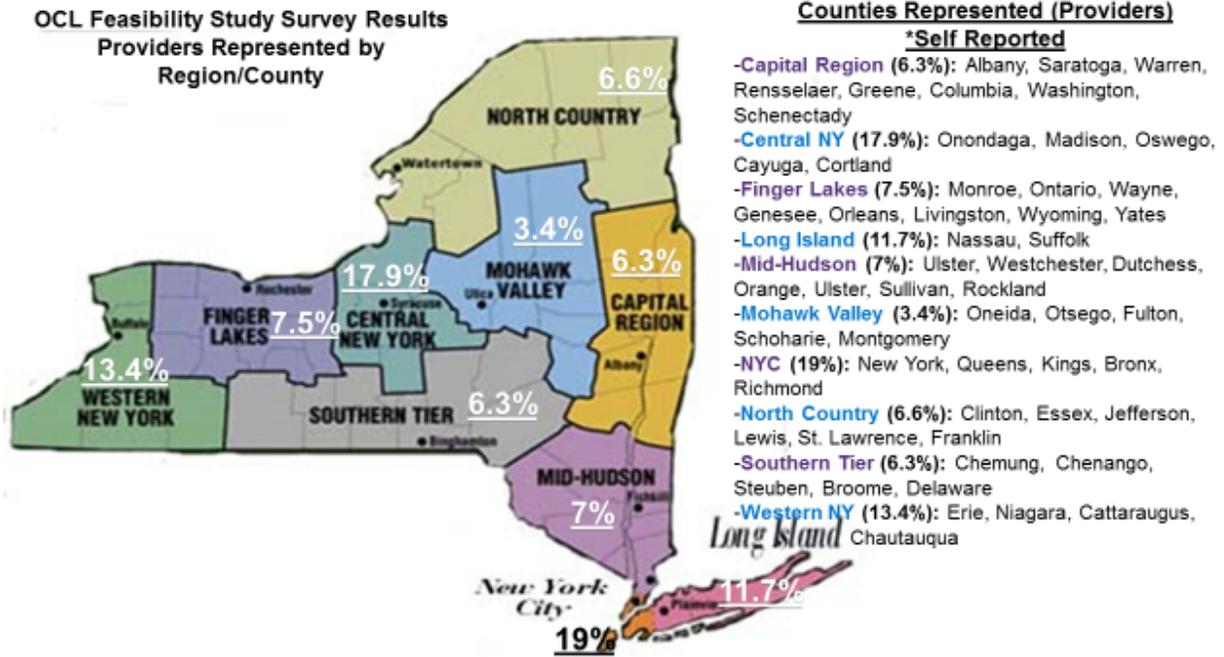
**Table 14. Do you consider yourself Latino/Hispanic?**

#	Answer	Response	%
1	Yes	25	3%
2	No	660	90%
3	Prefer not to answer	45	6%
	Total	730	100%

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Figure 2 indicates the distribution of provider responses by region and county.

**Figure 2. Counties Represented by Consumer Responses**



## V. Findings from Statewide Survey

As described previously, the purpose of the survey was to engage consumers and providers from across the New York State and get their feedback about the feasibility of creating a state level Office of Community Living. Separate surveys were developed for consumers and providers related to the goals of the OCL feasibility study. The findings in this section are organized around specific Part N objectives guiding the project:

- A. Evaluating Information and Access**
- B. Evaluating Service Delivery and Improvements**
- C. Reinforcing Balancing Incentive Program (BIP): Evaluating Barriers, Gaps, and Information about Needed Services**
- D. Strengthening No Wrong Door (NWD) Initiatives**
- E. Findings on Feasibility of Coordinating Aging and Disabilities Services: Leveraging Resources and Fiscal Impact on Services and Consumers**

In each of these topic areas, both consumers and providers were asked to select their responses to the multiple choice survey questions, and then explain in their own words their answer or expand on their concerns or issues. A thematic analysis of these open-ended responses was then conducted by CADER staff to identify major themes. The themes and sub-themes are presented in the following section, along with representative quotes from the surveys. The qualitative analysis of all open-ended responses yielded 13 major themes related to the Part N objectives of this project.

### A. Evaluating Information and Access

Knowing where to get information about services and actually obtaining them are key components of any long-term services and supports system—and this critical aspect addresses directly or indirectly many of the Part N objectives. Finding and accessing the best long-term services and supports presents difficult challenges for many providers, consumers, and their families. Nationally, the current LTSS system involves multiple programs and funding sources administered by many federal, state, and local agencies. Local administering agencies often use different, fragmented, and sometimes duplicative processes and requirements. Consequently, consumers trying to access services frequently are confronted with a confusing array of organizations and bureaucratic requirements at a time of vulnerability or crisis, which can result in people making decisions based on incomplete, and sometimes inaccurate, information about their options. To better understand issues around information and access to services in New York State, providers were asked about duplication in services across the state and/or between agencies. This section presents provider responses, as well as an analysis of additional comments about the question given by the provider respondents.

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- Overall, how much duplication in services is there across state and/or local agencies serving your consumers?

### Provider Perspectives on Duplication of Services

As shown in Table 15, when providers were asked to describe the level of duplication of services in their local area between state and local agencies, duplication of services was not identified as a significant problem. Overall, 10% of provider respondents indicated that there was “no duplication” of services. The largest response (53%) reported that there was “not very much” duplication of services, and 32% indicated that there was “some duplication” in services for their consumers. Only 5% of provider respondents indicated that there was “a lot” of duplication of services for their consumers.

An analysis was also done to examine whether the type of provider would have a different response on this question. When comparing agency type (aging, disabilities, combined, or other) there was no significant relationship between agency type and duplication in services, suggesting similar patterns of responses for providers from different agency types.

**Table 15. Provider Survey Question #5. Overall, how much duplication in services is there across state and/or local agencies serving your consumers? Would you say...?**

#	Answer	Response	%
1	Yes, there is a lot of duplication across service delivery	38	5%
2	Yes, there is some duplication across service delivery	239	32%
3	No, there is not very much duplication across service delivery	394	53%
4	No, there is no duplication at all	73	10%
	Total	744	100%

Providers were asked to explain their answers to this question by describing in their own words the duplication in services they observed or experienced. The analysis of responses identified a variety of themes related to duplication. The most common theme related to **Coordination or Communication**. Forty-six percent (46%) of responses identified duplication in assessments and applications, and another 22% mentioned multiple case managers working with a single consumer. The following quotes illustrate this theme:

- *“Because assessment work isn't/can't be shared effectively multiple organizations must conduct independent assessments creating most of the duplication. Organizations don't always understand limitations of programs or funding leading to inappropriate referrals and time lost to access care. No central clearing house exists for service provision and often we will not find out that a client has services*

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*from another provider until agencies 'bump into' each other at a client's home or the 'right' questions are asked to draw out that information from a client/family member who is trying to piecemeal services together to obtain as much help as possible. Clients sometime do not understand that providers often cannot cover/back up each other and attempt to interchange services and types of care.”*

- *“Most older adults are in need of services because they need assistance with activities of daily living, similar to younger individuals with disabilities. Yet so often services are siloed based on the individuals age or diagnosis. Information and referral services are provided by many organizations, but are often limited on the service system by which they are funded or intended to serve. Advocacy efforts are often duplicated and not always well coordinated.”*

Among the comments in this theme, several respondents indicated that duplication in services does not mean there were sufficient services to meet the needs of consumers, however:

- *“Duplication of service is not equal to enough services to meet the needs in the community. There are several case management programs (or care coordination)/services, several resources for information and assistance, several wellness programs, home health aide agencies, social adult day programs.”*
- *There are many organizations providing similar or the same services, but in all honesty, many of the most needed services have long wait lists, so duplication isn't a bad thing.*

Another prominent theme, mentioned by 12% of providers, involved concerns about **Navigating the System**. Comments identified with this theme refer to state regulations that negatively impact consumers, or note that different policies or rules between state and local levels can impact coordination or duplication:

- *“Differing standards for different programs, where disabilities, income or age vary for no discernible reason.”*
- *“Different regulations for different funders... One half of our agency has to do it one way and the other half another way. Time and effort reporting for example...we exhaust significant resources keeping it on track.”*

Overall, 6.4% of providers pointed out that **Duplication in Services Sometimes Benefited Consumers**:

- *“Multiple agencies provide the services described above, although we may be the only one with a program specific for seniors. The duplication does not mean that there is more service than the level of need. I believe that the duplication is necessary to meet the needs of the consumers in this area.”*
- *“Many of the same services are provided but to different people and in a different way.”*

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The remaining themes identified related to other Part N objectives, such as **Communication/Coordination**, which captures the experience consumers have in communicating with multiple providers (3% responses) and **Availability of Services** (4% of responses); in particular, the concern about funding for services, or competing between agencies for the same funding for consumers (5% of responses).

### **Consumer Perspectives on Accessibility**

To understand consumer perspectives on the accessibility of services, consumers were asked two related questions about their experience in accessing and enrolling in needed services:

- How difficult is it for you to find out about and get the services or assistance you need?
- If you use more than one service, did you find it confusing or difficult to enroll in the services you needed?

Of the 771 consumers who answered this question, almost 40% indicated they had at least some difficulty in finding out about and getting needed services, with 12% indicating they found it “very difficult”. Overall, 61% consumer respondents indicated they had little or no difficulty in finding out and obtaining about needed services. Thirty percent (30%) stated that it was “not at all difficult” to find out about and obtain services (see Table 16).

**Table 16. Consumer Survey Question #6: How difficult is it for you to find out about and get the services or assistance you need?**

#	Answer		Response	%
1	Very difficult		89	12%
2	Somewhat difficult		208	27%
3	Not very difficult		242	31%
4	Not at all difficult		232	30%
	Total		771	100%

Additional analyses were done to determine whether a consumer’s age, use of services or not, or if a consumer self-identified as a person with disabilities would influence how they answered this question. Older consumers stated that it was easier to find services than younger consumers, and persons with disabilities expressed having more difficulty in accessing and finding services than persons without a disability.

Table 17 shows the results to a similar question posed to consumers who already receive at least one service: “If you use more than one service, did you find it confusing or difficult to enroll in the services you needed?” 75% of consumer respondents indicated they did not find it confusing or difficult to enroll in services.

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**Table 17. Consumer Survey Question #7: If you use more than one service, did you find it confusing or difficult to enroll in the services you needed?**

#	Answer	Response	%
1	Yes	163	25%
2	No	481	75%
	Total	644	100%

Again, additional analyses were done to determine whether a consumer’s age, use of services or not, or if a consumer self-identified as a person with disabilities would influence how they answered this question. Older consumers again indicated that it was easier to find services than did younger consumers, but there was not a significant relationship between a consumer’s disability status and service use. Not surprisingly, those who currently use one or more services found it less difficult to find additional services than consumers who are not currently receiving services.

Consumers were then asked to explain in their own words the responses. The most frequently mentioned theme related to accessibility, **Services Provided by Providers and Informal Supports are Invaluable**, describes the many comments consumers made about the critical role of providers or family members in helping them obtain or get needed services. Overall, 43% of consumer responses addressed this theme:

- *“My daughter took care of everything for me. If I had to do it myself, I could not do it.”*
- *“Without help of my social worker it would be very difficult.”*
- *“I say very difficult because I couldn’t do it alone without Mom.”*
- *“Everything is taken care of by my children.”*
- *“Thankfully I have good support from my son’s service coordinator and our support broker. Also I know how to go about finding answers myself.”*

Collectively, these and other similar responses illustrate that the reason why consumer respondents did not express much difficulty in accessing or obtaining services is in large part because: A) many of the consumer respondents are currently receiving services and are therefore ‘connected’ to LTSS service providers; and B) the assistance given by the state’s LTSS provider network, as well as the instrumental supportive role assumed by many family members helps to ease the burden on consumers accessing services. The success of informal support and service providers for both older adults and persons with disabilities in connecting consumers to services cannot be understated.

Our thematic analysis of consumers’ open-ended responses identified a number of critical issues relating to accessing and obtaining services. The most frequently mentioned theme, **Accessing Services**, encompasses accessibility concerns identified by consumers. Eighteen percent (18%) of consumers identified accessibility issues in response to the two consumer survey questions “How difficult is it for you to find out about and get the services or assistance you need?” and “If you use more than one

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service, did you find it confusing or difficult to enroll in the services you needed?"

Consumers also identified **long wait lists**:

### Long Wait Lists

- *"It took from November to April to get Medicaid and have an aid [sic] so I could come home."*
- *"Took forever to get HCBS waiver in place for day-hab. Started two years in advance of graduation and still wasn't ready at graduation. Had to wait three additional months."*
- *"Trying to move from HCBS/ISS to self-direction, so far the application process has taken 18 months and counting."*
- *"In the end, we either didn't qualify or too long of a waiting list. My dad died before he was able to get transportation."*

Several other important themes related to access to services were identified: **Knowledge of Services** was mentioned by 17% of the consumer responses to the two questions listed above. The theme primarily includes concerns by consumers that they do not know what services are available to them, and captures the statements of many consumers who reported that navigating the system was difficult. **Workforce Issues** were identified by 8% of respondent comments on these issues. This theme captures respondent concerns about the shortage of direct care workers to serve older adults or persons with disabilities, and includes concerns about the quality of the workforce, high turnover rates, and overall dependability concerns. The theme **Availability of Services** was identified by 7% of consumer respondents. This theme captures consumer comments regarding of knowledge of available services. Consumers also mentioned specific services, including transportation, housing, and behavioral health. Consumer quotes related to these themes include:

### Knowledge of Services

- *"Have no idea where to even start looking."*
- *"It is not clear who to call and everything seems so expensive."*
- *"We are not really familiar with what is available."*
- *"Everyone passes the ball to someone else. The varying agencies seemingly have little knowledge of what each one does and there appears to be a lack of connection amongst them."*

### Workforce

- *"Getting the assistance is hard due to high turnover and a lack of staff"*
- *"I do see the case manager occasionally and I do tell them what I need. I do think they are trying. The \$10/hr. with no benefits is a hindrance to good employees. Every time I get comfortable with an aid [sic] she is on to a new job. I have been in this program for over 2 years and sometimes I tell my daughter, I feel like the guinea pig patient."*

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- *“We are not sure that we can find a well-trained and credential professional simply because no such training and credentialing system exists for professional who want to serve individuals with autism. The training needs to be in the area teaching life skills including self-management, functional communication, motor planning, assistive technology and prevocational skills specifically to individuals with autism.”*

The remaining access themes identified related to other Part N objectives most frequently mentioned include **Eligibility Criteria** (3% of responses) and **Coordination** (2% of responses). These and other themes are addressed more directly in answers to other Part N objectives, which are described more fully in later sections. Finally, given this strong endorsement by consumers of the assistance they receive in accessing services, it is not surprising that one of the strongest themes identified was **Satisfaction with Services**. Overall, 18% of consumer responses to these two questions expressed satisfaction with services. This theme will be explored more fully in the next section.

### B. Evaluating Service Delivery and Improvements

In the movement toward person-centered (LTSS) systems, the service experience of consumers with LTSS providers and state and local organizations is central. Consumer experiences of service quality are essential to understanding whether and to what extent the state’s current LTSS system is working for older adults and/or persons with disabilities. To assess this key Part N objective, providers and consumers were asked the following:

- Provider Survey Question #6: Overall, how well do you think services are working for your consumers now?
- Consumer Survey Question #5: Please tell us about your experiences with any assistance that you are receiving or have received in the past year. Overall, how satisfied would you say are you are with the services or assistance you’ve received?

### **Providers Perspectives on Service Quality**

As shown in Table 18, many providers indicated that services are working well for consumers. Almost one third of provider responses (32%) indicated that services are working “very well” for their consumers. Fifty-six percent (56%) indicated that services were working “somewhat well”; 10% indicated that services were working “not very well”; and 2% stated that services were working “not at all well” for consumers.

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**Table 18. Provider Survey Question #6: Overall, how well do you think services are working for your consumers now? Would you say . . . ?**

#	Answer		Response	%
1	Very well		241	32%
2	Somewhat well		425	56%
3	Not very well		73	10%
4	Not at all well		15	2%
	Total		754	100%

Additional analyses were conducted to assess whether these respondents would be different for providers from aging organizations versus providers from disabilities organizations. Results indicate that both provider groups answered this question about the same.

Providers were asked to expand on or explain their answer to this question in their own words. The theme **Satisfaction with Services** was mentioned in 15% of responses. The responses contained expressions of satisfaction with the current availability and quality of the LTSS service system for their consumers. Most of the comments addressed the provider’s agency or locally available services:

- *In general the consumers say they are very happy with our program.*
- *Individuals are happy and healthy. They come home to living environments of their friends and choose what activities they want to be a part of.*
- *For the consumers living in our catchment area, our program is able to assist with many of their service needs as expressed in the satisfaction surveys which we conduct on a yearly basis. [OUR] programs serve as a conduit to the broad base of services and supports available to seniors which they would otherwise have difficulty accessing.*
- *All clients get the service they need to remain safe and independent in the community.*

All other themes identified described concerns or gaps in services. The most frequently mentioned theme was **Availability of Services**. Almost 35% of provider respondents to this question expressed concerns about the availability of services. Two specific sub-themes were prominent in the responses: **Availability of Services** and **Availability of Funding**. Across the board, but especially in rural areas, providers described a general availability of basic and specialized services available, including transportation, housing, and behavioral health. Concerns about seeing increased needs for services, or concerns about the quality of services were included in this sub-theme, which was mentioned by 24% of provider respondents. **Availability of Services and Funding** was mentioned by 10% of respondents. Concerns raised by respondents include:

- *“More services are needed with expanded hours and ability to reach rural populations. Transportation is needed in triplicate.”*

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- *“Not enough safe, supportive affordable housing to help people avoid crisis or allow them to live a quality of life/need more direct services, including case management.”*
- *“Not enough services to help people stay in their homes as opposed to nursing home or assisted living.”*
- *“The limited number of options for housing, health care and employment for people both with and without disabilities in our relatively isolated rural county makes it difficult to provide an optimal quality of life for everyone. Transportation is also a concern for seniors and with people with disabilities in this rural area with limited transportation services.”*
- *“Elderly consumers receive limited services due to lack of funding. There is no funding for outreach and marketing from the state although we are required by contract to provide services to nearly 300 people each year. There is no state funding for non-legally blind elders who may be experiencing difficulty with the same tasks as those with more severe vision loss. There is no funding for transportation from the state agency.”*
- *“Not enough funding to meet the growing need, leaving waiting lists for services.”*

Another frequently identified theme that emerged was **Accessing Services**, with 18% of provider respondents providing comments addressing barriers to access. Sub-themes identified included **long wait times** (10% of responses) and **geographic concerns** (4% of responses):

- *“Currently our clients are put on waiting lists. Home care has a 6 month to one year wait list. Transportation is only available during the week 9 am -3 pm.”*
- *“Frail, isolated, poor seniors are grossly underserved, especially in rural areas. There are long waiting lists for personal care, PERS and other services. Only 13% of disabled seniors receive case management services in a given year.”*
- *“On affordable senior living, for our 800 apartments, we have a wait list of almost 600. Same thing on housing for people with disabilities.”*
- *“The wait list for services is too long and consumers are ill-informed for how the services work and the time gap that is present to receive services. Often I have seniors that are placed on wait lists for home care or additional services and end up being placed into a nursing home because the assistance isn't there when needed. The services are also limited. There is almost no funding or programs to assist with making home repairs to allow seniors to remain in their home. This would include wheelchair ramps, handicap accessibility modifications, walk-in showers, small home repairs etc.”*
- *“Way too much bureaucracy - families feel overwhelmed, wait lists get longer and longer, things have to be in crisis mode for services to kick in that will significantly bring relief, residential options have all but disappeared...”*
- *“In a rural setting it is hard to get the services for people without them having to travel an hour or more to get them.”*

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**Workforce** was also identified. This theme addresses concerns by providers about the shortage of home health aides or other direct care workers, and includes statements about the quality of the workforce, the high turnover rate (often due to low pay), as well as dependability concerns. Overall, 18% of provider respondents shared this concern:

- *“Because of low pay for many of the staff, there is high turnover. This creates a difficult environment for the men and women we support. It's VERY disruptive for our men and women when staff changes. Staff needs to be better trained in our residences regarding healthy cooking, and living a healthy lifestyle. With the high rate of obesity in people with DD, more emphasis needs to be placed on exercise and remaining healthy.”*
- *“Clients on case management or meals on wheels typically report that they cannot reach their social worker, or a general lack of involvement from the case management agency. The client caseloads are very high, and there are many needy seniors. In crisis situations, we have noticed that the agencies work very well together and things get done quickly. However, our focus should be on prevention.”*
- *“Financial issues are creating issues with retention of qualified staff leading to inconsistencies in quality of services.”*

**Navigating the System** is a theme that both providers and consumers have used. Many consumers report that navigating the system was difficult and that family and/or paid workers played big roles in helping consumers' access services. This theme also includes **Regulation** as a sub-theme. The **Regulation** theme includes statements by providers regarding changes to state regulations, different policies/rules between state and local levels, and managed long-term care. Sixteen percent (16%) of respondents made comments associated with this theme.

Another prominently mentioned theme is **Knowledge of Services**. This theme includes perspectives of both consumers and providers, and was mentioned by 14% of provider respondents. Provider responses indicate concerns that they do not know about all the types of services that are available across different agency settings as well as statements that their consumers do not know what services are available and that it is difficult to get services to people who need them. Additional comments address the need for more marketing, advertising, and outreach to educate/inform consumers, such as directories, a central website, or county or statewide number to call for information.

The **Eligibility Criteria** theme, identified by 8% of provider respondents, refers to provider challenges in getting services to consumers because of varying eligibility criteria, i.e., some might not qualify for Medicaid because of the strict income guidelines and therefore cannot get services, or some might be waiting for an official diagnosis but cannot get services until this happens.

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### Consumer Perspectives on Service Quality

To gain consumer perspectives on the Part N objective related to the evaluation of service delivery and improvement, consumer respondents were asked to give an overall assessment of services they were currently receiving or had received in the past year. The consumer responses to the question, “Overall, how satisfied would you say you are with the services or assistance you’ve received” are summarized in Table 19. These data show that 60% of respondents indicated they were “very satisfied” with their services. Forty percent (40%) of consumers expressed at least some concern about services; 27% indicated they were “somewhat satisfied”; 9% indicated they were “somewhat dissatisfied”; and 4% indicated they were “very dissatisfied.”

**Table 19. Consumer Survey Question #5: Please tell us about your experiences with any assistance that you are receiving or have received in the past year. Overall, how satisfied would you say you are with the services or assistance you’ve received?**

#	Answer	Response	%
1	Very satisfied	429	60%
2	Somewhat satisfied	196	27%
3	Somewhat dissatisfied	61	9%
4	Very dissatisfied	28	4%
	Total	714	100%

Older consumers expressed more satisfaction with their services than younger consumers, and there was no significant difference between a consumer’s disabilities status or service use expressed satisfaction with services.

Consumers were also asked to explain or clarify their answer to this question in their own words. The most frequently mentioned theme, which is consistent given the strong satisfaction results reported above, is **Services**. Fifty-four percent (54%) of consumers expressed satisfaction with services in their statements:

- *“I’m very satisfied with all the services that I’m both receiving and have received during the past, because they have help to improve my independent living skills.”*
- *“I am very satisfied with the services I have been able to get from the CDR. Without such a place, there is no telling where I would be at this time. My S.C. works very hard to help me be able to reach the goals that I have, and offers me alternatives when and if needed.”*
- *“I feel like I’m getting the help I need to be able to live independently.”*
- *“I love her. Couldn’t ask for a better, polite person bring me meals. She is almost the only one I see from Monday to Friday, once in a while a friend.”*
- *“The New York State Commission for the Blind and the Association for the Blind and Visually Impaired have provided outstanding service and are very valuable for maintaining employment in people who are blind or visually impaired.”*

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Respondents' open-ended statements revealed a variety of perspectives on the state's LTSS service system. The most frequent theme was **Availability of Services**, which encompasses comments by consumers about the availability of needed services, or concerns about the dependability of services. Overall, 20% of the consumer responses addressed this theme:

- *"The Office for the Aging is not providing advocacy services. There is a lack of interest in helping blind individuals. No computer/technology services. No blindness etiquette/courtesy."*
- *"I have to search daily for anything that was for a younger person...all programs were for 80 yrs. plus older people..."*
- *"There is NO agency that can provide transportation, except to a dr. appt. Mom gave up her license at age 97 and now she is housebound unless I drive her. People living in nursing homes get ALL services and transportation, but people trying to stay in their own homes independently are being discriminated against."*

Another frequently mentioned theme was **Workforce**. Overall, 15% of consumers mentioned concerns about the availability or dependability of direct care workers. :

- *"I believe the issue is-people do not choose home health aides as a career option, therefore agencies or individuals looking for help end up with people that only want to do this work temporarily, or as a stepping stone to a career that gives the individual a hope and future for a job with a decent wage. I have had some very good home health aides over the past 34 years, however until we can pay them better and also provide benefits to them, finding good home health aides is going to be a never ending battle!"*
- *"In general, I am satisfied with the services I receive, but turnover is way too high, and often I am left scrambling to find coverage."*
- *"Some of the workers are not dependable and do not show up. It's hard to find workers for \$10/hr."*
- *"The agencies have difficulty finding PCA replacements when one of them calls out or get sick long-term. There should be an incentivized pay structure that helps agencies recruit and maintain skilled caregivers for higher patients."*

The other major theme identified was **Accessing Services**, with 10% of consumers offering comments or statements expressing concerns with accessing needed services:

- *"I have had to advocate for everything. There is very little guidance and support in our area (Chautauqua County). We have considered moving to get more services."*
- *"As a caregiver, getting help for my 88 y/o mother was a challenge. She needed mental health services and connecting her with a psychiatrist was very difficult. She spoke only Spanish and we could not locate any Spanish-speaking geropsychiatrists to provide treatment."*
- *"One of the challenges for my mom is the required annual renewals for many programs such as telephone discount to prove she still receives Food Stamps,*

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*HEAP, etc. Often as she doesn't like paperwork she just doesn't do it which then sometimes means a break in service.*

- “Very long and slow process.”

This section has provided important input about consumers’ and providers’ views on evaluating service delivery and accessibility—a critical component of the Part N objectives, and one which will help identify barriers and gaps.

### C. Reinforcing the Balancing Incentive Program: Evaluating Barriers, Gaps, and Information about Needed Service

To gain insight into the Part N objective relating to barriers, gaps, information about needed services, and programs such as the Balancing Incentive Program (BIP), providers were asked two related questions:

- Provider Survey Question #8: How strongly do you agree that there are gaps in services for consumers now?
- Provider Survey Question #9: Do you know of any policies, regulations or any other issues that create barriers in providing quality services.

Responses indicate that both aging and disabilities providers believe there are gaps in information and barriers to services for consumers. As shown in Table 20, 92% of providers’ respondents stated that they “strongly agreed” or “somewhat agreed” that there are gaps in services for consumers now. In a related question, as shown in Table 21, 68% of provider respondents indicated that they know of “policies, regulations or other issues that create gaps in providing quality services.”

**Table 20. Provider Survey Question #8: How strongly do you agree that there are gaps in services for consumers now?**

#	Answer		Response	%
1	Strongly agree		346	47%
2	Somewhat agree		331	45%
3	Somewhat disagree		41	6%
4	Strongly disagree		23	3%
	Total		741	100%

**Table 21. Provider Survey Question #9: Do you know of any policies, regulations or any other issues that create barriers in providing quality services?**

#	Answer		Response	%
1	Yes		470	68%
2	No		225	32%
	Total		695	100%

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For each of these questions, providers were asked to explain in their own words the responses they gave to these questions. The open-ended responses identified a number of common themes, the most frequent being **Availability of Services**. Thirty-four percent (34%) of the comments made by providers were associated with this theme, which encompasses comments by providers and consumers about needed services. A significant proportion of these comments address the availability of funding for important and basic services:

- *“Accessible, affordable housing, quality health care, quality health care plans, quality home health aides are just a few of what services have gaps in our community.”*
- *“I believe there are big gaps in services specifically for the elderly population who are dealing with dementia and Alzheimer’s disease. They need more in-home support in order to be able to remain in their homes. There are also such limited services for the population of people who are diagnosed with mental illness and in NYC, finding affordable housing is big problem.”*
- *“In our community there is a HUGE need for homes and/or assistance for people with disabilities under the age of 60. These people do not and should not be forced to live their lives in homes that are designed for the frail elderly. Many times they are forced to as they require 24-hour supervision & assistance w/ meds etc. and need to be kept safe & from repeat trips to the emergency rooms.”*
- *“In our rural area individuals with disabilities and those who are gaining share in some of the gaps/barriers to service options. This includes but is not limited to affordable, accessible, and integrated housing options, access to consistent transportation to meet activities of daily living and medical services, and access to affordable in home assistance or affordable health care that adequately covers those services for individuals who are not MA eligible but not able to truly afford private pay options.”*
- *“Large gaps in services for individuals with developmental disabilities. Closure of programs, shortage of supportive housing options. Leaves individuals that have much to contribute to society from reaching their potential. Leaves them with a lot of time on their hands, living with aging parents who want the best for them and for them to be as independent as possible, but no option to live in a supportive setting. They lack recreational activities and opportunities to socialize. Transportation is a barrier for many. Paratransit will only serve those on a NFTA bus route. This is another huge problem.”*
- *“Gaps exist in 1) limited to no existing services for the elderly disabled who may still be living independently, 2) lack of coordination of services and planning to meet current and future senior population needs (IE: The increasing burden the Baby Boomer population will have on programs, services, and limited financial resources from providing agencies).”*
- *“Having to postpone appointments because there are no appropriate accommodations put in place such as access for blind, or interpreters for the deaf*

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*or ramps for people with mobility issues. This often creates a lapse in service and hence a discontinuation of benefits or missed deadlines.”*

- *“A reduction in funding sources or a restructuring of how the funding are allocated is the main issues we are facing. We diligently try to ensure our voices are heard when funding becomes an issue but it's a losing battle sometimes.”*

The second most frequently mentioned theme was **Navigating the System**. This broad theme includes sub-themes relating to conflicting program eligibility rules, bureaucratic policy and procedures, and comments, by both providers and consumers, about the type of system needed to improve access to services. Twenty-five percent (25%) of providers mentioned the difficulty their consumers have in navigating the LTSS system:

- *“Any policy that set rules based on diagnosis will limit access to services and by this then not offer people all that they could have. A “no wrong door” approach to community supports should be developed based on capacity versus deficits without then the worry of diagnosis.”*
- *“Complicated Medicare/Medicaid and other health care regulations are confusing to consumers as well as their ever-changing nature.”*
- *“Differing standards for different programs, where disability, income or age vary for no discernible reason.”*
- *“Silos for services create the most barriers. Why must an older adult find a housing agency to help them to pay their rent when they can no longer write checks or balance their accounts? It is inappropriate. A focus on creating true one stop neighborhood service centers would be wonderful. My agency has no funding at all to provide case management or housing assistance, yet that is the predominant need of my older adults as they enter their 70s, 80s and 90s.”*
- *“Very complicated and lengthy access to managed long term care—especially community based long term care—not understood by public in NY—leaving clients without help or uncertain what to do.”*
- *“Statewide there are many people who are undeserved or not served at all because they don't fit neatly into the various O-agency service criteria. Initiatives such as 'no wrong door' are essential but need to move from a conceptual stage to actual practice. The paperwork alone often prevents people from accessing needed services as they cannot navigate the very complicated service access systems. From personal experience this is especially true with people who are dual diagnosed as each state organization will argue that the other diagnosis is the primary one resulting in the individual not being served or not being served adequately. CMS regulations are another layer entirely that create barriers to service access and delivery.”*

The **Eligibility Criteria** theme refers to challenges in getting services to consumers because of varying program criteria. Twenty-one percent (21%) of providers offering comments or statements expressed concerns program eligibility rules and regulations:

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- *“Many people fall into an income gap where they either make too much money or not enough to receive services. There are also gaps in funding that cannot provide necessary home modifications that can allow an individual to age in place.”*
- *“Many of the emerging services are targeted toward Medicaid eligible individuals. There is still a huge need for programs/services to support those who are just over Medicaid eligibility.”*
- *“If the clients’ needs deviate from the norm it is very difficult to get services in place. For example, if a person aged 58 who is disabled and in need of services from the senior center. We are not able to serve them as they have to be aged 60 years. They may meet the criteria for need as for example a daily meal but are not entitled due to their age and there is nowhere for us to send them.”*
- *“Clients have to be home-bound for the most part to receive services, there are some clients who are not home-bound, but could benefit from services provided by this agency.”*

Two other frequently mentioned themes were identified. Slightly more than 13% of comments were related to **Accessing Services**, and an additional 13% mentioned **Workforce**:

### **Workforce**

- *“In the long term care settings the staff are not properly trained to assist resident consumers with the services needed. The agencies responsible for oversight of service providers are short staffed and ineffective at maintaining quality of services delivery to consumers. Large caseloads for service providers limit the contact with the consumer.”*
- *“I think the clients can benefit from more face time, one on one relationships with their worker. However, workers are often bogged down with a large amount of repetitive data entry instead of case development & relationship building.”*
- *“Too few case managers and too much time writing reports to funding providers such as NYS. Time consuming policies established by the area agency that go beyond the required NYS standards of contact with the clients.”*

### **Accessing Services**

- *“Applying for needed support services such as HEAP or affordable housing for seniors & people with disabilities is an arduous task for many.”*
- *“Some gaps are due to a lack of knowledge about available services. Often the elderly are too proud to ask for assistance. Lack of funding for services especially in our rural county creates the biggest gaps. Funding for services is needed for individuals who are not on Medicaid.”*
- *“Many times there are no resources to address client needs. There are 3-5 year wait lists for affordable senior housing, access to physicians through reliable*

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*transportation is unavailable, and there is a wait list for affordable home care services.”*

- *“When a client needs long term care services & they cannot privately pay for them & they do not qualify for Medicaid; they may be waiting for services on a wait list which can take over a year when they need services now. They almost have to wait until something worse goes on in their lives for any services to actual be implemented.”*
- *“However, I think we can prove that if you were looking at percentages, the rural counties would by far show the biggest percent of return on the funding based on population. We need a coordinator for rural counties that would assist in establishing equality no matter where you live in the state.”*
- *“Language and culture are barriers, and service providers' contracts do not keep up with the changing need, nor with supporting qualified staff. Space is a problem in NYC. To expand space - so as to create a more accessible, pleasing environment or to relocate to be more accessible is difficult given the cost of space and cost of construction. Some metrics should be reconsidered- such as reassessing what is considered a unit of service, whether senior centers should be evaluated on the number of meals or the number of attendees and participants in well-care programs.”*
- *“The six month waiting period before someone in long term care can be served by waiver programs and MFP. For whatever reason, we are finding that high risk individuals that are hospitalized and go on to sub-acute care can get stuck in the facility and is hard pressed to find help because of these waiting periods. Regionalization of waiver services leads to delays in receiving services for many. While regionalization of effort is good in many respects, more needs to be done to build local capacity to meet pressing needs. The calendar dynamics associated with MLTC plan coverage also leads to gaps in care.”*

This section has provided important input about consumers and providers views on the barriers and gaps in providing the best quality services and care to older adults and people with disabilities. An important theme revealed in this section related to having a stronger No Wrong Door system in New York State. This theme will be further explored in the next section.

### D. Strengthening the No Wrong Door (NWD) System

“No Wrong Door” (NWD) is an increasingly used term to describe the goal of person-centered LTSS systems. NWD systems are designed to facilitate access for consumers into the long-term services and supports system for older adults and people with disabilities. Sometimes referred to as “one-stop shops”, NWD systems are designed to address many of the frustrations consumers and their families experience when trying to find needed information, services, and supports. Through integration or coordination of existing aging and disabilities service systems, NWD systems, in principal, are designed

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so consumers may access the system at any point, and with any provider, and receive assistance about the full range of options that are available; provide objective information, advice, counseling and assistance; empower people to make informed decisions about their long-term supports; and help people more easily access public and private long-term services and supports. To gain insight into provider and consumer understanding of NWD initiatives and how the state’s current system of services for older adults and persons with disabilities is organized, providers and consumers were asked the following questions:

- Provider Survey Question #10: Overall, how concerned are your consumers about accessing or obtaining services?
- Consumer Survey Question #4: If you needed services or assistance, how confident are you that you know who to call or where to go?

As shown in Table 22, providers were concerned about the ability of the state’s LTSS service system to facilitate access for consumers. Seventy-seven percent (77%) of provider respondents indicated that they were “very concerned” or “somewhat concerned” about their consumers being able to access services. Both aging and disabilities providers expressed similar concerns about their consumers’ access to services.

**Table 22. Provider Survey Question #10: Overall, how concerned are your consumers about accessing or obtaining services?**

#	Answer	Response	%
1	Very concerned	318	43%
2	Somewhat concerned	323	44%
3	Not very concerned	73	10%
4	Not at all concerned	20	3%
	Total	734	100%

An analysis of the open-ended responses revealed themes identified previously: 40% of provider comments related to **Availability of Services**; 25% were related to **Accessing Services**; and 21% were associated with **Navigating the System**. Two additional themes mentioned frequently by providers included **Workforce** (12% of responses) and **Knowledge of Services** (11% of responses).

A different picture emerges from the analysis of consumer responses on the same issue. When asked “If you needed assistance or a service, how confident are you that you know who to call or where to go?” Forty-seven percent (47%) of consumers indicated they were “very confident” they would know who to call or where to go, and an additional 37% indicated they were “somewhat confident” in locating or accessing help. Only 16% of consumer respondents indicated they were “not very confident” or “not at all confident” about accessing or obtaining services (see Table 23). All consumers, regardless of age,

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whether they self-identified as having a disability, or if they were or were not receiving services answered the questions about the same.

**Table 23. Consumer Survey Question #4: If you needed assistance or a service, how confident are you that you know who to call or where to go?**

#	Answer	Response	%
1	Very confident	393	47%
2	Somewhat confident	303	37%
3	Not very confident	85	10%
4	Not at all confident	48	6%
	Total	829	100%

Consumers provided open-ended comments to explain or expand on their answer to this question, and almost 100% of responses addressed the theme **Where Consumers Would Go to Access Services**. The three primary sub-themes identified address where consumers stated they go or would go to obtain information or gain access to services: Seventy percent (70%) of consumers indicated they would go to their local aging or disabilities service provider; 24% indicated they would go to someone in their family for help; and 7% indicated they would call 911:

### Call Local Aging or Disabilities Service Provider

- *I would call NY Connects.*
- *If I needed to contact anyone for services, I would start by contacting my nearest Independent Living Center.*
- *Call different agencies, ask friends who have had services.*
- *Calling my local Department of Social Services and or contacting case manager at the Independent Living Center in my area.*

### Family Provides Assistance

- *Beginning with family members I would then approach your office. I have had help there in the past.*
- *Call neighbor across the street.*
- *First I would talk to my Mom because she knows. I think my service coordinator could help me find help as well.*

This section has provided important input about consumers and providers views on the state’s No Wrong Door system. The next section will discuss whether coordinating aging and disabilities services could help strengthen any of the challenges that have been articulated in the previous sections.

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### E. Findings on Feasibility of Coordinating Aging and Disabilities Services: Leveraging Resources and Fiscal Impact on Services and Consumers

Under Part N, NYSOFA was directed to seek “public input about the creation of an office of community living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities.” The primary goal of the project was to consult with stakeholders, providers, individuals, and their families to gather data and information on current services and supports and provide feedback on the potential impact of creating an Office for Community Living (OCL). In this last section, responses from consumers and providers to questions that openly address this issue are provided. Based on conversations with the steering committee, the Office of Community Living was not named in the questions, and no details about what state level coordination between aging and disability services might entail were provided. Respondents were encouraged to consider the questions as worded and to answer as best they could. The following questions were posed:

- Provider Survey Question (PS) #11: Would there be any advantages if aging and disability services were more coordinated in the state of New York?
- Provider Survey Question (PS) #12: Would there be any disadvantages if aging and disability services were more coordinated in the state of New York?
- Provider Survey Question (PS) #13: How confident are you that a state level coordination of aging and disability services could improve access or quality of services to consumers?
- Consumer Survey Question (CS) #9: How much of an impact would state level coordination of aging and disability services have on your services?

#### **Provider Perspectives on an OCL**

Provider responses were mixed about the potential advantages or disadvantages of a state level Office of Community Living, with many expressing ‘don’t know’. As shown in Tables 24 and 25, in response to the question “Would there be any advantages if aging and disability services were more coordinated in the state of New York?” 57% of provider responses indicated there would be advantages; 11% stated that there would not be any advantages; and 32% indicated they did not know. In response to the question “Would there be any disadvantages if aging and disability services were more coordinated in the state of New York?” 28% of respondents indicated there would be disadvantages; 24% stated there would not be any disadvantages; and 48% indicated they did not know.

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**Table 24. Provider Survey Question #11: *Would there be any advantages if aging and disability services were more coordinated in the state of New York?***

#	Answer		Response	%
4	Yes		422	57%
5	No		83	11%
6	Don't know		235	32%
	Total		740	100%

**Table 25. Provider Survey Question #12: *Would there be any disadvantages if aging and disability services were more coordinated in the state of New York?***

#	Answer		Response	%
4	Yes		203	28%
5	No		177	24%
6	Don't know		354	48%
	Total		734	100%

Analyses were also conducted to determine whether providers from aging organizations differed in their assessment of these questions from disabilities providers. Results indicated that providers from disabilities organizations and combined aging and disabilities organizations were more likely to believe there were advantages if aging and disabilities services were more coordinated in New York State than providers from aging organizations. They were also less likely to agree that there were disadvantages to greater coordination of aging and disabilities services in comparison to aging providers.

Uncertainty about the OCL feasibility study is also reflected in provider responses to the question: “How confident are you that a state level coordination of aging and disability services could improve access or quality of services to consumers?” As shown in Table 26, only 12% of provider respondents from all organizations answered they were “very confident” that a state level coordination of aging and disability services would “improve access or quality of services to consumers.” Almost the same number, 11% of respondents, indicated they were “not confident at all” that greater consolidation would improve services. Almost half (47%) of respondents indicated that they were “somewhat confident” that great consolidation would improve access or quality of services, and 30% indicated they were “not very confident” about the benefits of greater consolidation.

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**Table 26. Provider Survey Question #13: How confident are you that a state level coordination of aging and disability services could improve access or quality of services to consumers?**

#	Answer	Response	%
1	Very confident	87	12%
2	Somewhat confident	338	47%
3	Not very confident	219	30%
4	Not confident at all	82	11%
	Total	726	100%

Providers were encouraged to provide explanations for their responses to the three questions. Overall, 45% of provider responses indicated strong opposition to consolidation of any kind, a theme titled **Disadvantages of Merging Aging and Disabilities Services**. Just over 34% of provider comments expressed strong support for greater consolidation, labeled as **Benefits of Merging Aging and Disabilities Services**. Finally, 13% of providers indicated they did not have enough information to make an informed assessment, a theme titled **More Information is Needed on the Plan for Merging Aging and Disabilities Services**. Because these questions are central to the overall goals of the project, several representative quotes are provided:

**Disadvantages of Merging Aging and Disabilities Services**

- *“It seem that it would be easier for the consumer if the coordination of services remained at the local level. The local level has a history of having good working relationships with the agencies that they contract with.”*
- *“Aging does not equal disabled. Mixing social services with medical model services is a big mistake.”*
- *“Aging has shown competency in coordinating services so joining with disability concerns me. Example: NY Connects.”*
- *“Aging is a natural thing for everyone and people with disabilities should not be carved out of services.”*
- *“Although both populations experience some of the same limitations, they are a completely different population.”*
- *“Both populations have their unique needs and both need to have greater attention paid to them. Combining efforts would merely diminish the support, attention and resources for each.”*
- *“Coordination of services is always a positive goal, however aging is not synonymous with disabilities and many individuals with physical or intellectual disabilities or mental illness and related disabilities have very different needs from those of older adults, particularly growing numbers of the oldest-old including centenarians.”*
- *“I can’t really think of what the advantages would be of creating a huge agency that covers such a broad range of individual needs. Certain disabilities would get*

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*lost and go underserved and seniors, as always, would get the least amount of services.”*

- *“I don't think that the two groups see themselves as having the same or similar interests.”*
- *“I don't think this would benefit the senior citizens at all...there are many options for the disabled but we tend to forget about our elderly...”*
- *“I feel that seniors are a special population with their own special needs. I realize that even if the two populations were to unite, there would still be a need to specialize and sub-divide (once again) to focus on seniors!”*
- *“In a small agency such as ours, we lack expertise with disabilities services. We have "our hands full" educating ourselves in the field of aging, staying informed of changes in benefits and other governmental programs. It would appear the quality of our services would suffer if we had to dilute our expertise further.”*
- *“It is my sense that this type of collaboration will add in losing the individuality of receiving services. An aged person who is also frail has different quality of life issues than someone who is younger and frail. The number of seniors are growing and to fragment them further would not be helpful to them.”*
- *“Not all in the aging population are disabled! Please think about the implications of merging these departments, especially for aging persons who are not disabled. Grouping these two populations with vastly different needs together would mean that the quality of services would decrease and the knowledge base for case managers would have to double. Specializing in aging means that case managers can focus on the issues of this population and better serve their clients.”*
- *“Not from a program or service provision. Benefits only to disabilities field BUT NO ADVANTAGE TO AGING FIELD. Have worked for years to improve aging as a field of choice for professionals. This will put it further into the dark ages.”*
- *“NYSOFA and the AAAs have a certain culture and so do the Independent Living Centers. There is overlap there to be sure but these are 2 different things and operate from two different perspectives. A well-intended "merger" could become more of a burden for all concerned.”*
- *“Although our older adult clients are primarily disabled, they are pretty "invisible", particularly the homebound folks; therefore, any effort that dilutes the services and advocacy efforts that supports them would be a disadvantage.”*
- *“It would dilute the visibility of programs among stake holders and give legislators fodder to cut programs further. This is the wrong direction; "coordination" will lead to combining services which will lead to funding cuts. The issues will become lost even more than they are in the legislative agenda.”*
- *“Fighting over funding pots of money. Regulations vary and would need to be consistent - or modified.”*
- *“I don't think the two populations are necessarily compatible nor the services necessary akin to one another and able to be coordinated.”*

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- *“I think keeping them separate gives people options to go where they are comfortable. If all of the agencies that provided services to the aged and disabled populations were combined into one, not as many individuals would be served.”*
- *“Many of the people we support are young, vibrant and want to lead active lives in the workforce and in the community. I would think there could be a huge disconnect in the kinds of services they want/need to lead their lives and the kind of support older adults need. While both groups benefit from supports in their homes/communities, i think in many cases, the focus is very different, except for those people with disabilities who are also older adults.”*
- *“Most seniors do not identify as having a disability and are offended to be looked at that way. The "medical model" of services is still very prevalent in the senior community - the idea that a disability should be fixed, rather than the environment being the impediment. Some seniors also find the strong advocacy base of the disabilities community too pushy.”*
- *“The combination of these two populations with the great range and scope that each has will create an organization too large to meet all the needs creating more gaps. Also a segment of the aging population is not disabled but require some care to meet their needs. This is an important distinction to the elder, needing help vs disabled, and must stay clearly defined to insure that elders feel comfortable to ask for the help they need when they need it.”*

### **Benefits of Merging Aging and Disabilities Services**

- *“If aging and disabilities services were coordinated, the consumers would get better services as there are similar issues with the aging and disabled. Resources could be better coordinated.”*
- *“A single point of access could help people know what their options are so they can make informed choices.”*
- *“Almost 50% of those we serve are 50+ years old. Additionally, as we age the chance of becoming disabled increases exponentially. While there are philosophical differences between the IL and aging providers I don't think those differences are insurmountable in the agencies complimenting [sic] each other.”*
- *“Any time you can effectively coordinate services, care improves. The elderly and the disabled have some (but not all) of the same needs. This would go towards providing a more comprehensive model of care.”*
- *“ANYTHING being more coordinated is a good thing. We often provide services to consumers and then once they are linked with another resource, we may get another call requesting the same service we just provided because the client does not share information properly, or are looking to take advantage on any/all services. I believe that the disabilities needs to be addressed by the professional in that field but coordination/centralized case management across NYS would be a tremendous advantage, especially for social workers seeking resources. Example, multiple applications being submitted by various agencies for Medicaid,*

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*social security, housing etc. The consumer is not always knowledgeable and/or communicative about what has been done for them.”*

- *“Better coordination would allow people to know what services they qualify for more easily, especially if it meant making sure that programs all had the same rules and definitions, to the extent allowed by law.”*
- *“Better oversight and direction of services and initiatives to improve the lives of people with disabilities.”*
- *“Communication between departments and programs is essential. Creating teams of people from different departments/different roles that traditionally do not work together would be a positive change.”*
- *“Frequently, disabled persons face the same challenges as the elderly but are not able to privy themselves of services that are solely earmarked for the senior community.”*
- *“Hopefully this would bring a renewed focus to services for older adults and people with disabilities in general. It may also help to eliminate some of the program barriers that currently exist.”*
- *“People with disabilities have many of the same needs as older New Yorkers. If the two groups could coordinate on a policy level, they would have a stronger combined voice in areas such as long term care, housing, physical access etc.”*
- *“I don't see a drawback to two groups with the same or similar interests and concerns combining their voices.”*
- *“There is rarely a detrimental effect from coordination. The two populations use many of the same services and, when they don't, coordination will not negatively affect service delivery.”*
- *“There needs to be less compartmentalization of people and more individual understanding.”*

### **More Information is Needed on the Plan for Merging Aging and Disabilities Services**

- *“I am not sure that it would create the expertise needed for either. But there seems to be some natural overlap that might increase service delivery.”*
- *“I am not sure if coordinating would mean more regulations, higher costs etc. then I would have to really think about that.”*
- *“It is difficult to say whether a unified system would be better, although it would help prevent misdirection of services. On the other hand, many people have the arrangements they currently have because they are what work best for them, or may simply be unwilling to try something new.”*
- *“We do not know what coordination would look like and what principals would inform the work of the agencies (or new agency if applicable).”*
- *“Unsure of agency and interest groups' cooperation.”*

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### Consumer Perspectives on Consolidation

As shown in Table 27, most consumers indicated that greater state-level coordination of aging and disability services would have an impact on the services they receive. Of the responses received, 44% indicated that greater coordination would have “a great deal of impact” on their services; 28% indicated that it would have “some impact”; 13% answered that greater coordination would have “not very much impact”; and 15% stated that it would have “no impact at all.”

**Table 27. Consumer Survey Question 9: How much of an impact would state level coordination of aging and disability services have on your services?**

#	Answer		Response	%
1	A great deal of impact		218	44%
2	Some impact		138	28%
3	Not very much impact		62	13%
4	No impact at all		73	15%
	Total		491	100%

Further analysis of this questions showed that younger consumers more likely to believe that consolidation would have a bigger impact than older adults. There was no significant difference in responses between disability status or if they currently received services or assistance.

Consumers were given the opportunity to explain what type of impact they anticipated, and whether it would be positive or negative. More than 52% of all consumer responses were identified with the theme **Benefits of Merging Aging and Disabilities Services**, and 19% of consumer responses addressed the theme **Disadvantages of Merging Aging and Disabilities Services**:

#### **Benefits of Merging Aging and Disabilities Services**

- *Coordinating services are important. I.e. more people get help, less waste in \$\$\$, services, & man power. Less fraud.*
- *Coordination may level the reimbursement field, increasing service availability for the elderly.*
- *It would impact services for sure. If the state handed services to MLTC there would be cherry picking and less services for all because they are insurance companies looking to make a profit over actual care. If the state handles it and keeps the people centered polices in place through ILC's that would be great as they work hard to keep people in their homes, not institutions, with services in place to make them successful at aging in place. OFA's also educated and have that same philosophy, it would make for a solid marriage.*
- *Synergy would motivate increased collaboration and improved efficiency of engagement*

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### Disadvantages of Merging Aging and Disabilities Services

- *My needs are different from "aging individuals". What does blindness / visual impairment have to do with the senior population? I'm still trying to build a career, travel and be involved in my community. I'm dealing with getting around the city safely, crossing the street, getting talking traffic signals, using the subway safely, and commuting to the outer boroughs. I don't associate with the elderly, nor do I want to be in their company. The focus on the elderly is on health issues, scam issues, dealing with loss / grieving and going to doctor visits. That's not my world!*
- *Services for those with disabilities and for the elderly should not be combined. Also, services for people with different types of disabilities should be separated from each other. If all are lumped together, everyone will suffer because consumers won't be able to get services from those most familiar with them.*
- *So many older adults, and worry that the way services are delivered to aging folks would be laid down for (mostly) well but I/DD young and middle aged folks.*
- *Impact would not be positive. The needs of the aging population is very different from those of people with disabilities. This approach might save money but would have a negative impact on each system.*

Other themes identified in consumer responses to this question addressed

**Accessing Services** (8% of responses); **Navigating the System** (6% of responses); **Availability of Services** (5% of responses); **Workforce** (4% of responses); and **Knowledge of Services** (4% of responses). These themes have been described in previous sections.

### F. Summary and Acknowledgment

The results of the consumer and provider survey were designed to provide stakeholders in New York State's aging and disabilities communities an opportunity to provide input on the feasibility of greater state-level coordination between aging and disabilities services. The survey was developed in consultation with members of study's steering committee, and disseminated widely throughout the state. NYSOFA and steering committee members worked diligently, under tight time constraints, to disseminate the surveys to consumers and providers in communities statewide. Findings from the survey present provider and consumer perspectives on the quality of services received or provided in New York State. Overall, providers expressed less satisfaction with the quality of available LTSS, citing issues with the availability of important services, consumer knowledge about and access to services, and difficulties in coordination. In some important aspects, the providers appear to have successfully shielded consumers from some of these system shortcomings, as consumers were much more likely to offer satisfactory comments about services than providers. The strong satisfaction findings, however, were not unanimous, and consumers were not hesitant to express concern about a number of service quality issues in the LTSS system in New York State.

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G. Key Themes, Recommendations, and Fiscal Impacts

**Table 28: Summary of Key Themes from Consumers and Providers**

KEY THEMES FROM PUBLIC INPUT PROCESS	
MAJOR THEMES	SUB-THEMES
<b>Satisfaction with Services</b>  <b>CONSUMER AND PROVIDER SURVEYS</b>	<ul style="list-style-type: none"> <li>• Services are working well.</li> </ul>
<b>Satisfaction with Services</b>  <b>FROM OCL FORUMS</b>	<ul style="list-style-type: none"> <li>• <i>“Services are not as good as they could be due to the shortage of workers (home health). Providers spend a lot of time advocating to get services for their clients. Services also suffer because of the long wait-list for programs.”</i></li> <li>• <i>“There is room for improvement in service delivery. Staff is lacking, and some staff do not have the correct information to lead the consumers to the proper services.”</i></li> </ul>
<b>Coordination/Communication</b>  <b>CONSUMER AND PROVIDER SURVEYS</b>	<ul style="list-style-type: none"> <li>• No coordination between the case managers. Often consumers have multiple service providers/agencies that they are working with and providers are not communicating with one another about consumers. Providers/agencies are not coordinating and care is silo-ed.</li> <li>• There is duplication in assessments and applications. There is duplication of services being provided to consumers by multiple organizations. There are many case managers working with one person.</li> <li>• Consumers have difficulty communicating their needs to providers.</li> <li>• There may be lack of coordination, but duplication is a good thing.</li> <li>• Collaboration between providers/agencies is important and it is working well.</li> </ul>

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<p><b>Coordination/Communication</b></p> <p><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• <i>“The consumer has to make telephone calls to see if I can get a different person who will give me better information on the question, because many times the person answering the phone doesn’t know it.”</i></li> <li>• <i>“Duplication of services and not enough partnering going on.”</i></li> </ul>
<p><b>Accessing Services</b></p> <p><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• There are geographic concerns in accessing service, particularly for those in rural areas of the state. There are consumers who cannot get to the service provider/agency.</li> <li>• Language barriers make it difficult for consumers to access services. Materials/websites are not ADA compliant or do not work with assistive technology.</li> <li>• Excessive and/or confusing paperwork/forms, for both consumers and providers make it difficult for consumers to access services. This includes requiring forms to be submitted online.</li> <li>• Long wait times for consumers to speak with providers, for consumers to be approved for services, or for services to start makes accessing services difficult.</li> <li>• Consumers don’t always accept services for many reasons, one of which is the stigma associated with receiving services. Providers are not always able to reach people in need of services.</li> </ul>
<p><b>Accessing Services</b></p> <p><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• Issues about duplication and access</li> <li>• <i>“Difficulty around accessing services for older adults and individuals who are disabled due to guidelines and coordination at different levels of government.”</i></li> <li>• <i>“Not easy to enroll in services.”</i></li> <li>• <i>“People indicated that the 60% of consumers reporting no difficulty in accessing services doesn't match their experience in the field over many years and they asked whether we have analyzed the respondents who did have trouble accessing services.”</i></li> </ul>

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	<ul style="list-style-type: none"> <li>• <i>“An individual could be referred for a nursing home transition and diversion waiver it might be 6 months before they can get all the bureaucracy to get on services.”</i></li> </ul>
<p><b>Eligibility Criteria</b></p> <p><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• Consumers face challenges in getting services because of varying eligibility criteria.             <ul style="list-style-type: none"> <li>• For example, consumers might not qualify for Medicaid because of the strict income guidelines and therefore cannot get services.</li> <li>• Consumers might be waiting for an official diagnosis and cannot get services until this happens, and in the meantime can fall through the cracks and get lost in the system.</li> </ul> </li> </ul>
<p><b>Eligibility Criteria</b></p> <p><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• <i>“Service gaps exist due to the different eligibility criteria for older adults and individuals with disabilities.”</i></li> <li>• <i>“There are different eligibility rules at the State level organizations maybe due to the fact that aging and disability consumers represent different constituencies.”</i></li> <li>• <i>“There are many gaps in services due to a lack of programming and the highly regulated eligibility requirements.”</i></li> </ul>
<p><b>Where Consumers Would Go to Access Services</b></p> <p><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• Contact or walk in to an aging or disability services provider or other professional</li> <li>• Contact emergency service provider or 911</li> <li>• Contact informal support person – family, friend</li> <li>• Conduct research on service options and then contact them</li> </ul>
<p><b>Where Consumers Would Go to Access Services</b></p> <p><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• Was not raised at OCL Forums</li> </ul>

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<p><b>Concern About Availability of Services</b></p> <p><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• There is a general concern with services availability, ranging from transportation, housing, behavioral health, etc.</li> <li>• Providers are seeing an increased need for services.</li> <li>• Concerns about the quality of services.</li> <li>• There are gaps in services.</li> <li>• Consumers are not receiving the services they want.</li> <li>• Services are not working well; there is dissatisfaction.</li> <li>• There is a concern with funding for services.</li> <li>• Providers/agencies are competing for the same funds and consumers.</li> <li>• Providers and consumers are concerned they will not have enough money for the services consumers need.</li> </ul>
<p><b>Concern About Availability of Services</b></p> <p><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• <i>“In rural areas, it is so difficult to access services because they are lacking or simply not available (transportation, home health aides, services for the visually impaired). It makes sense to work together as both populations have the same goal, to live in the community, and it’s impossible for every individual to know where to go for every service. Application processes also make it difficult. Some believe the NY Connects expansion has made this easier, and that there should be more focus on providing services not combining agencies.”</i></li> <li>• <i>“Waiting lists already exist of some non-Medicaid LTSS such as EISEP, home delivered meals, case management and transportation”</i></li> <li>• <i>“The number of services provided do not equate the number of consumers. Accessing services and navigating the system is extremely difficult.”</i></li> <li>• <i>“Mental health services for our elderly population are lacking.”</i></li> <li>• <i>There is a lack of services, as individuals mostly receive information, not services. Also there is a lack of home care providers. Providers believe</i></li> </ul>

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	<p><i>disability focuses on prevention, while aging focuses on socialization, so the needs are different.</i></p> <ul style="list-style-type: none"> <li>• <i>“There are gaps in services around transportation and home care. The ILC’s are trying to bridge this gap by assisting all populations.”</i></li> </ul>
<p><b>Workforce</b></p> <p><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• There is a general concern with availability of providers.</li> <li>• Concerns about the quality, qualifications, and training of the workforce.</li> <li>• High turnover rates, often due to low pay for providers.</li> <li>• Concerns about providers’ dependability (i.e. no call/no shows).</li> </ul>
<p><b>Workforce</b></p> <p><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• <i>“Often delays in getting assessments because of the lack of understanding on what department to direct you to. In some instances, you have to fight for services to stay out of a nursing home.”</i></li> <li>• <i>“You’re only as good as the service professional that you reach and what is available shifts over time. I think that takes real level knowledge, by people who are going to have that knowledge, available to everybody in the system where they are supported.”</i></li> <li>• <i>Funding and staff are lacking to provide adequate services to the population.</i></li> </ul>
<p><b>Knowledge of Services</b></p> <p><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• Providers don’t know about all the types of services that are available across different agency settings.</li> <li>• Consumers don’t know what services are available.</li> <li>• More marketing, advertising, and is needed to educate/inform consumers.</li> <li>• There should be a single central website and one number to call for information about all services.</li> </ul>
<p><b>Knowledge of Services</b></p>	<ul style="list-style-type: none"> <li>• Was not raised at the OCL Forums</li> </ul>

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<b>FROM OCL FORUMS</b>	
<p><b>Navigating the System</b></p> <p><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• Navigating the system is very difficult for providers, consumers and their families.</li> <li>• State changes regulations frequently which negatively impacts consumers and makes navigating the system challenging.</li> <li>• There are conflicting program eligibility rules, which makes navigation challenging.</li> <li>• Bureaucratic, policy, procedural barriers make it difficult to navigate the system.</li> <li>• There are different policies/rules at different state and local levels.</li> <li>• Negative comments/concerns about MLTC.</li> <li>• Negative comments/concerns about OPWDD Front Door process.</li> <li>• A single point of entry would make it easier for consumers and providers (more than NWD – one point of entry for all services).</li> <li>• Consumers shouldn't have to repeat their stories multiple times and complete the same type of paperwork each time they interact with a different agency.</li> </ul>
<p><b>Navigating the System</b></p> <p><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• Navigating the system is extremely difficult. Individuals who have services know where to go, but others do not. Some are afraid collaboration would make services lost. Every level across the state is that the system is extremely difficult to navigate.</li> <li>• <i>“I cannot imagine for somebody coming into the system probably in crisis and without even knowing how to get in the system much less to access the services that they need.”</i></li> <li>• <i>“Very difficult for even the layperson to navigate the system.”</i></li> <li>• Ability to go through the system</li> <li>• Indicated that navigation was a huge problem.</li> <li>• There are gaps in the services that allow people to remain at home, but the silos are beginning to break down.</li> </ul>

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	<ul style="list-style-type: none"> <li>• <i>“It’s fragmented and that individual has to work with one case manager for school, one case manager for disability, one case manager for seniors.”</i></li> <li>• <i>“there needs to be a central point in each county that has the resources and information to help navigate anyone, whether it’s disabled, aging, pediatric, whatever, to the right program</i></li> </ul>
<p><b>Services Provided by Providers and Informal Supports are Invaluable</b></p> <p align="center"><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• Many consumers rely on family or friends to access and receive needed services. They contact one of their informal support persons when they need assistance.</li> <li>• Many consumers rely on professionals to access and receive needed services. They contact or walk in to a service provider when they need assistance.</li> <li>• Some consumers feel they could really benefit from someone to assist them in accessing, finding, or seeking services, and they don’t have that.</li> </ul>
<p><b>Services Provided by Providers and Informal Supports are Invaluable</b></p> <p align="center"><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• <i>“Services are invaluable when they’re receiving them.”</i></li> </ul>
<p><b>Benefits of Merging Aging and Disabilities Services</b></p> <p align="center"><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• Shared resources.</li> <li>• Better collaboration among providers.</li> <li>• Less wasted time navigating the system.</li> <li>• Less duplication of services, applications, assessments.</li> <li>• One stop shopping for all services; one application; one agency.</li> </ul>

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<p><b>Benefits of Merging Aging and Disabilities Services</b></p> <p align="center"><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• <i>Both populations have similar needs and share a difficulty when accessing services. This is an opportunity to help individuals better navigate the system and meet the needs of the growing population.”</i></li> <li>• <i>“There is a lot of good information out there that some agencies cannot access because of silos. By combining, both groups can learn from one another.”</i></li> <li>• <i>“The OCL would be incredibly helpful for providing information or referring someone to the appropriate resource.”</i></li> <li>• <i>“OCL under one umbrella, could offer a lot more coordination and infrastructure. They were supportive due to research that shows us that when you have services under one agency, you can get better outcomes.”</i></li> <li>• <i>“There is a lot of good information out there that some agencies cannot access because of silos. By combining, both groups can learn from one another.”</i></li> <li>• <i>Sees the needs continuing to increase. They want OCL to move forward if it is done in a thoughtful deliberate way.</i></li> <li>• <i>“OCL has the potential to break down barriers and provide a “one-stop-shop” so it is easier to navigate services.”</i></li> <li>• <i>“An Office of Community Living would offer more coordination between aging and disabilities stakeholders.”</i></li> <li>• <i>“An umbrella for service providers to all populations for the agency use resources and knowledge that each of the communities have, to strengthen what we have”</i></li> </ul>
<p><b>Disadvantages of Merging Aging and Disabilities Services</b></p>	<ul style="list-style-type: none"> <li>• Loss of identity – one group being subsumed by the other.</li> <li>• Loss of funding.</li> </ul>

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<p align="center"><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• Loss of services.</li> <li>• Fearful of increased government/State involvement and/or regulations.</li> <li>• Provision of services is better at the local level.</li> <li>• There are important differences between the groups. Aging is not a disability.</li> <li>• Providers cannot be experts in everything.</li> <li>• Poorly planned coordination can be a disaster. It would need to be very thoughtful</li> <li>• Lack of confidence that the State will do this right.</li> <li>• Needs of consumers across the State are too diverse. A “one size fits all” approach will not work.</li> </ul>
<p><b>Disadvantages of Merging Aging and Disabilities Services</b></p> <p align="center"><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• They didn’t want extra levels, making it more difficult not only for providers in an already complicated system, but even more so for the consumers who have less of an understanding of how the system works.</li> <li>• People were trying to see where the aging population and disabilities population have services that overlap, mentioning caregiver and respite as the only two.</li> <li>• <i>“People with a disability condition need specific needs met and are unique. No Wrong Door was still a cumbersome process.”</i></li> <li>• <i>“Both groups are different and by combining agencies, funding or services will be lost to the other group.”</i></li> <li>• Merging agencies will put a significant risk to individuals.</li> <li>• <i>“The last thing we need is another layer of bureaucracy.”</i></li> </ul>
<p><b>Fiscal Impact</b></p> <p align="center"><b>FROM OCL FORUMS</b></p>	<ul style="list-style-type: none"> <li>• There are concerns around loss of funding and creating OCL to save money. Yet others understand this is not about funding, that it is a logical approach as the needs of the two populations are similar.</li> <li>• <i>“Pool those resources and be able to help more people and, you know, share information and not have people going from one door to another door</i></li> </ul>

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	<p><i>to another door which is I think the whole purpose of this.”</i></p> <ul style="list-style-type: none"> <li>• Combining services will result in a loss of funding, services, and an increase in employee layoffs. Older adults and young individuals have different needs, and should not be served by the same entity. Also, concerns about funding were addressed. Yet, some individuals believe we can work better by collaborating and leveraging resources.</li> <li>• <i>“There needs to be more funding available to be able to best leverage resources.”</i></li> <li>• People are concerned about the disparity between downstate and other regions, in terms of quality of services. They want more rural funding. They question the cost savings involved and if there is, they would like that savings to go back and shared amongst the agencies.</li> <li>• <i>“This is being done to save money. By combining, both groups will be competing for funding. There is no evidence that combining agencies results in efficiency. It’s too early to tell if merging is a good idea, but breaking down the silos would be helpful for providers and benefit their consumers.”</i></li> <li>• More funding at the local level.</li> </ul>
<p><b>More Information is Needed on the Plan for Merging Aging and Disabilities Services</b></p> <p align="center"><b>CONSUMER AND PROVIDER SURVEYS</b></p>	<ul style="list-style-type: none"> <li>• How would the merger of services be implemented?</li> <li>• Suggestions on how to successfully merge are needed.</li> <li>• A clear vision or leader is needed. (What’s the plan? Who’s going to structure the merger?)</li> <li>• Merging services would be a good idea, but people lack confidence in the State to carry it out.</li> </ul>
<p><b>More Information is Needed on the Plan for Merging Aging and Disabilities Services</b></p>	<ul style="list-style-type: none"> <li>• <i>“Balance of whatever goes forward with the community living effort not only helping the disabled individuals in the aging people with a lot of their issues but we're also providing the</i></li> </ul>

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<p align="center"><b>FROM OCL FORUMS</b></p>	<p><i>wellness to prevent people from being in the long-term services down the road.”</i></p> <ul style="list-style-type: none"> <li>• <i>“Be deliberate in bringing together resources.”</i></li> <li>• <i>Concerned about gaps because coordinating services does not create services.</i></li> <li>• <i>“I think if we looked forward through an Office of Community Living the potential is there to remove some of the barriers with the services that have not been successful in the past.”</i></li> <li>• <i>“More coordination and collaboration would be efficient and helpful. However, combining agencies is not the only way to do this.”</i></li> </ul>

**The following key themes are derived from respondent feedback collected through the survey and via the public forums:**

**Service Satisfaction:** All respondents are concerned with retention, training, and availability of the long-term services and supports workforce. Consumers expressed the need for more competitive salaries to support recruitment and retention in the aging and disabilities fields. Both the disabilities community and aging network expressed the desire for a system that will assist those who have functional limitations and require assistance to remain in the community of their choice.

**Coordination/Communication:** Both the disabilities community and aging network experience disjointed and/or uncoordinated systems.

**Eligibility Criteria:** Respondents reported inconsistent application of program benefit and eligibility rules and an overly burdensome bureaucracy.

**Workforce:** Workers’ expertise is highly valued by services providers and service recipients. Survey respondents and regional forum commenters emphasized the need to maintain existing expertise in any new system configuration.

**Navigating the System:** Survey respondents indicated that navigating the long-term services and supports (LTSS) system can be challenging, citing fragmentation, silos, lack of coordination, and concerns with inconsistently applied policies and regulations. The value of a single point of entry was a common theme.

**Services Provided by Providers and Informal Supports are Invaluable:** Informal supports are critical for both older adults and those living with a disability to remain in the

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community successfully. Professional service providers are also vital to service recipients and caregivers.

**Advantages of Merging Aging and Disabilities Services:** Survey respondents and forum attendees expressed the need for better state-level LTSS coordination, with the ultimate goal of reducing duplication of efforts and maximizing limited resources.

**Disadvantages of Merging Aging and Disabilities Services:** Consumers and providers from both the aging and disabilities communities expressed the need to maintain a distinct voice representing their communities, avoid increased bureaucracy, and sustain existing funding levels.

**More Information is Needed on the Plan for Merging Aging and Disabilities Services:** Respondents of the survey and forum were unclear about the impact of any changes to the LTSS system until more information is available, and more input should be gathered from the community prior to implementation of any changes. Respondents also expressed that any changes should benefit the consumer in both the aging and disabilities communities by removing barriers to accessing services, reducing bureaucracy, and increasing coordination.

**Other:** Additional input from a broader spectrum of stakeholders, including under-represented populations, can help inform future discussions.

### **RECOMMENDATIONS:**

**Proposed recommendations are based on survey results, feedback from the forums, and other sources.**

The following principles guide the proposed recommendations:

- Current resources and/or systems would be leveraged wherever possible;
  - Any systemic changes within the state that seek to increase coordination and consistency should not lead to service gaps or delays, or result in a loss of historical knowledge and expertise; and
  - The community should be given the opportunity to learn about and provide feedback on suggested changes to the system prior to implementation.
1. Identify best practices for service coordination by aging and disabilities providers in other states specifically related to workforce, which would have potential for replication in New York State. Cost to implement this recommendation would require further analysis.

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2. Survey and evaluate performance measurement tools that measure service satisfaction. Cost to implement this recommendation would require further analysis.
3. Identify best practices for service coordination by aging and disabilities providers in New York and other states that have the potential for replication throughout the state including mapping and identifying programs that serve individuals in their communities of choice. Cost to implement this recommendation would require further analysis.
4. Continue to develop and fund the enhanced NY Connects system and the Enhanced No Wrong Door (ENWD). The NY Connects system was established in 2006 and has been significantly expanded in 2015. Under the Balancing Incentive Program (BIP), NY Connects functionality will improve access through enhanced linkage to services statewide.

Implementation will result in improved access to services for consumers.

Consumers will be able to access information via website, phone, in person, or home visit to achieve the following goals:

- All Individuals receive standardized information and experience the same eligibility process;
  - A coordinated process that guides the individual through the functional and financial eligibility determination process; and
  - Functional and financial screening data are accessible to NWD staff so that eligibility determination and access to services can occur efficiently.
5. Consider expansion of facilitated enrollment for programs impacting older adults and individuals with disabilities, with the goal of streamlining the eligibility process and improving the application process. Cost to implement this recommendation would require further analysis.
  6. Explore the potential of creating/enhancing a system that utilizes a lead case manager to coordinate services. Cost to implement this recommendation would require further analysis.
  7. Explore the potential of a unified IT platform for aging and disabilities organizations that are responsible for service provision (medical/non-medical) with the goal of enhanced care coordination. Cost to implement this recommendation would require further analysis.
  8. Explore opportunities to leverage the development of the state's integrated eligibility system, including an intuitive, user friendly single application for all

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federal/state programs. Cost to implement this recommendation would require further analysis.

9. Explore opportunities for expansion of presumptive eligibility. Cost to implement this recommendation would require further analysis.
10. Consider utilizing standardized metrics for non-clinical community-based LTSS. Cost to implement this recommendation would require further analysis.
11. Relevant state agencies and existing state committees should work with NYSOFA to further explore OCL feasibility study outcomes and the resulting recommendations.

## VI. Appendices

### A. Authorizing Statute

#### **Health and Mental Hygiene (HMH) (S2007-B/A3007-B) Chapter 57**

##### **PART N**

Section 1. Purpose. The purpose of this act is to seek public input about the creation of an office of community living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities.

§ 2. Data and information collection.

(1) The director of the state office for the aging, in collaboration with other state agencies, will consult with stakeholders, providers, individuals and their families to gather data and information on the creation of an office for community living. Areas of focus shall include, but not be limited to, furthering the goals of the governor's Olmstead plan, strengthening the No Wrong Door approach to accessing information and services, reinforcing initiatives of the Balancing Incentive Program, creating opportunities to better leverage resources, evaluating methods for service delivery improvements, and analyzing the fiscal impact of creating such an office on services, individuals and providers. The state office for the aging shall also examine recent federal initiatives to create an administration on community living; and examine other states' efforts to expand services supporting community living integration, and local and/or regional coordination efforts within New York.

(2) In order to ensure meaningful public input and comment regarding the activities of subdivision one of this section, there shall be a series of public meetings held across the state, organized to ensure that stakeholders in all regions of the state are afforded an opportunity to comment.

§ 3. Reporting. The director of the state office for the aging shall submit to the governor, and to the temporary president of the senate and the speaker of the assembly, a report and recommendations by December 15, 2015, that outlines the results and findings associated with the aforementioned collection of data and solicitation of feedback. Such report shall include, but not be limited to, the director's assessment, after taking into consideration input from all stakeholders, whether establishment of such an office would be beneficial to the populations served and the state as a whole, the information gathered to make such assessment, an analysis of all information gathered, all alternatives considered, the impact and effect any proposed change may have on existing programs and services, and an assessment of related fiscal impacts on localities, the state and non-governmental entities serving the elderly and disabled communities in each of the respective communities.

§ 4. This act shall take effect immediately.

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### B. OCL Kick-Off Webinar



## Office of Community Living Feasibility Study Webinar

November 4, 2015

November 4, 2015

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# Welcome

- Executive Chamber  
Division of Health



## Overview

- Corinda Crossdale,  
Director
- New York State Office  
for the Aging



## Accessibility

- Webinar will be recorded and posted on <http://www.aging.ny.gov/>
- Power Point Posted on Website
- Power Point Material Available in Word form so can be translated into any language and can be accessed via screen reader.



## Purpose & Rationale

Health and Mental Hygiene (HMH) (S2007-B/A3007-B) Chapter 57

### PART N

- Section 1. Purpose. The purpose of this act is to seek public input about the creation of an office of community living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities.



## Purpose & Rationale

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- (1) The director of the state office for the aging, in collaboration with other state agencies, will:
  - consult with stakeholders, providers, individuals and their families to gather data and information on the creation of an office for community living.
  - areas of focus shall include, but not be limited to, furthering the goals of the governor's Olmstead plan, strengthening the No Wrong Door approach to accessing information and services, reinforcing initiatives of the Balancing Incentive Program, creating opportunities to better leverage resources, evaluating methods for service delivery improvements, and analyzing the fiscal impact of creating such an office on services, individuals and providers.
  - The state office for the aging shall also examine recent federal initiatives to create an administration on community living; and examine other states' efforts to expand services supporting community living integration, and local and/or regional coordination efforts within New York.



## Purpose & Rationale

- (2) In order to ensure meaningful public input and comment regarding the activities of subdivision one of this section, there shall be a series of public meetings held across the state, organized to ensure that stakeholders in all regions of the state are afforded an opportunity to comment.

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Such report shall include, but not be limited to, the director's assessment, after taking into consideration input from all stakeholders, whether establishment of such an office would be beneficial to the populations served and the state as a whole, the information gathered to make such assessment, an analysis of all information gathered, all alternatives considered, the impact and effect any proposed change may have on existing programs and services, and an assessment of related fiscal impacts on localities, the state and non-governmental entities serving the elderly and disabled communities in each of the respective communities.



## Areas of Focus

1. Furthering the goals of the governor's Olmstead plan,
2. Strengthening the No Wrong Door approach to accessing information and services, reinforcing initiatives of the Balancing Incentive Program,
3. Creating opportunities to better leverage resources,
4. Evaluating methods for service delivery improvements, and
5. Analyzing the fiscal impact of creating such an office on services, individuals and providers.



## OCL Feasibility Populations

Types of Disabilities (based on Centers for Disease Control)

Individuals of all ages with challenges/limitations in:

- Vision
- Movement
- Thinking
- Remembering
- Learning
- Communicating
- Hearing
- Mental health
- Social relationships



## OCL Feasibility Populations

### Health Conditions

- This term refers to illness, disease, disorder, injury or trauma. The condition is usually a diagnosis. For example, autism spectrum disorders, spina bifida, and traumatic brain injury are health conditions.

### Body Structures

- Body structures are physical parts of the body. For example, heart, legs, and eyes are body structures.

### Body Functions

- Body functions describe how body parts and systems work. For example, thinking, hearing, and digesting food are body functions.

### Functional Limitations

- Functional limitations are difficulties completing a variety of basic or complex activities that are associated with a health problem. For example, vision loss, hearing loss, and inability to move one's legs are functional limitations.

### Activity

- Activity means doing a task or action. For example, eating, writing, and walking are activities.



## OCL Feasibility Populations

### Participation

- Participation means being involved in a life situation and fully participating in society. For example, attending school and playing sports. This also means including people with disabilities in all aspects of a communities' political, social, economic and cultural life.

### Participation Restrictions

- Participation restrictions are problems a person may have in life situations.

### Environmental Factors

- Environmental factors are things in the environment that affect a person's life. For example, technology, support and relationships, services, policies, and the beliefs of others are environmental factors.

### Personal Factors

- Personal factors relate to the person, such as age, gender, social status, and life experiences.



## § 2. Data and information collection.

- The state office for the aging shall also examine recent federal initiatives to create an administration on community living; and examine other states' efforts to expand services supporting community living integration, and local and/or regional coordination efforts within New York.



## Center for Aging & Disability Education & Research (CADER)

Scott Miyake Geron, Ph.D., MSW  
Bronwyn Keefe, Ph.D., MSW,  
MPH



## CADER Mission Statement

*"The Center for Aging and Disability Education and Research (CADER) is dedicated to strengthening the workforce that provides health and long-term supports and services to older adults and people with disabilities."*



## CADER LTSS Projects

- Partners with 20 statewide training programs including AAAs, ILCs, ADRCs
- Worked with more than 450 aging and disability service providers
- Trained over 20,000 workers in LTSS in the last 3 years
- Worked with ACL to develop competencies for workers in No Wrong Door Systems



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Boston University School of Social Work



## Role on Current Project

- Develop brief state-of-the-state report for the advisory Committee
- Help NYSOFA develop surveys and other data collection procedures
- Conduct 3-5 in-person meetings around the State
- Conduct 10-20 interviews with key stakeholders
- Analyze all findings from the project
- Complete final report of all findings for NYSOFA



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## Federal Administration for Community Living (ACL)

ACL was initially established on April 18, 2012, bringing together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities to achieve several important objectives including, reducing the fragmentation that currently exists in Federal programs addressing the community living service and support needs of both the aging and disability populations; enhance access to quality health care and long-term services and supports for all individuals; and promote consistency in community living policy across other areas of the Federal government.



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## Federal Vision of No Wrong Door System

The most recent thinking from ACL can be found in "The No Wrong Door" funding announcement released in June 2014. A criteria of this funding was that the following state agencies must be included as full partners in co-leading the planning process:

- the State Medicaid Agency
- the State Unit on Aging
- the state agencies that serve or represent the interests of individuals with physical disabilities and individuals with intellectual and developmental disabilities
- the state authorities administering mental health services



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## State of the States: Aging and Disability

- Based on NASUAD's 2014 *State of the States in Aging and Disability Agency* report, restructuring continues to be common among state agencies. States are continuing to reorganize how they conduct business and deliver services
- The most notable change in state organization is the incorporation of services for individuals with developmental disabilities into the same agency as the unit on aging. Between 2012 and 2014, the percent of states reporting that these services were part of the agency grew from 20 percent to 40 percent (NASUAD, 2014)



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## Massachusetts Example: Aging & Disability Integration

- In 2004, MA restructured HHS agencies
- The goal was to break down silos and consolidate, in particular, a main goal was to decentralize Medicaid, which was a major organizational change
- Prior to 2004, there was a separate state Medicaid office and now this has moved to HHS
- All agencies are now under the umbrella of HHS



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## Massachusetts Example: Lessons Learned

- Rebalancing costs have been successful
- This has not been easy!
- Requires a change in culture in all departments, at all levels
- Needs institutional commitment
- Requires looking at the way government is organized and be willing to change



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## Advisory Committee

The advisory Committee will involve meaningful input from key stakeholders including individuals with disabilities, their advocates, Area Agencies on Aging, Centers for Independent Living, local Medicaid agencies, local organizations that serve or represent the interests of individuals with physical disabilities, individuals with intellectual and developmental disabilities, and individuals with mental/behavioral health needs, Veteran Service Organizations, as well as service providers, and other relevant public and private entities.



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## In-Person Meetings

- Conduct at least three to five in-person meetings across the state of New York, included but not limited to key identified stakeholders
- The purpose of these in-person meetings is to gather preliminary information as well as reactionary information as it relates to perceptions, beliefs, and perspectives pertaining to the creation of an Office of Community Living



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## Phone Interviews & Surveys with Key Stakeholders

- CADER will work with NYSOA and the Project Advisory Committee to identify important stakeholders in aging and disability organizations across the state
- CADER will conduct phone interviews with 10-20 stakeholders, with equal numbers from aging and disability constituencies
- CADER will assist in creating surveys to gather information via NYSOA website portal



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## Data Analysis & Final Report

- CADER will analyze transcripts, interviews, and qualitative data collected via in-person and phone meetings and surveys
- Findings will be reviewed by the advisory Committee to provide a continuous feedback loop throughout the project and maintain stakeholder involvement
- CADER will provide a final report that includes an analysis of all findings



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**Scott Miyake Geron, Ph.D., MSW**

[sgeron@bu.edu](mailto:sgeron@bu.edu)

**Bronwyn Keefe, Ph.D., MPH, MSW**

[bronwyn@bu.edu](mailto:bronwyn@bu.edu)

**Center for Aging & Disability  
Education & Research (CADER)  
Boston University  
School of Social Work**

[www.bu.edu/cader](http://www.bu.edu/cader)



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Boston University School of Social Work



## Gathering of Public input

- Greg Olsen,  
Executive Deputy  
Director



## § 2. Data and information collection.

- (1) The director of the state office for the aging, in collaboration with other state agencies, will:
  - consult with stakeholders, providers, individuals and their families to gather data and information on the creation of an office for community living.



## Gathering of Public Input

- Website – to give the public an opportunity to provide initial input on creation of OCL
  - Provide Input via a survey tool posted on New York State Office of Aging website.
  - <http://www.aging.ny.gov/CommunityLiving/index.cfm>.
- CADER Survey
- Regional Information – CADER survey results shared for reaction/feedback during regional listening sessions
- Advisory Committee/Subgroups



## Survey Information

- <http://www.aging.ny.gov/CommunityLiving/index.cfm>.

### Survey Questions:

- What do you see as a strength of the process that was discussed?
- What do you see as a weakness of the process?
- Can you identify any opportunities that were not touched on?
- Can you identify any barriers or threats to this process?
- Any additional information you can provide regarding the process?



## Process Timelines

- Dr. Angelia Smith Wilson, Program Integrity Officer



## Process Timelines

- May- June: advisory Committee Formation
  - Bi-Monthly meetings
  - Subcommittees as needed
- May-August: Data Collection
- August- September: Data Analysis
- September – October – Regional Stakeholder meetings
- December 31<sup>st</sup>: Final Report to Governor and Legislature



## Report to Governor and Legislature

- Outlines the results and findings associated with the collection of data and solicitation of feedback.
- Report will include,
  - the director's assessment whether establishment of such an office would be beneficial to the populations served and the state as a whole,
  - the information gathered to make such assessment,
  - an analysis of all information gathered,
  - all alternatives considered,
  - the impact and effect any proposed change may have on existing programs and services, and
  - an assessment of related fiscal impacts on localities, the state and non-governmental entities serving older adults and persons with disabilities.



## How You Can Help

### Advisory Committee Development

- 20 person committee
  - Tasks to include but not be limited to:
    - Assistance in the gathering of public input
    - Assistance in the creation of the survey tool
    - Facilitation of workgroups
    - Helping to Assure Accessibility
    - Responsible for the development and formation of subcommittee's as deemed appropriate
    - Facilitation in the final recommendations that are to be included in the report to the Governor



## Nominations for Advisory Committee

- Looking for diverse individuals to represent individuals of all ages with challenges/limitations in:
  - Vision
  - Movement
  - Thinking
  - Remembering
  - Learning
  - Communicating
  - Hearing
  - Mental health
  - Social relationships



## Nominees

Please send your recommendations to:

Sharon.Foley@aging.ny.gov



### C. Letter of Invitation to Steering Committee



**ANDREW M. CUOMO**  
Governor

**Office for  
the Aging**

**CORINDA CROSSDALE**  
Director

**GREG OLSEN**  
Executive Deputy Director

Name, Title  
Agency  
Advisory Committee Letter of Invitation

June 19, 2015

Dear \_\_\_\_\_:

The New York State Office for the Aging (NYSOFA) respectfully requests your participation on a newly formed steering committee as the Office prepares to study the feasibility of creating an Office of Community Living, as authorized by Part N of Chapter 57 of the Laws of 2015. This process requires input, feedback, and guidance from the aging and disabilities private, public, and community sectors. Your knowledge and experience will serve as an important resource in meeting the goals and intent of the legislation.

The steering committee will meet from July through December 2015, on an as needed basis. Committee members are expected to participate in several meetings, which will assist in driving the progress and success of this feasibility study. More information will

**Office of Community Living Feasibility Study**

be forthcoming regarding the first meeting, which will be held Friday, July 10 from 10am-3:00pm in Albany, NY.

Enclosed are some reading materials that will be part of the discussion at the July 10 meeting. I appreciate your consideration in partnering with NYSOFA on this endeavor. If you have any questions or need additional information, please feel free to contact Dr. Angelia Smith-Wilson, Program Integrity Officer, at [angelia.smith-wilson@aging.ny.gov](mailto:angelia.smith-wilson@aging.ny.gov).

Sincerely,  
 Corinda Crossdale  
 Director  
 New York State Office for the Aging

**D. Steering Committee Members**

<b>Name</b>	<b>Title</b>	<b>Organization</b>
Lisa Alford	Commissioner	Onondaga County Office for the Aging
Maria Alvarez	Director	Statewide Senior Action Council
Donna Beal	Executive Director	Mercy Care for the Adirondacks
Valerie Bogart	Director	Evelyn Frank Legal Resources Program, NY Legal Assistance Group
Joe Bravo	Executive Director	Independent Living Network of NY (Westchester Independent Living Center)
Floyd Cameron		New York State United Teachers
Ann Marie Cook	President/CEO	Lifespan of Greater Rochester, Inc.
Bruce Darling	President/CEO	Center for Disability Rights
Denise Figueroa	Executive Director	Independent Living Center of the Hudson Valley
Beth Finkel	State Director	AARP New York State Office
Briana Gilmore	Director of Public Policy	New York Association of Psychiatric Rehabilitation Services (NYAPRS)
Maria Hansen	Consumer	
Linda James	Program Coordinator	Southwest Family Resource Center
Igal Jellinek	Executive Director	LiveOn NY
Diane Lang	Social Worker	Albany Medical Center
Edie Mesick	State Government Relations Executive	UJA Federation of New York
Lindsay Miller	Executive Director	NY Association on Independent Living

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Nancy Miller	Executive Director/CEO	VISIONS/Services
Bryan O'Malley	Executive Director	Consumer Directed Personal Assistance Association of New York State
Rebecca Preve	Director	Franklin County Office for the Aging
Michael Romano	Director	Oneida County Office for the Aging
Lisa Rosano Kaczowski	Director	Justice Center- TRAUD

**E. State of the State**

**I. Background on Aging and Disability Services**

In the past 12 years, the movement to combine services for older adults and younger persons with disabilities has accelerated as a result of federal funding in 2003 to create Aging and Disability Resource Centers (ADRCs) (O’Shaughnessy, 2011; Putnam, 2011). While there are many benefits to combining aging and disability services, there is also some evidence that suggests that these efforts can be challenging for a number of reasons. Primary among these is that aging and disability organizations have very different histories and service philosophies (Kane, 2007; Putnam & Stoeber, 2007; DeJong, 1979). In particular, Independent Living Centers (ILCs), which emerged in the 1970s as a core agency for people with disabilities, have a service philosophy that emphasizes consumer control, self-help and advocacy, and peer models to guide services (<http://www.mtstcil.org/skills/il-3-standards.html>). In this context, consumer controlled means that the “power and authority” to make decisions, arrange for services, and manage independent living are vested in the individual (National Council on Independent Living, 2013).

In contrast, within the aging world, the concept of consumer-directed choice is a recent philosophical shift. Historically the elder care system, organized around Area Agencies on Aging (AAAs), has emphasized the protection and safety of older adults (Simon-Rusinowitz & Hofland, 1993). Aging programs and the delineation of services for older adults were enacted through public policy in 1965 through the Older Americans Act (OAA). This act was passed to “help people age 60 and older maintain maximum independence in their homes and communities, with appropriate supportive services, and to promote a continuum of care for the vulnerable elderly” (National Health Policy Forum, 2011). The OAA authorizes a wide range of service programs through a national network of 56 State agencies on aging, 629 area agencies on aging, nearly 20,000 service providers, 244 Tribal organizations, and 2 Native Hawaiian organizations representing 400 Tribes (AoA, 2010). The key services provided by AAAs include but are not limited to: access services such as information and assistance; interdisciplinary case management; intake and assessment; development and implementation of individual

## Office of Community Living Feasibility Study

services plans and reassessment of needs; in-home services; protective services; investigations of abuse and neglect of elders; caregiver support; and nutrition services (Community Resources Information, Inc., 2013).

Safety and services provided by professionals in order to protect the well-being of older adults has been at the heart of aging services (Kunkel & Nelson, 2006). This can sometimes counter the philosophy of disability advocates who state that they are their own life experts and should determine what life choices they want to make (Kane, 2007). Therefore, the merging of aging and disability organizations could prove challenging due to the variations in service delivery philosophies between these two organizations, but as the next sections will show, there are many benefits and examples of successful methods in bringing these two entities together.

### **II. Benefits and Challenges in Combining Aging and Disabilities Agencies**

Many of the services for older adults overlap with those for people with disabilities making it possible to improve efficiencies if combining aging and disability agencies. The decision to merge these entities is multi-faceted, and includes reasons such as streamlining services, easing access for consumers, and pooling resources (Administration for Community Living, 2013; O'Shaughnessy, 2011; Putnam, 2007), yet there are also challenges which stem from the differences in public policy for older adults and people with disabilities (Putnam, 2007). According to Simon-Rusinowitz and Hofland (1993), "extreme heterogeneity both within and between the aging and disabilities communities can limit consensus about an aging or disabilities agenda; let alone a unified agenda for both groups" (p. 160). This has far reaching implications for organizations and workers serving both groups. Putnam (2011) stated that some of the challenges in cross-network collaborations are "variance in organizational mission, distinctive professional training, competition for program funding, and lack of investment in common goals" (p. 328). All of these challenges are important to address early on in the development of a coordinated aging and disabilities organization.

The advantages of collaboration between aging and disability service networks are visible nationwide as well as at the state and community levels. Historically, both networks worked independently to secure funding and to fight discrimination and availability of services outside institutional settings. In the broadest sense the advantages of collaboration between aging and disability networks on any level is the combined effort to ensure the shift from institutional care to home and community-based services is based on choice, self-determination, and the right to determine individual quality of life. It will take creative and sustained collaboration to create a new norm. At the national and local levels the advantages of collaboration between services for older adults and services for people with disabilities include (Executive Office of Elder Affairs, 2011):

- Increased consumer access to a broader array of options for living independently

## Office of Community Living Feasibility Study

- An opportunity for aging and disabilities networks to advocate together on legislation and policies that enhance the ability of individuals to live independently in the community
- A shared or compatible vision and mission
- Networks that serve populations who need functional assistance
- Networks of local non-profits with local consumer-controlled boards
- Access to various funding bases
- Shared commitment to serving individuals in the settings and manner of their choice, and to diverting individuals from institutionalization and/or transitioning individuals out of institutions and into home and community-based supports

### III. Examination of Federal Initiatives and the Administration for Community Living

In 2012, a new federal administration, namely the Administration for Community Living (ACL), was created that combined the efforts and goals of the Administration on Aging (AoA), the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability. ACL is focused on streamlining access to long-term care and creating one point of entry for people of all ages, incomes, and ability levels to come for information about what services are available to them and what options they have in accessing them. ACL's mission is to "maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers" (Administration for Community Living, 2013).

On July 22, 2014, President Obama signed the Workforce Innovation and Opportunity Act (WIOA), which had sweeping organizational changes for ACL and its programs. This act further combined and transferred other governmental agencies into ACL. Through this Act, the following entities were transferred from the U.S. Department of Education and are now under the umbrella of ACL: (1) The Independent Living Services and Centers for Independent Living programs; (2) The Assistive Technology Act programs; and (3) The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The impetus of this transition was to bring all programs that have a strong alignment with ACL's mission together under one organizational entity. As stated by ACL, "by uniting our teams and combining our efforts, we will be able to reach farther and be more effective in our mission to ensure that people with disabilities and older adults have the services and supports they need to live the lives they want, fully participating in the communities they choose"

([http://www.acl.gov/NewsRoom/NewsInfo/2015/2015\\_06\\_01.aspx](http://www.acl.gov/NewsRoom/NewsInfo/2015/2015_06_01.aspx)).

Since July of 2014, ACL has been making organizational changes to administer these programs and this goal was fully realized and announced on June 1, 2015. As of that date, all staff, contracts, grants, and other programs have fully merged. As such, the most recent organizational chart for ACL now encompasses the following offices

([http://www.acl.gov/NewsRoom/NewsInfo/2015/2015\\_06\\_01.aspx](http://www.acl.gov/NewsRoom/NewsInfo/2015/2015_06_01.aspx)):

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- **The Administration on Aging (AoA)** – this administration continues to lead initiatives impacting older Americans and their caregivers and families. AoA works closely with regional offices, state and area agencies on aging, tribal grantees and community service providers to plan and direct programs as authorized under the Older Americans Act and other legislation.
- **Administration on Disabilities (AoD)** – this administration was newly created under the WIOA 2014. The Administration on Intellectual and Developmental Disabilities and Independent Living Administration are now part of the AoD. The AoD works with states, communities and partners in the disability networks to increase the independence and community integration of individuals with disabilities.
- **Center for Integrated Programs** – this Center bridges the aging and disability administrations and handles the programs that address both AoA and AoD, such as consumer access and protection programs, as well as programs and initiatives that promote the use of self-directed and person-centered service models.
- **The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)** – this institute supports research, development, and dissemination and related activities designed to contribute to community living and participation, employment, and health and function of individuals of all ages with all types and degrees of disabilities.

To continue to further these goals, ACL, the Centers for Medicare and Medicaid (CMS) and the Veterans Health Administration (VHA) are working to develop a No Wrong Door (NWD) system to create “a person-centered, community-based environment that promotes independence and dignity for individuals” (<http://www.acl.gov/Programs/CDAP/OIP/ADRC/index.aspx>). The philosophy of NWD is that people should not be turned away at any place within the health and human services system when they come for assistance. NWD supports easy access to information and individual counseling to help people discover and understand what long-term services are available to them. It also supports their caregivers. The ultimate goal of the NWD program is to serve people of all ages. The development of Aging and Disability Resource Centers (ADRCs) in some states were partially funded by ACL to support efforts to streamline access to long-term services and support (LTSS) options. ADRCs are part of the broader NWD system in which all people, older adults and people of all ages with disabilities, can come to for access to LTSS. Currently there are 530 ADRCs nationwide in 54 out of 56 states and territories (an average of about 9 per state). The goal is to have an ADRC in every community where people of all incomes and ages can obtain information on the long-term supports available to them.

The most recent thinking from ACL can be found in “The No Wrong Door” funding announcement released in June 2014 and a subsequent funding announcement released on May 19, 2015. A criteria of this funding was that the following state agencies

## Office of Community Living Feasibility Study

must be included as full partners in co-leading the planning process to create a No Wrong Door System:

- the State Medicaid Agency
- the State Unit on Aging
- the state agencies that serve or represent the interests of individuals with physical disabilities and individuals with intellectual and developmental disabilities
- the state authorities administering mental health services

It is clear from this summary that the federal vision for aging and disability services is one that coordinates aging and disabilities programs under one administrative office, such as the federal Administration for Community Living has done. While ACL was created to better organize and centralize programs and services for aging and disabilities, some states have reorganized and others have been experimenting with structure designed to meet similar goals and have learned critical lessons on best practices along the way. The upcoming section will describe three states who have experience in combining aging and disability state offices together under one umbrella and can serve as an example for the State of New York as they explore the feasibility of creating a NY Office for Community Living.

### IV. State Report Interviews

The National Association for State Units on Aging and Disability (NASUAD) released a report entitled “*State of the States in Aging and Disability: 2014 Survey of State Agencies*”, and found that restructuring state agencies is a common theme happening across the country. NASUAD distributed questionnaires to state leaders and found that many states are reorganizing how they envision and deliver services to older adults and people with disabilities. One of the most significant changes is that in 2014, 40% of states reported that they have combined aging and disability state offices, which is up from 20% in 2012. Based on this report, we chose three states to interview about their experiences in combining aging and disability state offices for the following reasons:

1. **Massachusetts** – this state has all aging and disability service agencies under a combined Health and Human Services umbrella agency. They are a Part A grantee receiving funding from ACL to develop the federal vision for the No Wrong Door System and serve as a high performing national model for providing long-term services and support to all state residents with these needs. They are also a Balancing Incentive Program (BIP) state (**note:** BIP are authorized grants from CMS to states to increase access to non-institutional long-term services and supports).
2. **Pennsylvania** – this state has stand-alone agencies for aging and disabilities, but has some previous experience in trying to combine these agencies. They were recently awarded a grant from ACL in July 2014 under the funding title “*Transforming State LTSS Access Functions into a No Wrong Door System for All Populations and Payers: Statewide Implementation.*” They are also a BIP state.

## Office of Community Living Feasibility Study

3. **Texas** – this state is an appropriate for comparison to NY because of its size and diversity across the state. Texas has all aging and disability service agencies under a combined Health and Human Services umbrella agency. Texas received the same funding as PA in July of 2014 to create a NWD system. Texas is also a BIP state.

### 1. State Example: Massachusetts Summary

#### Organization of Aging and Disabilities Services in Massachusetts

In 2004, Massachusetts restructured all Health and Humans Services agencies. Mass Health (Medicaid) was at the center of the reorganization because they fund services for aging, physical disabilities, intellectual disabilities, commission for the blind, and the VA. Currently, there are 16 different agencies that are under the umbrella of the Executive Office of Health and Human Services (EOHHS). All state agencies, except for the Executive Office of Elder Affairs (EOEA), have commissioners who report to the EOHHS secretary. EOEA is the exception as they are written in the Massachusetts statue as an executive office and a department of EOHHS; therefore, this is the only agency that has its own Secretary. The EOEA Secretary also reports to the EOHHS Secretary. The EOHHS Secretary has oversight for all departments and can administer Medicaid money to each agency. Prior to 2004, there was a separate state Medicaid office, which has subsequently moved under the umbrella of EOHHS. The goal for Massachusetts during the restructuring was to decentralize Medicaid and other state offices in order to break down the silos that were occurring due to having separate state offices. Massachusetts created an Office of Long-Term Services and Supports who reports to the EOEA Secretary and the Assistant Secretary of Mass Health (Medicaid). Massachusetts brought these services together because they fund services for older adults and people with disabilities, and this has created a better working relationship with a deeper understanding of funding streams.

#### Impact of Coordinated State Aging and Disabilities Agencies in Massachusetts

When Massachusetts was asked about the impact coordinated agencies has had on the local level, service delivery, and consumers, they commented that there is some resource competition among individual agencies at the local level, but that the rebalancing of costs have been successful. They mentioned that there was some competition among ILCs and AAAs around consumers, i.e. the PC attendant program is funded by Mass Health (Medicaid) and funding is based on referrals so agencies can compete for the same resources. They believe that the impact on services has been positive, which is exemplified by an increase in offerings, and further evidenced by the increase in the number of waivers (from 5 to 10 during this time).

Additionally, MA is one of 18 states participating in the ACA opportunity known as BIP (Balancing Incentive Payment Program). Through BIP, MA is enhancing its No Wrong Door system with a No Wrong Door Call Center and a website that will improve access to community long-term services and supports and allow consumers to gain access to

## Office of Community Living Feasibility Study

Medicaid sooner. MA is creating a marketing campaign for the NWD Call Center and for the MA ADRC network. MA has also increased staffing by 11 in their enrollment centers in an effort to streamline applications for those seeking Medicaid. The goal of these initiatives are to enhance the experience of the consumer and streamline access for those seeking services in MA.

### **Best Practices and Lessons Learned in Massachusetts**

Massachusetts said that the most important lesson learned was to recognize that there needed to be a change in culture at the Executive Office of Elder Affairs and other state departments. It was important to have institutional commitment during this time of change. Massachusetts reports that the reorganization of state offices was successful because they had “good public managers” with years of experience and talent who could help mold and shape this vision. Massachusetts stated that one of the most important best practices they realized was that, “it is critical to look at the way government is organized and be willing to change that blueprint”, and without internal support and willingness to change it would make a challenging effort even more difficult. Massachusetts also believes that another best practice is the willingness to provide new authority to agencies that are combining under one umbrella. In fact, they stated that one of the problems they see in the ACL model is that there has been no authority given to AoA and that should have been addressed prior to the federal integration.

### **Benefits and Challenges to Combining Aging and Disabilities Services**

Massachusetts reported that the benefits to combining aging and disabilities services and other state offices were to decrease bureaucracy, to reorganize Medicaid, and promote organizational change through breaking down the silos in the state agencies. There have also been challenges in doing this as stated by the following comment, “this has not been easy”. It required skilled leadership, collaborative planning, and open communication. Further, some challenges were also evident in the overall management of the agencies as exemplified by the fact that during this time, the secretary of EOEI went from managing a \$300 million budget to managing a \$2.5 billion budget. This was an incredible increase in responsibility and required great skill in managing this larger budget and programs.

## **2. State Example: Pennsylvania Summary**

### **Organization of Aging and Disabilities Services in Pennsylvania**

In the state of Pennsylvania, all state agencies are separate stand-alone agencies. Each state agency has a Secretary and Deputy Secretary who reports to the Governor. In 2007, the Office for Long-Term Living (OLTL) was created to bridge the Department of Aging and the Department of Public Welfare (the office that manages Medicaid). They still remained separate entities at this point, but were tasked with working together. In 2009, the Governor proposed legislation, which was approved, to consolidate the Department of Aging and OLTL into one single combined state agency to manage all of the long-term

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living needs of older adults and people with disabilities across the state of PA. The decision to merge these state agencies was made at the recommendation of the Governor, and because this process was not inclusive and done without consultation from the legislature, there were many people who were displeased by the decision and process. The combined state agency existed for approximately three years before it was decided to separate these agencies back into a separate Department of Aging and an Office for Long-Term Living. Currently, OLTL is an office under the Department of Human Services and the Department of Aging is a stand-alone agency. It was believed that the “voice of the seniors needed to be independent again” and the new Governor in 2011 separated these offices once again.

### **Impact of NOT Having Coordinated State Aging and Disabilities Agencies in Pennsylvania**

Since the separation of the state aging and disabilities agencies in PA, the silos are building back up again and there are policy differences between the Department of Aging and OLTL as they are not coordinating policy initiatives together. This impacts consumers and service delivery at the local level. For example, Adult Protective Services is a different organization from Elder Protective Services and there is variation in how to handle protective services issues based on age. It is challenging when consumers “bridge” between disability and aging services and find variation between the two systems. This is further exemplified by fragmentation in policies, protocols, and operating procedure manuals. This is felt by consumers in that they have duplicate paperwork and different eligibility criteria – all of which present barriers for consumers and leaves them feeling frustrated. Comments heard from consumers are, “we don’t know where to go” or “it’s very difficult to find information to help me.”

### **Best Practices and Lessons Learned in Pennsylvania**

There were many lessons learned in Pennsylvania during this time of merging and then subsequent separating of the aging and disabilities agencies, and there is still some lingering pain associated with this. One of the most important lessons that came from this experience was the importance of being inclusive and transparent. Many state officials felt that this decision was made “in the dark of the night” without consultation from the legislature, state or local offices, or stakeholders. This seemed to set the stage for distrust among the disparate agencies. Some of the distrust was further amplified by the variance in the size of the agencies merging and in the people they serve. For example, at the time of the consolidation, the Department of Aging had 100 employees and the Department of Public Welfare had 6,000 employees and many felt that there was not enough planning on how these employees would work together. As it turned out, due to the lack of internal planning, there were Department of Aging employees being managed by the Department of Public Welfare and vice a versa without enough thought about how this structure would happen. This led to much confusion. Furthermore, there was great concern that the issues facing the aging population would be superseded by the needs of the population served by the Public Welfare Department. Some of the challenges were

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that the data and payment systems were not able to communicate with one and other, which led to a further lack of coordination and frustration when trying to merge agencies.

One of the most important lessons learned in PA was that the process needs to be transparent and it needs to include internal (state office employees) and external (stakeholders, local level agencies, consumers) representation in the process from beginning to end. Some of the best practices required are that when staff from different agencies merge, they need to be re-trained and oriented around a core set of knowledge and skills. It is critical to allow for adequate time and planning if combining agencies and find ample opportunities for stakeholder involvement. It is also important to have advocacy group input from both aging and disabilities groups because even though these groups are coming together, they need to feel independent and openly address fears of being “overtaken” by one group or the other.

### **Benefits and Challenges to Combining Aging and Disabilities Services**

Some of the benefits of combining aging and disabilities services is in the goal to provide a better experience for the consumer. For example, through Pennsylvania’s Balancing Incentive Program (BIP), they are working on ways to enhance the consumer’s experience by creating a front-end facing portal to reduce the compartmentalizing that can happen when learning about services. Another issue PA is working on is whether there is a way to find common elements on all the varied assessments for each agency so that the consumer is not having to repeat the same information over and over again. PA is not planning on moving to one unified assessment for all agencies, but is trying to streamline some of the common data elements.

The future outlook for PA in merging aging and disabilities might be worked out through the implementation of managed long-term services and support, but there is still a lot old history that needs to be reconciled as they reflect back on why this did not work years ago and how they could do this better in the future. The door to bringing these agencies together is not completely closed, yet opening it right now might seem too soon for those that were involved in the first consolidation.

### **3. State Example: Texas Summary**

#### **Organization of Aging and Disabilities Services in Texas**

Prior to 2004, there were 13 state agencies, one of which was the Department of Health and Human Services Commission (HHSC), with the other 12 located under this department. At this time, the Department of Aging was one of the 13 agencies and had a staff of 35 people. In 2004, the Texas legislature decided to consolidate these 13 agencies into five agencies through the Sunset Commission review (whose task is to review government agencies every 12 years before they “sunset” or expire). The Sunset Commission reviews the strengths and weaknesses of agencies that are about to expire and makes recommendations about the structure. In 2004, the Sunset Commission

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recommended that aging and disabilities state agencies merge together to form the Department of Aging and Disability Services (DADS). DADS consolidated aging, intellectual disabilities and physical disabilities under one organizational entity. Medicaid is located at HHSC. Each of the agencies have a Commissioner who reports to the Executive Commissioner of HHSC. More changes are ahead for Texas as this was the legislative session to review the structure of the five agencies once again and in May 2015 it was decided that they would reorganize these offices again. Over the next two years, Texas will take the five remaining offices and further consolidate them. By 2016, DADS and the Department of Assistive and Rehabilitative Services (DARS) will be consolidated and merge into HHSC. DARS currently oversees vocational rehabilitation and the ILCs in Texas.

The climate in state organizations and the impetus to merge agencies is very different in Texas than in many other states as these changes are dictated by the Sunset Commission every 12 years. In essence, the Commission tells the state departments that certain agencies are being consolidated (or not) and it is up to these departments to work to make this transition. As such, there is a limited amount of stakeholder involvement in making these decisions – it is up to the state agencies to execute the decision of the Sunset Commission. There was some interest group participation leading up to the legislative decision where stakeholders involved in issues surrounding services for people with intellectual and developmental disabilities were advocating for the consolidation of services hoping for an outcome that would lead to distributing resources more equitably. After the decision to merge was made back in 2004, the state offices formed workgroups to guide and manage the merger.

### **Impact of Coordinated State Aging and Disabilities Agencies in Texas**

For Texas, it is hard to determine the impact of coordinated state aging and disabilities offices at the local level. In some ways the two are different intended consequences – macro vs. micro goals – state agency alignment vs. integration of services at the community and local level. For Texas, the impetus was at the macro level: bringing agencies together that were felt to be redundant through the Sunset Commission review. The sentiment in Texas is that the consolidation has had a greater impact on the state agencies and is less dramatic at the local level. Another important intended impact on the merger of state agencies was the belief that there would be financial savings. These savings were likely overestimated as there were tremendous costs in merging large state agencies into one system through staff time/effort, merging paperwork and IT systems, to name a few.

Texas has been a leader in managed care for long-term services and supports (MLTSS) and in the Money Follows the Person (MFP) and, as such, has been working with many of the local agencies, i.e., AAAs, ILCS, and ADRCs, to collaborate and bring these “front door” entities together in order to better coordinate service delivery. These initiatives, along with having consolidated state agencies, have eliminated many barriers at the

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state level. At the local level, there are still variations in AAAs' service delivery models in comparison to how disabilities organizations provide services.

### **Best Practices and Lessons Learned in Texas**

Once again, because this decision to merge was decided by the Sunset Commission, there was a general lack of input from the local level agencies and consumers; however, there was input from all levels of staff at the state agencies. If appropriate or possible, Texas does believe that a best practice would be to include input from all levels of agencies and staff at both the state and local level, along with stakeholder input. Stakeholder groups are important and having their leadership in government and legislature is critical. Texas was clear that stakeholders have been involved in policy planning and are vocal within the legislature, so there was involvement for stakeholders in certain arenas.

Texas made these changes in 2004 with two guiding principles: (1) "don't fix what isn't broken"; and (2) "consumers need to be served during this transition and the public needs to be protected" – don't lose sight of this while these changes are occurring. Further, there needs to be strong internal support during this transition – all levels of staff (including IT systems) need to be operating cohesively. It is critical to continually look forward and ask "what would be the best way to organize and improve services" throughout. Key best practice advice: "don't short circuit input and keep your eyes on the prize." Provide ample opportunities in innovative ways to gather input. Texas, like New York, is a large state with many rural areas and it is a challenge to find ways to get input across the state. They have found that videoconferencing works the best as it allows for a much greater amount of people to be involved in the process, especially those in remote areas or people who have concerns with mobility or transportation.

### **Benefits and Challenges to Combining Aging and Disabilities Services**

Texas believes that having an integrated state agency has provided better visibility to the issues facing older adult and people with disabilities and has increased the influence on making changes through having a combined state office. An important challenge to consider is the genuine concern that by merging agencies, something will be lost by one agency or both. There can be a lot of "doomsday" predictions around this issue and it is important to validate and consider these concerns, but at the end of their merger, it was evident that many of the concerns about what might be lost was replaced with some significant gains in partnership. For example, prior to 2004, the Texas Department of Aging had only 35 employees. After the consolidation, this Department under DADS, became an agency with 17,000 employees and a budget of \$6.5 million and is now the biggest agency under the Department of Health and Human Services. This consolidation and growth has allowed them the opportunity to increase their visibility and leverage additional resources; although, it must be noted that these changes have not led to an expansion of services for consumers.

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### V. Conclusion and Next Steps

As New York State embarks on exploring the feasibility of creating a combined state aging and disabilities office, there are many important lessons that can be learned from this analysis. Some of the key points to consider are:

- Don't short-circuit the input process and include input from state, local, and other key stakeholders throughout the process
- Be transparent and inclusive
- Careful planning and consideration of structural changes cannot be underestimated
- Strong leadership is critical

This review is the first step in the feasibility study and will serve as background information on what is happening around the country. An Advisory Board has also been formed that includes key stakeholders from aging and disabilities organizations across the state of New York. They will guide the process for the feasibility study in many ways, such as making recommendations for gathering data, reviewing process decisions, and providing input on the listening sessions across the state. It is important to remember that the goal of this project, as stated in the 2015-16 NYS budget is the following: "The purpose of this act is to seek public input about the creation of an office of community living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities". The steering committee and state representatives remain committed to the public input process and the exploration of the feasibility in combining aging and disabilities agencies in New York.

### F. Survey – Consumers

#### NY Consumer Survey

The purpose of this survey is to seek broad public input about coordinating services for older adults and individuals of all ages with disabilities with the goal of improving service delivery and program outcomes. This survey seeks your opinion about your experiences in obtaining services in order to live independently in the community. Before you choose to participate, there are few things you should know:

**Your responses are confidential and anonymous. You can choose not to answer any question. You will not be penalized in any way if you choose not participate. Even if you get many copies of the survey, please respond to the survey once.**

We have a few questions about any assistance you are receiving now that helps you to live in the community. This can be from a family member or friend, or from a paid worker or agency. We'd like to know about your experiences with these kinds of services and supports. We'd also like to know if you have other needs that are not being met that would

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make it easier for you to live in the community, or that you will need if you are returning to the community. We are interested in knowing about any services or assistance that could help you live independently in the community. **When thinking about services or assistance, please think of any government sponsored (local, state or federal) service or assistance you receive.**

If you have any questions about the survey, please contact Abbey Lavazzo at NYSOFA (Phone: 518-391-4553; email: [abbey.lavazzo@aging.ny.gov](mailto:abbey.lavazzo@aging.ny.gov)). Thank you!

1. What age group are you in? Please check one.

- Under 18
- 18-35
- 36-50
- 51-59
- 60-74
- 75-84
- 85+

2. Please indicate if you are a person with a disability:

- Yes
- No

If YES, and if you are comfortable sharing more information, please explain.



3. Are you receiving any assistance now from family members, friend(s), a paid worker, or from an agency to help you live independently in the community? Again, when thinking about services or assistance, please think of any government sponsored (local, state or federal) service or assistance you receive.

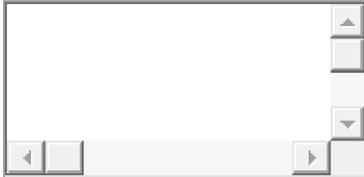
- Yes
- No

If YES, please describe the assistance or services you are getting and whether they are from a family/friend or worker/agency. Please try to be as specific as you can. For example: *“I receive homemaker and transportation services from ABC agency.” “My sister comes every day to help with laundry and bathing.”*

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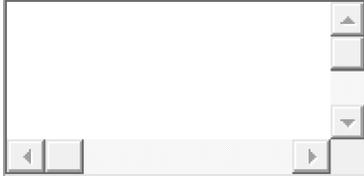
If NO, please describe the supports or services that would help make your life easier to live independently in the community. Again, we are interested in knowing about any services or assistance that could help you live independently.



4. If you needed assistance or a service, how confident are you that you know who to call or where to go?

- Very confident
- Somewhat confident
- Not very confident
- Not at all confident

Please describe how you would get assistance or services.



5. Now please tell us about your experiences with any assistance that you are receiving or have received in the past year. Overall, how satisfied would you say you are with the services or assistance you've received?

- Very satisfied
- Somewhat satisfied
- Somewhat Dissatisfied
- Very Dissatisfied

Please explain in the space provided.

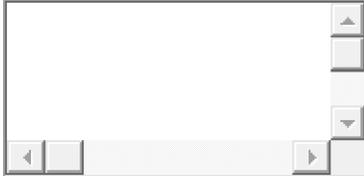


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6. How difficult is it for you to find out about and get the services or assistance you need?  
Please explain your response. Would you say:

- Very difficult
- Somewhat difficult
- Not very difficult
- Not at all difficult

Please explain in the space provided.



7. What would make it easier for you to find out about and get the services or assistance you need?



8. If you use more than one service, did you find it confusing or difficult to enroll in the services you needed?

- Yes
- No

Please explain in the space provided.



9. How much of an impact would state level coordination of aging and disability services have on your services?

- A great deal of impact
- Some impact
- Not very much impact
- No impact at all
- Don't know

Please explain in the space provided.

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10. Please tell us anything else about the services or assistance you receive or who provides them.



We have just a few more questions. The following questions will help us understand a little more about you.

11. What is your gender?

- Male
- Female
- Transgender

12. I identify my race as: (You may check more than one)

- American Indian or Alaska Native
- Black or African American
- Asian
- Native American or Pacific Islander
- White
- Prefer not to answer

13. Do you consider yourself Latino/Hispanic?

- Yes
- No
- Prefer not to answer

14. What city/county do you live in?



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15. Are you receiving:

- Medicare
- Medicaid
- Both
- Neither

15. Are you covered by private insurance of any kind?

- Yes
- No

### G. Survey – Providers

#### NY Provider Survey

The purpose of this survey is to seek broad public input about coordinating services for older adults and individuals of all ages with disabilities with the goal of improving service delivery and program outcomes. This survey seeks your opinion about your experiences in providing services in order to help others live independently in the community. Before you choose to participate, there are few things you should know:

**Your responses are confidential and anonymous. You can choose not to answer any question. You will not be penalized in any way if you choose not participate. Even if you get many copies of the survey, please respond to the survey once.**

Thank you for taking the time out of your busy schedules to answer this survey. We are asking you to complete this as we know you may have the best understanding of how services are working for consumers in your communities. Your opinions and ideas are important to us!

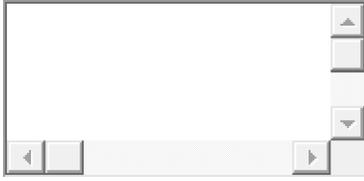
If you have any questions about the survey, please contact Abbey Lavazzo at NYSOFA (Phone: 518-391-4553; email: [abbey.lavazzo@aging.ny.gov](mailto:abbey.lavazzo@aging.ny.gov)). Thank you!

1. Can you describe the type of agency where you work?

- Aging
- Disability
- Combine aging/disability
- Other

Please describe your agency in the space provided.

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2. What percent of your job involves working with or for older adults (that is, persons 60 years of age or older) and their families?

- 25% or less
- 26 to 50%
- 51 to 75%
- 76% or more

3. What percent of your job involves working with or for people with disabilities of all ages and their families?

- 25% or less
- 26 to 50%
- 51 to 75%
- 76% or more

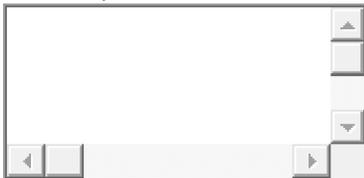
4. What long-term living services and support do you (or your organization) provide?



5. Overall, how much duplication in services is there across state and/or local agencies serving your consumers? Would you say?

- Yes, there is a lot of duplication across service delivery
- Yes, there is some duplication across service delivery
- No, there is not very much duplication across service delivery
- No, there is no duplication at all

If YES, please describe the duplication in service delivery in as much detail as you can.



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6. Overall, how well do you think services are working for your consumers now? Would you say:

- Very well
- Somewhat well
- Not very well
- Not at all well

Please explain in the space provided.



7. Please identify best practices in service quality and delivery that you know of (these do not have to be from your agency or in your part of the state).



8. How strongly do you agree that there are gaps in services for consumers now?

- Strongly agree
- Somewhat agree
- Somewhat disagree
- Strongly disagree

Please explain in the space provided.



9. Do you know of any policies, regulations or any other issues that create barriers in providing quality services?

- Yes
- No

Please explain in the space provided.

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10. Overall, how concerned are your consumers about accessing or obtaining services?  
Would you say they are:

- Very concerned
- Somewhat concerned
- Not very concerned
- Not at all concerned

Please explain in the space provided

11. Would there be any advantages if aging and disability services were more coordinated in the state of New York?

- Yes
- No
- Don't know

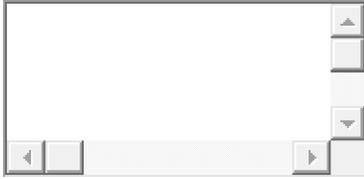
Please explain in the space provided.

12. Would there be any disadvantages if aging and disability services were more coordinated in the state of New York?

- Yes
- No
- Don't know

Please explain in the space provided.

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13. How confident are you that a state level coordination of aging and disability services could improve access or quality of services to consumers? Would you say you are:

- Very confident
- Somewhat confident
- Not very confident
- Not confident at all

Please explain in the space provided.



14. Do you think state level coordination of aging and disability services would have an impact on your work or the work of your agency? Would you say:

- Yes, a great deal
- Yes, somewhat
- No, not very much
- No, none at all
- Don't know

Please explain in the space provided.



Just a few more questions. These questions will help us understand a little more about you.

15. What age group are you in? Please check one.

- 18-35
- 36-50
- 51-59

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- 60-74
- 75-84
- 85+

16. What is your gender?

- Male
- Female
- Transgender

17. I identify my race as: (You may check more than one)

- American Indian or Alaska Native
- Black or African American
- Asian
- Native American or Pacific Islander
- White
- Prefer not to answer

18. Do you consider yourself Latino/Hispanic?

- Yes
- No
- Prefer not to answer

19. What city/county do you work in?

20. Other comments:

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### H. Disabilities Listed

A disability is any condition of the body or mind that makes it more difficult for a person with the condition to do certain activities and interact with the world around them, according to the Center for Disease Control and Prevention (CDC).

CDC categorizes disabilities in nine (9) sections: Vision, movement, thinking, remembering, learning, communicating, hearing, mental health, and social relationships.

<u>Learning</u>	<u>Communicating</u>	<u>Hearing</u>	<u>Mental Health</u>	<u>Social Relationships</u>	<u>Physical Disabilities</u>	<u>Multiple Disabilities</u>	<u>Vision</u>	<u>Movement</u>	<u>Thinking</u>	<u>Remembering</u>
ADHD (5)	early dementia (3)	Deaf (4)	Mental Health (11)	developmental disability (9)	COPD (9)	blind/fibromyalgia/heart/arthritis/neuromuscular/asthma/allergies	Blind (44)	fibromyalgia (3)	TBI (5)	Intellectual Disability (3)
learning disability (7)	dementia (3)	slight hearing loss (1)	Anxiety (7)	Conduct Disorder (1)	degenerative disc (5)		visual impairments (4)	neuromuscular condition (1)	Micro cephalic (1)	memory issues (1)
mental retardation (2)	Autism (23)	hearing loss (12)	fetal alcohol syndrome	Behavioral Disabilities (1)	Spina Bifida (2)	learning disability/muscular dystrophy (1)	congenital glaucoma	Due to Cancer I have no muscles in front of my left thigh (1)	fragile X syndrome (1)	fragile X syndrome (1)
severe ADHD (1)	Tourette syndrome(2)	almost no hearing even with a hearing aid (1)	Obsessive Compulsive Disorder (1)	social anxiety disorder	Spinal Cord Injury (7)	Micro cephalic/mental retardation/developmental delays	vision problems (6)	Muscular Dystrophy (M)	borderline intelligence (1)	
down syndrome	speech problems (1)		bipolar (5)		Cerebral Palsy (7)		low vision (1)			
mild mental retardation (2)	Alzheimer's disease(3)		depression (12)		heart condition (7)	Deaf & Blind due to Usher Syndrome	Retinitis Pigmentosa (1)	developmental delays (1)		
			schizophrenia (7)		Hydrocephalus (1)	Spina B/hydrocephalus	Glaucoma (1)	Erbs Palsy (1)		
			schizoaffective (1)		Crohn's Disease (1)		eye sight problems(1)	hyptonia (1)		
			OCD (1)		Arthritis (20)	Developmental, Behavioral, Physical and Psychological disabilities	macular degeneration (1)	Klippel Feil Syndrome		

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<u>Learning</u>	<u>Communicating</u>	<u>Hearing</u>	<u>Mental Health</u>	<u>Social Relationships</u>	<u>Physical Disabilities</u>	<u>Multiple Disabilities</u>	<u>Vision</u>	<u>Movement</u>	<u>Thinking</u>	<u>Remembering</u>
			post traumatic stress disorder (1)		ileostomy (1)	Autism, has severe ADHD, seizure disorder	fighting to keep an eye from going blind (1)	myasthenia gravis		
					quadriplegic	Deaf & Blind	blind in one eye (1)	foot issues (1)		
					Asthma (5)	Anxiety and Depression		Rheumatoid Arthritis (2)		
					congestive heart failure (1)	Dementia/arthritis/ Crohns		Multiple Sclerosis (1)		
					stroke (9)	Asperger's/ADD/L D		Parkinson's Disease(2)		
					epilepsy (2)	deafness & autism		Muscular disorder (1)		
					Allergies (1)	multiple disabilities		have difficulty walking or standing (4))		
					osteoarthritis (5)	cervical spine & cardiological issues		I need assistance in walking (2)		
					neck injuries (1)	TBI/developmental disability		hemiplegia (1)		
					High Blood Pressure(1)	blind in one eye and has arthritis		left arm & leg weak (1)		
					mild cognitive impairment (1)	learning/epilepsy		Parkinson's Disease(2)		
					physical disabilities(5)	COPD/back & neck injuries/asthma/diabetes/high blood pressure		balance and coordination problems (2)		
					seizures(4)	Autism/LD/DD/Erbs Palsy/seizures/diabetes, hyptonia/hip dysplasia		terribly shaking (1)		

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<u>Learning</u>	<u>Communicating</u>	<u>Hearing</u>	<u>Mental Health</u>	<u>Social Relationships</u>	<u>Physical Disabilities</u>	<u>Multiple Disabilities</u>	<u>Vision</u>	<u>Movement</u>	<u>Thinking</u>	<u>Remembering</u>
					SSI Disability (5)	retinitis pigmentosa		Poor mobility (8)		
					diabetes (3)	depression & strokes				
					osteoporosis (2)					
					Williams syndrome (1)	inoperable degenerative congenital back problem & foot issues				
					Hip dysplasia (1)	Autistic/ Tourette's syndrome/ epileptic/ OCD comorbid				
					knee amputee (1)	Asperger's, OCD & Tourette syndrome				
					dyspnea (1)	pain in right knee and fibromyalgia				
					past ovarian cancer patient with no evidence of disease but side problems from chem (1)	knee amputee/spine/nerve damage/TBI				
					trauma to body (1)	osteoarthritis and fibromyalgia				
					incomplete quadriplegia (1)	Arthritis and mobility issues				

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<u>Learning</u>	<u>Communicating</u>	<u>Hearing</u>	<u>Mental Health</u>	<u>Social Relationships</u>	<u>Physical Disabilities</u>	<u>Multiple Disabilities</u>	<u>Vision</u>	<u>Movement</u>	<u>Thinking</u>	<u>Remembering</u>
					mestastic breast cancer (1)	TBI and incomplete quadriplegia				
					Hydra dentist suppurativa (1)	rheumatoid arthritis/ mesastic breast cancer/ dementia				
					back trouble (1)	Autism & ADHD				
					Bad legs (1)	legally blind & back trouble				
					Problem right foot (1)	heart problems/mental issues & arthritis				
					Chronic coronary artery disease (1)	blind & bad legs				
					Williams Syndrome(1)	chronic coronary artery disease & diabetes type II				
					cervical spine issues (1)	macular degeneration /hearing aide/heart problems/severe arthritis in back				
					Environment al Physical (1)	bipolar & ADHD				
					balance problems(1)	Autism, fragile X syndrome, anxiety disorder				
					hip replacement (2)	Autistic/borderline intelligence/ADH D/ Conduct Disorder				

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<u>Learning</u>	<u>Communicating</u>	<u>Hearing</u>	<u>Mental Health</u>	<u>Social Relationships</u>	<u>Physical Disabilities</u>	<u>Multiple Disabilities</u>	<u>Vision</u>	<u>Movement</u>	<u>Thinking</u>	<u>Remembering</u>
					methicillin-resistant Staph Aureus (1)	double amputee with cardiac issues				
					congestive heart failure (1)	arthritis/ terribly shaking/ difficulty walking				
					Celiac Disease (1)	bipolar disorder/ severe depression/ post traumatic stress disorder/ COPD				
					Complex regional syndrome (1)	osteoarthritis/4 rods in back/ chronic pain/ limited mobility/ on oxygen				
					Double amputee (1)	vision problems/ arthritis/ spinal stenosis				
					cardiac issues (1)	severe arthritis and poor mobility				
					hip surgery (1)	broke back and diabetic				
					complex regional pain syndrome (1)	balance issues and memory issues				
					OCD comorbid (1)	COPD/Arthritis/ Cellulitis/ Obese				
					polio (1)	Parkinson's and short gut syndrome				
					back problems (1)	mental issues and hearing loss				

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<u>Learning</u>	<u>Communicating</u>	<u>Hearing</u>	<u>Mental Health</u>	<u>Social Relationships</u>	<u>Physical Disabilities</u>	<u>Multiple Disabilities</u>	<u>Vision</u>	<u>Movement</u>	<u>Thinking</u>	<u>Remembering</u>
					frozen shoulders (1)	totally blind & bipolar				
					fibromyalgia (2)	deaf & vision impaired				
					Below-Knee Amputation (1)	back trouble/ arthritis/ spinal stenosis/ scoliosis				
					Multiple Sclerosis (1)	scoliosis/osteoporosis/arthritis/heart problems				
					severe PTSD (1)	muscular disorder & degenerative disk				
					Scoliosis of the spine (1)	Autism/fragile x syndrome/anxiety disorder				
					Spinal muscular atrophy (1)	Williams Syndrome/ developmentally disabled				
					severe diabetic (1)	Arthritis and balance problems				
					quadriplegic due to muscular dystrophy (1)	stroke as toddler/memory issues/hemiplegia				
					back trouble (1)	poor mobility/vision impairments/ hip replacement/ congestive heart failure				
					spinal stenosis (1)	Celiac disease/ COPD/ Complex Regional Syndrome/ anxiety/ depression				
					short gut syndrome (1)	had a stroke and left arm & leg are weak/ heart problems				

## Office of Community Living Feasibility Study

<u>Learning</u>	<u>Communicating</u>	<u>Hearing</u>	<u>Mental Health</u>	<u>Social Relationships</u>	<u>Physical Disabilities</u>	<u>Multiple Disabilities</u>	<u>Vision</u>	<u>Movement</u>	<u>Thinking</u>	<u>Remembering</u>
					methicillin-resistant Staph Aureus (1)	COPD/ poor mobility/arthritis/ walker & wheelchair				
					Cellulitis (1)	memory issues and lactose intolerant				
					Obese (1)	cerebral palsy/ arthritis				
					Broke back (1)	hard of hearing/asthma/ legally blind/ epilepsy/ panic attacks				
					Adult macular degeneration (1)	severe diabetic/ limited mobility/ learning disabilities				
					lactose intolerant (1)	back problems/frozen shoulders/ fibromyalgia				
					spinal stenosis (1)	hard of hearing and fighting to save one eye from going blind				
					4 rods in back (1)	degenerative disc disease/ scoliosis of the spine/ osteoarthritis				
					on oxygen (1)	severe PTSD and anxiety				
					chronic pain (1)	after a stroke/balance/ coordination and speech problems				
					back surgery (1)	Blind/Below-Knee amputation/ multiple sclerosis				
						fibromyalgia/asthma/ arthritis				

## Office of Community Living Feasibility Study

### I. Regional Forum Announcement



**Office for  
the Aging**

**ANDREW M. CUOMO**  
Governor

**CORINDA CROSSDALE**  
Director

**GREG OLSEN**  
Executive Deputy Director

### **Register Now:**

### **Public Forums Announced for Office of Community Living Feasibility Study**

Chapter 57 of the Laws of 2015 (S2007-B/A3007-B) authorized the New York State Office for the Aging (NYSOFA) to study the feasibility of creating an Office of Community Living (OCL). The legislation requires NYSOFA to seek public input about the creation of an Office of Community Living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities.

NYSOFA has commissioned the Center for Aging and Disability Education and Research (CADER), Boston University to facilitate the OCL feasibility study. In addition, NYSOFA has convened a steering committee comprised of key stakeholders from the aging, disabilities, and both aging and disabilities to assist with gathering information pertaining to the feasibility of an Office for Community Living in New York State.

A combined effort from the principal researchers from CADER along with the Steering Committee designed a survey to gather input from consumers and providers from both the aging and disabilities populations across New York State. Preliminary survey data will be presented at the public forums to gather additional input, guidance and recommendations from stakeholders.

### **Each location will be physically accessible for all and provide:**

1. ASL Interpreting
2. Communication Access Real Translation (CART)
3. Language Interpretation/Translation (request need to be made in advance)

We respectfully request attendees come fragrance free (not wearing any scented products or washing with them) to accommodate participants with chemical/fragrance sensitivity.

If you require additional accommodations (ex. tactile interpreting, assistive listening devices, etc.) to participate in the forum, please advise when registering.

## Office of Community Living Feasibility Study

-Pre-registration *is required* due to space capacity. Please register at: <https://www.surveymonkey.com/r/OCLforumregistration>. In addition, you can also register by calling Abbey Lavazzo at (518)391-4553 or email, [abbey.lavazzo@aging.ny.gov](mailto:abbey.lavazzo@aging.ny.gov)

-All public forums will be recorded and posted on the NYSOFA website under the Office for Community Living tab: <http://aging.ny.gov/CommunityLiving/index.cfm>

The public is invited to attend any of the following forums:

**September 21, 9:00-11:00a.m.**

Empire State Plaza Meeting Room #6  
Concourse Level  
Albany, NY 12210

**September 30, 1:00-3:00p.m.**

Brooklyn Borough Hall  
209 Joralemon St.  
Brooklyn, NY 11201

**September 21, 2:00-4:00p.m.**

West Side Ballroom  
253 New York Road  
Plattsburgh, NY 12903

**October 1, 10:00a.m.-12:00p.m.**

Mount St. Mary College, Hudson Hall  
330 Powell Ave.  
Newburgh, NY 12550

**September 22, 10:00a.m.-12:00p.m.**

Onondaga Community College, Storer  
Auditorium  
4585 W Seneca Turnpike  
Syracuse, NY 13215  
(Use parking lots 2 or 4)

**October 7, 9:00-11:00a.m.**

Mt. Olive Baptist Church  
701 E Delevan Ave.  
Buffalo, NY 14215

**September 22, 2:30-4:30p.m.**

Southern Tier Independence Center  
135 E Frederick St.  
Binghamton, NY 13094

**October 7, 1:30-3:30p.m.**

Pieters Family Life Center  
1025 Commons Way  
Rochester, NY 14623

**September 30, 9:00-11:00a.m.**

Town Hall Auditorium  
1 Independence Hill  
Farmingville, NY 11738

**Office of Community Living Feasibility Study**

**J. Registration List (Regional Forums)**

<b>Region</b>	<b>Location, Date, Time</b>	<b>Providers Registered</b>	<b>Consumers Registered</b>	<b>Total Number Registered</b>
Capital Region	Albany, NY: 9/21 9:00-11:00AM Empire State Plaza Meeting Room 6	39	20	59
North Country	Plattsburgh, NY: 9/21 2:00-4:00PM West Side Ballroom	35	9	44
Central NY	Syracuse, NY: 9/22 10:00AM-12:00PM Onondaga Community College, Storer Auditorium	44	14	58
Southern Tier	Binghamton, NY: 9/22 2:30-4:30PM Southern Tier Independence Center	36	7	43
Long Island	Farmingville, NY: 9/30 9:00-11:00AM Town Hall Auditorium	17	4	21
New York City	Brooklyn, NY: 9/30 1:00-3:00PM Brooklyn Borough Hall	53	62	115
Mid-Hudson	Newburgh, NY: 10/1 10:00AM-12:00PM Mount St. Mary College, Hudson Hall	22	22	44
Western NY	Buffalo, NY: 10/7 9:00-11:00AM Mount Olive Baptist Church	40	6	46
Finger Lakes	Rochester, NY: 10/7 2:00-4:00PM Pieters Family Life Center	47	14	61

## Office of Community Living Feasibility Study

### K. Survey to Collect Feedback

OCL Regional Forum Feedback

#### 1. What forum did you attend?

- 9/21: Albany, NY
- 9/21: Plattsburgh, NY
- 9/22: Syracuse, NY
- 9/22: Binghamton, NY
- 9/30: Farmingville, NY
- 9/30: Brooklyn, NY
- 10/1: Newburgh, NY
- 10/7: Buffalo, NY
- 10/7: Rochester, NY
- I did not attend a forum.

#### 2. Please provide your feedback on the following themes:

##### Key Theme #1: Accessing Information and Services

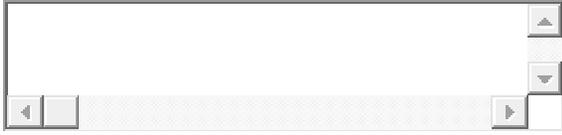
##### 3. Key Theme #2: Evaluating Service Delivery & Improvements

##### 4. Key Theme #3: Evaluating Barriers, Gaps, and Information About Needed Services (Reinforcing the Balancing Incentive Program [BIP])

##### 5. Key Theme #4: Evaluating the No Wrong Door (NWD) Initiatives

##### 6. Key Theme #5: Evaluating the Impact if Services were More Coordinated (Leveraging Resources & Fiscal Impact on Services and Consumers)

## Office of Community Living Feasibility Study



### L. NYSOFA Testimony at Assembly Standing Committee on Aging

Good morning Assemblyman Cymbrowitz, my name is Greg Olsen and I am the Executive Deputy Director of the New York State Office for the Aging.

I am pleased to be here today to describe the authorization that Chapter 57 of the laws of 2015 granted NYSOFA in regard to seeking input about the creation of an office of community living (OCL) and the extensive process and steps NYSOFA developed and implemented to meet the intent of the law.

The purpose of PART N of the Health and Mental Hygiene Article VII bill passed on March 31, 2015 (S2007-B/A3007-B) was “to seek public input about the creation of an office of community living with the goal of providing improvements in service delivery and improved program outcomes that would result from the expansion of community living integration services for older adults and persons of all ages with disabilities”.

The law directed the state office for the aging, in collaboration with other state agencies, to consult with stakeholders, providers, individuals and their families to gather data and information on the creation of an office for community living.

The legislation defined the areas of focus, which include:

- Furthering the goals of the governor's Olmstead plan.
- Strengthening the No Wrong Door approach to accessing information and services.
- Reinforcing initiatives of the Balancing Incentive Program.
- Creating opportunities to better leverage resources.
- Evaluating methods for service delivery improvements.
- Analyzing the fiscal impact of creating such an office on services, individuals, and providers.

The law also required NYSOFA to examine recent federal initiatives to create an administration on community living; and examine other states' efforts to expand services supporting community living integration, and local and/or regional coordination efforts within New York.

In an effort to ensure meaningful public input, the law required NYSOFA to hold a series of public meetings across the state to ensure that stakeholders in all regions of the state are afforded an opportunity to comment.

## Office of Community Living Feasibility Study

Finally, the law required NYSOFA to provide a report and recommendations by December 15, 2015, to the Governor and Legislature that outlines the results and findings associated with the aforementioned collection of data and solicitation of feedback.

The following are the timelines and actions NYSOFA took to meet the intent and requirements of the law.

### **April – May 2015**

- Development of project timeline.
- Solicited to hire a consultant to assist with the data collection, analysis of data collected, other state models and structure of the federal ACL.
- Consultant secured weekly meetings to discuss scope of work began.
- Intern solicited and received from SUNY Albany to assist with project.
- Initial discussion on creation of steering committee begins.
- Consultant studies ACL structure and several state structures in preparation for kickoff webinar.
- Kickoff webinar held on May 20 included outlining the scope of work based on the law; a brief report on federal ACL and state structures; the process for developing the steering committee and request for steering committee members; the process to collect information from the public; the ability to access a survey to weigh in on the process; timelines for the process; and ways stakeholder could help.

### **June – July 2015**

- Received recommendations for steering committee members and selected 21 members. 21 members represented: 10 aging, 9 disabilities, 2 aging and disabilities.
- Initiated development of surveys to capture required data as prescribed by Part N.
- Initiated development of outreach plan, expectations of steering committee members and tentative locations of regional forums.
- Held steering committee kickoff meeting explaining scope of work, project plan with timelines and deliverables, and expectations of steering committee members.
- Worked with steering committee to develop and finalize survey instrument.
- Worked with steering committee on distribution plan for survey, including commitment of steering committee members to distribute the survey among their networks and to assist consumers in filling out the survey and submitting surveys to CADER for analysis.
- Worked with 22 state agencies to disseminate survey to their networks.
- NYSOFA distributed survey to 59 area agencies on aging (AAA) directors and to internal provider and consumer lists.

### **August – October 2015**

- Survey open to public.

## Office of Community Living Feasibility Study

- CADER begins analysis of data, focusing on quantitative data to present preliminary findings at regional forums.
- Steering committee holds two conference calls to discuss regional forums, expectations at regional forums, assistance needed from members to identify accessible locations, and to develop the forum public announcement.
- NYSOFA works with steering committee members and AAAs to secure locations, assure appropriate technology and space capacity, and secure American Sign Language Interpreters and Communication Access Real Time Translation (CART) for each event.
- NYSOFA, CADER and several steering committee members travel 2,646 miles to attend nine regional forums in two weeks to present preliminary data and to receive initial reaction from the public.
- Web-based survey is developed and open for regional forum participants to provide additional written reactions under any of the themes presented.
- CADER analyzing the qualitative data from the survey and including regional forum feedback into its analysis.

Throughout this process, in order to assure maximum participation by the public, all materials were posted to NYSOFA's website in advance so they could be accessible in other languages and to those with visual impairments.

One of the primary responsibilities of the steering committee members was to assist in not only getting the electronic survey out to those who can access it via computer, but to assist those who cannot access it that way and need to complete it via paper and pen. Steering committee members were selected to represent various and age and disability interests, but they were also selected to assist in the survey being completed by those who cannot access it online.

There are three phases to the feasibility study.

- Phase I was the collection of data via the survey. There has been a very good survey response rate that is representative of aging, disabilities and aging and disabilities both from the consumer and the provider perspective.
  - The information presented at the regional listening forums was Quantitative Data, which are data that deals with numbers and broad themes.
  - The qualitative data, those that are descriptive take much more time to analyze and that process will be completed at the end of October/early November.
- Phase II was the regional listening forums where the initial Quantitative data can be shared for comment, feedback, reaction and discussion. As mentioned earlier, we conducted 9 regional listening forums and had created on our website an opportunity to continue to provide input on the major themes that were discussed.

## Office of Community Living Feasibility Study

- Phase III, the final Phase, will be developing the report and recommendations based on an analysis of the Qualitative and Quantitative data as well as the regional forum listening sessions. This will be completed early in December in order to meet the legislation report date of December 15, 2015.

It is important to note that the survey target audience were people who are receiving services from various systems, providers of services from various systems and caregivers/family members. Because our charge was to study the feasibility of creating an office of community living with the goal of improving access and quality services and identifying gaps in the system, what is working well and what is not working, it is imperative to receive responses from recipients of the services and those that provide the services.

It was never our intent to survey the general public. They would have no knowledge of the services system because they don't currently use it.

At this point in the process, we are awaiting the full analysis from CADER, inclusive of the survey results, the regional forums and analysis of other states so that we can provide our report and recommendations.

I would be happy to answer any questions that you may have.







# Office for the Aging

**Two Empire State Plaza  
Albany, NY 12223-1251**

Andrew M. Cuomo, Governor  
Corinda Crossdale, Director  
Greg Olsen, Executive Deputy Director

[www.aging.ny.gov](http://www.aging.ny.gov)