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IDD and Dementia

Report

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SECTION 1 EXECUTIVE SUMMARY

The National Plan to Address Alzheimer’s Disease (2014) calls for a coordinated effort to develop workforces in aging, public health, and intellectual and developmental disabilities that are dementia-capable and culturally-competent. In response to this directive, the U.S. Administration on Community Living presents the findings and resources in this white paper to community of providers who primarily serve older adults. It provides a broad overview of the services and support system for persons with intellectual and developmental disabilities (IDD) affected by dementia and their caregivers, examples of cross-network initiatives, and resources for improving dementia care across agencies and organizations that serve this population.

This white paper presents the current state of services and support system for persons with IDD who have dementia. There is recognition in the aging and IDD networks that states are in a transition period where the future of services will be more person-centered and focused on integration in the community (see Appendix A).

Research shows that age-related health problems among people with intellectual disabilities are similar to those in the general population, including the development of dementia in later life (Heller et al., 2010; May & Kennedy, 2010; McCallion et al., 2013). However, the prevalence of dementia in people with Down syndrome at middle and early elderly ages is higher than in the general population (Ball et al., 2008; McCarron et al., 2014).

Similar to the general population, early detection and diagnosis of dementia for persons with IDD is challenging and standardized tools used with the general population are not recommended for use with persons with IDD. Delay in diagnosis of AD in the IDD population often results in delayed treatment resulting in a reduced therapeutic window for effective use of medications. A variety of screening instruments, the need for comprehensive dementia evaluation and treatment options are described in this paper.

Existing IDD services, financing and the settings in which they are delivered, may differ from the services that older adults tend to access. However, similar to aging programs, many of the services available to individuals with IDD focus on maintaining or improving functioning, such as providing assistance with basic tasks of everyday life or with skills related to independent living in the community. Research points to Medicaid as key to financing the services and supports provided to individuals with IDD. Data analyzed on the services and financing of the IDD systems show that almost a quarter of the estimated 4.7 million people with IDD in the United States (24% or 1.1 million) receive long-term services and supports through publicly funded state IDD agencies. The primary home and community-based services that individuals with IDD access are: in-home support services that are non-medical, non-institutional residential care facilities, community habilitation or therapeutic services, and adult day services.

To date, efforts to develop a dementia-capable and culturally-competent system of care across agencies and organizations has included training staff in aging and dementia care issues for people with intellectual disabilities and ensuring that formal services and family care

supports are prepared for dementia. Resources and program development considerations are presented in this paper to help build greater capacity to provide home and community-based services to an increasing number of persons with lifelong disabilities who are developing dementia, with a focus on collaboration to advance dementia-capability across aging and IDD systems. These considerations ensure that:

- Dementia awareness education is available to persons with IDD, their caregivers and service providers;
- Information and assistance services serving the aging and IDD networks identify those individuals with IDD and dementia and their caregivers who contact them (e.g. Aging and Disability Resource Centers);
- Persons with IDD and dementia are referred for appropriate diagnosis;
- Program eligibility and resource allocations take into account the impact of cognitive disabilities on an aging population of persons with IDD; and
- Dementia-capable home and community-based services available to the general population capable of serving persons with IDD and dementia.

SECTION 2 INTRODUCTION

Although it is well known that older people are at higher risk for Alzheimer's disease and dementia, it is less well known that individuals with intellectual disabilities, especially Down syndrome, are also at high risk of the disease. The need for enhanced community-based support for persons with intellectual disabilities and dementia and their caregivers will expand as the overall population ages. With the aging of the population, the number of older people will increase significantly over the next 20 years, a trend that will be mirrored among older adults with an intellectual disability (National Task Group on Intellectual Disabilities and Dementia Practice [NTG], 2012). Age-related health problems among people with intellectual disabilities are similar to those in the general population, including the development of dementia in later life (Heller et al., 2010; May & Kennedy, 2010; McCallion et al., 2013).

The prevalence of dementia in people with Down syndrome at middle and early elderly ages is higher than in the general population (Ball et al., 2008; McCarron et al., 2014). Chromosome 21 plays a key role in the relationship between Down syndrome and Alzheimer's disease as it carries a gene that produces one of the key proteins involved with changes in the brain caused by Alzheimer's (Moran, 2013). Adults with Down syndrome experience "accelerated aging," where certain conditions and physical features that are common for aging adults occur at an earlier age than the general population (Moran, 2013).

This paper aims to provide the community of providers who primarily serve older people with a broad overview of the services and support system needed by persons with intellectual and developmental disabilities (IDD) who also have dementia. It provides background information on the prevalence, characteristics, diagnosis, and treatment of dementia for persons with IDD. The paper provides a description of the types of long-term services and supports (LTSS) provided and paid for by both public and private funding sources and examples of initiatives to build cross-population dementia capability.

This paper makes frequent use of the term *intellectual and developmental disabilities (IDD)*. *Intellectual disability* is defined as a disability that originates before age 18 and is characterized by significant limitations in both intellectual functioning and in adaptive behavior, which includes many everyday social and practical skills. Determining if a person has an intellectual disability is complex. An IQ test can be used to measure limitations in intellectual functioning. Limitations in adaptive behavior can be measured by evaluating conceptual, social, and practical skills. (American Association on Intellectual and Developmental Disabilities [AAIDD], 2013). The most common syndromes associated with intellectual disability are autism, Down syndrome, Fragile X syndrome, and Fetal Alcohol Spectrum Disorder (The Arc, 2015).

The term *developmental disability* means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental or physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: Self-care; Receptive and expressive language; Learning; Mobility; Self-direction; Capacity for independent living. Also, reflects the individual's needs for a combination and sequence of special interdisciplinary, or generic services, individualized supports, or other forms

of assistance that are of lifelong or extended duration and are individually planned and coordinated (Developmental Disabilities Assistance and Bill of Rights Act of 2000). Developmental disability encompasses intellectual disability but also includes physical disabilities, such as cerebral palsy, traumatic brain injury, and epilepsy (AAIDD, 2013). Developmental disabilities can be identified through a process of developmental monitoring and developmental screening. Physicians examine children at their well-child visits for developmental delays, termed developmental monitoring. If any problems are identified, developmental screening can be conducted through the use of short tests to determine if learning is typical or delayed (CDC, 2015).

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SECTION 3 ISSUE BACKGROUND

Dementia refers to changes in memory and other cognitive skills severe enough to affect a person's ability to perform daily social and occupational activities. Alzheimer's disease (AD), the most common cause of dementia, is a progressive brain disease for which there is no cure, and it affects an estimated 5.2 million Americans over age 65, and approximately 200,000 people younger than 65 (Alzheimer's Association, 2014a). Many of the people affected by younger onset dementia will be those with Down syndrome (NTG, 2012). Individuals with other intellectual disabilities characterized by developmental delays and impairments in social function are also at risk for AD (Strydom et al., 2009). The life expectancy for people with IDD is similar to that of the general population, and the number of adults with IDD aged 60 years and older has been projected to nearly double from 641,860 in 2000 to 1.2 million by 2030, primarily as a result of improved longevity (Heller et al., 2010). The mean age at death ranges from the mid-50s for those with more severe disabilities or Down syndrome to the early 70s for adults with mild/moderate IDD (Heller et al., 2010).

Down syndrome is the best known and most prevalent biologically-based condition associated with IDD (Stancliffe et al., 2012). The prevalence of Down syndrome increases among children born to women who conceived at age 35 or older. The prevalence of Down syndrome rose from 9.0 per 10,000 live births in 1979 to 11.8 in 2003 in 10 representative U.S. regions, largely because of later ages of childbearing (Zigman, 2013). Although estimates vary, a recent study estimated that there were approximately 250,700 people with Down syndrome in the United States as of January 2008 (Presson et al., 2013). Prevalence rates of AD among people with Down syndrome are reported to increase with age. Estimates based on a number of studies range from 10% to 25% in the 40 to 49 age group, 20% to 50% in the 50 to 59 age group, and 30% to 75% among those aged 60 and over (Ball et al., 2008). Perhaps the most dramatic data are found in a longitudinal study of 80 women with Down syndrome aged 40 and older at the start of the study. After 14 years of regular assessments, 89.6% had been clinically diagnosed with dementia, the average age of diagnosis was 55.41 years (SD = 7.14), and there was a median survival of 7 years after diagnosis (McCarron et al., 2014). One study also found that women with Down syndrome have an increased risk of dementia if they start menopause at an early age (Coppus et al., 2010).

Although it is well established that adults with Down syndrome are at high risk for developing AD in middle age, the risk of dementia for people with intellectual disabilities other than Down syndrome has not received as much research attention. Prevalence studies of AD in the intellectual disability population without Down syndrome have found varying results—some with rates greater than the general population and others with rates similar to the general population (Strydom et al., 2010, 2013). For example, a recent study of people with intellectual disabilities other than Down syndrome found an incidence of dementia among people aged 65 and older five times higher than in the general population (Strydom et al., 2013). On the other hand, one study of 117 people with intellectual disability without Down syndrome did not find that the prevalence of dementia or AD was significantly different from the general population (Zigman et al., 2004).

Identifying cognitive decline in people with Down syndrome can be challenging because cognitive difficulties can be related to lifelong deficits or to changes resulting from dementia (Devenny et al., 2000). A number of early symptoms of AD in people with Down syndrome have been identified, including memory loss, disorientation, and changes in personality, behavior, and speech (Ball et al., 2008; Strydom et al., 2010). Behavioral and personality changes can include aggression, irritability, apathy, and decreased social engagement (Strydom et al., 2010). People with Down syndrome and AD also can experience neurological symptoms, such as seizures and myoclonus—the sudden, involuntary jerking of muscle—to a greater extent than the general population with AD (Ball et al., 2006; Urv, Zigman, & Silverman, 2010). Many frontal lobe–related symptoms are more common at an early stage of dementia among adults with Down syndrome. These symptoms include prominent personality and behavior changes such as irritability, aggression, self-abusive behavior, slowness, loss of interest in activities, social withdrawal, apathy, and decreased social engagement (Ball et al., 2006; Deb et al., 2007a; O’Caoimh et al., 2013; Strydom et al., 2010). It is difficult to distinguish AD from new-onset behavioral disorders or other psychiatric illnesses, which are common in older adults with Down syndrome (McCarron et al., 2014; O’Caoimh et al., 2013).

As people with Down syndrome move to the middle stages of dementia, cognitive functioning becomes more impaired, similar to declines in the general population, with complex cognitive functions and visual organization beginning to deteriorate (Alzheimer’s Association, 2014a; Strydom et al., 2010). Other changes for people with Down syndrome and dementia can be in the area of functional abilities, changing from mild impairment in personal hygiene in the early stage of dementia to inability to dress or eat as the disease progresses (Strydom et al., 2010). As dementia progresses to the late stages in people with Down syndrome, they are unresponsive to their environment and no longer speak (Strydom et al., 2010).

Much less research has been done on dementia symptoms of people with intellectual disabilities other than Down syndrome. One study found that early symptoms of dementia were marked by a general decline in functioning, whereas memory loss or other changes in cognitive function were not as prominent early on. Behavioral or emotional changes followed declines in functioning, such as changes in mood, lower energy levels, and hallucinations. In the late stages, incontinence and difficulty walking were common (Strydom et al., 2010).

Nearly a quarter of all persons with IDD live with family caregivers who are aged 60 or older (Braddock et al., 2013). By the time people with IDD who are living at home reach early old age, their parents tend to experience adverse health impacts, such as obesity, poorer self-rated health, limitations in activities of daily living (ADLs), and poor health-related quality of life, because of the stress of long-term caregiving (Seltzer et al., 2011). Older family caregivers, particularly parents, often fear that in the event of the parents’ death their children will not have adequate services to meet their needs and a place to live (Llewellyn et al., 2004). Family caregivers of adults with an intellectual disability and dementia may have additional challenges in continuing to provide care at home compared to solely caring for individuals with intellectual disabilities or individuals with dementia. Such challenges may include needing certain home modifications or caring for individuals who require assistance with a higher number of ADLs (McCallion et al., 2005).

SECTION 4 SCREENING, DIAGNOSIS, AND TREATMENT

In the general population, evaluation for a cognitive impairment is often prompted by the individual or a reliable informant who reports concerns regarding cognitive changes to a physician or other health care provider. Assessing for a cognitive impairment in someone with an IDD can be a more complicated task. It is often difficult to obtain an accurate personal history and to document the individual's baseline level of functioning when there is not ongoing involvement from family, physicians, or care staff. In addition, there may be poor record-keeping from childhood. Individuals with IDD are often served by different care providers through their lifetime (Moran et al., 2013) and family members or others who have known the person for a long time may not be able to objectively report on the person's preexisting abilities (Ball et al., 2004; Kirk et al., 2006).

Without an accurate history, a baseline level of performance cannot be established, which is critical for assessing cognitive and behavioral change (Ball et al., 2004; Jokinen et al., 2013; Kirk et al., 2006; Krinsky-McHale & Silverman, 2013; McCarron et al., 2014; Nieuwenhuis-Mark, 2009). Studies suggest conducting a detailed assessment between 25 and 40 years of age to establish the individual's baseline level of performance for individuals with Down syndrome (Jokinen et al., 2013; Kirk et al., 2006; O'Caoimh et al., 2013) and at age 50 for those with other intellectual disabilities (Jokinen et al., 2013; Kirk et al., 2006). Experts recommend periodic reassessments, after baseline has been assessed, so that substantial changes can be identified (Aylward et al., 1997; Kirk et al., 2006; Krinsky-McHale & Silverman, 2013; O'Caoimh et al., 2013).

4.1 Screening

Screening tools are used to identify people with possible dementia and to refer them for diagnosis and services. There is wide variability in cognitive functioning of individuals with IDD, therefore experts suggest that it is not advisable to use standardized neuropsychological tests to assess for decline in functioning with this population. Also, the results cannot be compared to general population norms, and many neuropsychological tests have not been validated for use in individuals with developmental ages less than 5 or 6 years (O'Caoimh et al., 2013). It is also difficult to discern dementia-related memory decline from a person with IDD because he or she may never have developed the specific level of cognitive skills measurable by standard memory tests (Aylward et al., 1997; McCarron et al., 2014; Pyo, 2011). Individuals with intellectual disabilities may not perform well on many neuropsychological tests because they require good communication and dexterity, intact sensory function, and good compliance by the individual undergoing the test (McCarron et al., 2014; Prasher, 2004). Sensory changes such as hearing and vision impairments are common in individuals with Down syndrome and may also affect their ability to participate in cognitive testing. It is important to use longitudinal screening approaches so that changes can be measured over time and to consider changes in not only cognition but also personality, behavior, and ADLs when evaluating for dementia (O'Caoimh et al., 2013).

There are a variety of screening instruments that are used with adults who have intellectual disabilities, and some instruments are not applicable for all persons with such

disabilities. For instance, some measures may be at such a low level as to make the detection of initial cognitive changes very difficult to identify in individuals with intellectual disabilities who have higher intelligence. These types of measurement problems are called “ceiling effects” (Hutchinson & Oakes, 2011). Other instruments such as those used for the detection of dementia among the general population are not suitable for people with intellectual disabilities because of a “floor effect,” meaning that the questions are too difficult for the individuals being tested (Deb et al., 2007b).

There are different types of dementia screening instruments for people with IDD, including observer rated scales, direct neuropsychological tests, and adaptive behavior measures. Some instruments are easily administered and can be used by family members or staff, and others are more complicated and require a provider who has undergone specialized training. Observer rated scales involve the reporting of behavioral changes by a knowledgeable informant. To establish whether there has been a change in cognitive status, observer rated scales should be used with caregivers or relatives who have known the person for a long period of time (Ball et al., 2004; Deb et al., 2007b). Observer rated scales appear to be more useful for the diagnosis of dementia in people with an intellectual disability than neuropsychological tests (Deb & Braganza, 1999). Observer rated scales include the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID), Dementia Questionnaire for Persons with Mental Retardation (DMR), and CAMDEX, an adaptation of the Cambridge Examination for Mental Disorders of Older People with Down Syndrome.

Neuropsychological tests are objective and standardized measures of an individual’s performance on prescribed tasks known to be linked to a specific brain structure or pathway. Some neuropsychological tests originally developed for the diagnosis of dementia in the populations without an intellectual disability have been modified for use in people with such disabilities (Deb & Braganza, 1999). Modified tests include the Severe Impairment Battery (SIB), Test for Severe Impairment (TSI), and Down Syndrome Mental Status Examination (DSMSE).

The inadequacies of using cognitive testing with people living with IDD led to the development of instruments that assess an individual’s adaptive behavior. Adaptive behavior is defined as a person’s ability to cope on a day-to-day basis with the demands of his or her environment (Hutchinson & Oakes, 2011). Adaptive behavior measures for assessing cognitive impairment in people with IDD use informants to report an individual’s ability to function socially and perform ADLs. These measures include Adaptive Behavior Dementia Questionnaire (ABDQ), Adaptive Behavior Scale (ABS), and Daily Living Skills Questionnaire (DLSQ). Regardless of the choice of instrument, the National Task Group Recommendations for the Evaluation and Management of Dementia (Moran et al., 2013) emphasize the importance of using the same instrument consistently over time to recognize change in relation to the person’s baseline.

4.2 Diagnosis

A comprehensive dementia evaluation includes a full physical examination by a trained specialist who understands assessment procedures for persons with IDD (McCarron et al., 2014). The National Task Group Recommendations for the Evaluation and Management of Dementia

(Moran et al., 2013) describe the steps of an evaluation to include gathering medical and psychiatric history, obtaining a description of the person's current functioning and comparing it to his or her baseline, a thorough physical examination including a review of systems and the medication list, obtaining pertinent family history, and assessing for psychosocial issues.

Significant psychosocial issues may include leaving the family home, frequent turnover/departure of paid caregivers, witnessing the declining health or death of someone close to the individual, and experiencing decline in one's own health, functional ability, or employment status. Assessment of these issues could identify triggering events or coexisting disorders that can influence an individual's cognitive and functional performance (Moran et al., 2013).

Magnetic resonance imaging (MRI) plays a limited role in the diagnosis of AD in individuals with Down syndrome. MRI can detect changes in the brain associated with AD but currently has limited validity and reliability. MRI findings are to be considered in combination with clinical assessment (Prasher, 2003).

Often a person with IDD, including Down syndrome, may demonstrate dementia symptoms but may not be evaluated until his or her care providers are troubled by the behavior (Strydom et al, 2010). One study presented case examples of "diagnostic overshadowing," where service providers or family members attribute the onset of new symptoms to a person's Down syndrome rather than considering the potential for dementia. Families in this study were not aware of the potential for early-onset AD in their relative and, once they noticed behavioral changes, sought psychiatric assessment rather than evaluation for dementia. The potential for overshadowing is heightened when care providers lack knowledge or understanding of intellectual disability and the potential for AD or another dementia. Overshadowing can lead to provision of poor or inappropriate supports and inadequate care management (Carling-Jenkins et al., 2012).

4.3 Treatment

Changes in behavior, loss of function, and personality and emotional changes in people with intellectual disabilities may be the result of medical or psychiatric conditions other than dementia, such as heart disease, obesity, diabetes, nutritional deficiencies, thyroid abnormalities, hearing or visual impairments, changes in gait or balance, adverse drug reactions, depression, sleep disorders, and pain (Jokinen et al., 2013; O'Caoimh et al., 2013). Individuals with IDD and dementia have more health comorbidities than those without dementia (Strydom, 2010). For example, epilepsy is significantly more common in people with IDD and dementia compared to people with IDD without dementia (McCarron et al., 2014). Sleep apnea is common in adults with Down syndrome, and treating sleep disturbance in an individual with IDD and dementia may involve use of continuous positive airway pressure therapy. Occupational and physical therapists can help treat changes in ADLs as the dementia worsens in an individual with IDD (Moran et al., 2013.).

Nonpharmacologic approaches, such as behavioral strategies, can be effective when working with individuals living with IDD and dementia. A 2007 review of the literature indicates that most families adapt well to a family member with IDD. However, some families of adults

with IDD and behavioral challenges are at risk for poor physical and mental health outcomes. (Heller, 2007). Recommendations for families caring for people with intellectual disabilities and dementia are to use stage-based approaches to communication, initiate low-cost environmental adaptations that support independence and avoid conflicts, reduce demand situations, reconnect with previously successful behavioral approaches, and proactively find ways to avoid stresses and to increase enjoyment of valued activities (Jokinen et al., 2013; McCallion et al., 2005; McCarron et al., 2010). The Caregiving Difficulty Scale – Intellectual Disability (CDS-ID) (McCallion et al., 2005) is also available to help identify caregivers at risk and the areas where they are experiencing challenges.

Research results are mixed regarding the efficacy of pharmaceutical therapies for dementia in persons with IDD. Pharmaceutical concerns include maximum and exact dosage and drug treatment cessation. Delay in diagnosis of AD in the IDD population often results in delayed treatment resulting in a reduced therapeutic window for effective use of medications. Cardiac and respiratory problems and differences in physiology such as metabolism and heart rate require additional consideration when exploring pharmaceutical therapy options for individuals with IDD. If the person is on multiple medications, clinicians must be knowledgeable of known and potential drug interaction implications, as well as poor medications compliance (Mohan, 2009; Moran et al., 2013; Prasher, 2004).

SECTION 5 SERVICES AND FINANCING SYSTEM

This section aims to inform the community of providers who primarily serve individuals aged 60 or older about the services and support system that individuals with IDD generally access. This section describes typical services available in most states. It is important to acknowledge that, with the promulgation of the Centers for Medicare and Medicaid (CMS) “home and community-based settings rule,” states are in a transition period to further develop their array of services to be more person-centered and integrated in the community. This has implications for all populations receiving Medicaid-funded home and community-based services (HCBS) as well as for individuals with dementia and Alzheimer’s. (See Appendix A for a brief description of the CMS settings rule.)

Existing IDD services, and the settings in which they are delivered, may differ from the services that older adults tend to access. Many of the services available to individuals with IDD are habilitative in nature, focusing on helping this population acquire and improve skills to be more independent in the community. When individuals with IDD develop dementia, their caregivers and their primary providers must learn to navigate between the two systems developed around each specific population.

5.1 Long-term Services and Supports Financing System for Individuals with Intellectual or Developmental Disabilities

Adults with IDD often require services and supports that focus on maintaining or improving functioning, such as providing assistance with basic tasks of everyday life (e.g., bathing or dressing), or with skills related to independent living (e.g., preparing meals or managing money). As of June 30, 2012, almost a quarter of the estimated 4.7 million people with IDD in the United States¹ (24% or 1.1 million) received LTSS through publicly funded state IDD agencies (Larson et al., 2014).

The programs and policies under Medicaid are key to financing services and supports provided to individuals with IDD. Medicaid accounted for 78% of total public spending on individuals with IDD in FY2011. The remaining 22% of public spending on individuals with IDD included 12% for state-only programs that generally supported county government–operated group homes and day programs, or other community supports. Other federal funds, including Supplemental Security Income payments and Title XX Social Services Block Grant funding, accounted for 10% of spending (Braddock et al., 2014).

Historically LTSS were primarily provided in institutional-based settings for individuals with IDD (e.g., intermediate care facilities for individuals with IDD [ICF/ID]). Now, the large majority of Medicaid LTSS spending for individuals with IDD is for home and community-based services (HCBS). Spending for individuals with IDD accounts for 70% of all spending on Medicaid HCBS waivers (Ng et al., 2014). The concentration of Medicaid spending on HCBS

¹ In 2012, there were an estimated 4.7 million total people (adults and children) with IDD in the United States based on the estimated total U.S. population of 314 million and prevalence estimates for people with IDD of 1.49% (Larson et al., 2014).

rather than institutional-based LTSS for individuals with IDD varies widely across states. For example, in FY2013, New York state ranked number one for spending on IDD and HCBS with 51%² of their HCBS Waiver spending going towards IDD. Other examples of the top five include Maine at number two, Vermont at number three, Washington, DC at number four, and Minnesota at number five. Mississippi came in at 50th only 19% of LTSS spending for individuals with IDD on HCBS (Braddock et al., 2015).

Table 1 identifies the primary services that individuals with IDD generally access, including their estimated expenditures and number of service users. These services include the following categories: in-home support services that are non-medical, non-institutional residential care facilities, community habilitation or therapeutic services, adult day services, and intermediate care facilities for individuals with IDD. Other than the intermediate care facilities for individuals with IDD, these services are not specific to individuals with IDD but are the services most relevant to the needs of individuals with IDD.

Table 1
LTSS for Individuals With IDD—In-Home Support Services (Nonmedical)

Provider Type	Definition	Estimated Expenditures	Estimated Number of Service Users
Personal Care Assistant Services	Home care services that are not considered skilled medical care. Services include assistance with ADLs (e.g., bathing, dressing, eating) and instrumental activities of daily living (IADLs) (e.g., money management, medication). The providers include home health aides, certified nursing assistants, personal care aides, nurse’s aides, homemakers, and companions.	13% of total public spending for individuals with IDD went toward personal care assistance services in 2013 ^a	293,956 individuals accessed in FY2013 ^a
Family Support Services	Services and supports that provide support to caregivers of individuals with IDD. Services include respite services, financial services such as cash subsidies and vouchers, in-home supports such as personal assistance or homemaker services, assistive technology and environmental modification, adaptive medical equipment, health and professional services, family counseling and/or training, parent support groups, transportation, recreation activities, specialized clothing, and dietary services.	7% of total public spending for individuals with IDD went toward family support programs in FY 2013 ^a	464,043 individuals accessed in FY2013 ^a

² States' ranking, highest to lowest, on federal-state Waiver spending per citizen of the general population (Braddock et al., 2015).

Provider Type	Definition	Estimated Expenditures	Estimated Number of Service Users
Non-Institutional Residential Care Facilities and Services	Residential support services that focus on individuals with IDD. The residential facilities provide assistance in acquiring, retaining, and improving self-help, socialization, and/or adaptive skills by a provider with round-the-clock responsibility for the residents' health and welfare in a residence that is not a single-family home or apartment.	63% of total public spending for individuals with IDD is for residential care facilities and services that have 15 or less beds in 2012. ^b	422,654 individuals with IDD living in residential care facilities in 2012: ^b 366,191 individuals with IDD residing in residential care facilities with 1 to 6 beds 56,463 individuals with IDD residing in residential care facilities with 7 to 15 beds.
Community Habilitation or Therapeutic Services	Enable individuals with IDD to acquire or improve skills to help them become more independent. Habilitation therapists work with individuals with IDD to teach a variety of important skills and improve behavior. These services may include physical and occupational therapy, speech-language pathology, and other services for people with developmental disabilities.	Not available	Not available
Adult Day Services	Regularly scheduled activities in nonresidential settings. Activities include assistance with or improvement in self-help, socialization, and adaptive skills that enhance social development and develop skills in performing ADLs and community living. Adult day services for individuals with IDD may focus particularly on employment-related or educational instructions. Adult day services also include meals and day habilitation services that focus on enabling the participant to attain or maintain his or her maximum potential and are coordinated with any needed therapies in the individual's person-centered services and supports plan, such as physical, occupational, or speech therapy.	Not available	Estimated around 500,000 in 2011 ^c

(continued)

Table 1 (continued)
LTSS for Individuals with IDD—In-Home Support Services (Nonmedical)

Provider Type	Definition	Estimated Expenditures	Estimated Number of Service Users
Intermediate Care Facilities for Individuals with ID/DD	Diagnosis, treatment, or rehabilitation for individuals with intellectual disabilities; provides, in a protected institutional setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration for health or rehabilitative services to help individuals function at their greatest ability.	\$12.8 billion in 2012 ^d	95,500 residents in 2010 ^e

^aBraddock et al., 2014.

^bLarson et al., 2014.

^cButterworth et al., 2011.

^dEiken et al., 2014a

^eEiken et al., 2014b

5.2 Home and Community-Based Services

The primary funding vehicle through which states provide Medicaid HCBS to individuals with IDD is through Section 1915(c) of the Social Security Act HCBS waiver programs. Enrollees in IDD waiver programs accounted for over 40% of total HCBS waiver participants (approximately 582,000 enrollees of a total of 1.4 million enrollees), but 70% of all spending on HCBS waivers (\$27.4 billion of a total of \$38.9 billion) in FY2011 (Ng et al., 2014). In FY2011, the average per enrollee spending was \$47,058 for individuals with IDD in HCBS waivers, compared to the average per enrollee spending of \$12,283 among enrollees aged 65 or older and enrollees with physical disabilities in HCBS waivers (Ng et al., 2014).

Expenditures for people with IDD are high, in part, because people with IDD use more round-the-clock in-home and out-of-home residential support rather than services provided during part of the day (Rizzolo et al., 2013). A study of 88 HCBS waivers found that more than half of spending for individuals with IDD (53%) was for residential habilitation services, which includes such services as assistance with ADLs, community inclusion, transportation, adult educational supports, and social and leisure skill development, that help the participant to reside in the most integrated setting appropriate to his or her needs (Rizzolo et al., 2013).

5.2.1 In-Home Support Services

Almost three-quarters of individuals with IDD (71% in FY2013) live with family caregivers (Braddock et al., 2014). Of these individuals living with family caregivers, almost a quarter (24%) reside with family caregivers who are aged 60 or older and another 35% with family caregivers who are between age 41 and 59 (Braddock et al., 2014). When examining individuals with IDD who use publicly financed LTSS (i.e., served by the state IDD agencies), an estimated 56% lived in the home of a family member in FY2012 (Larson et al., 2014). Of these individuals with IDD living in the home of a family member, 39% received supports funded through a Medicaid HCBS waiver in FY2012. The remaining 61% were on the caseloads

of state IDD agencies but may not have been receiving any Medicaid HCBS waiver LTSS or state-funded LTSS except perhaps case management. Some may have been using a Medicaid state plan service benefit such as personal care assistance or a family subsidy funded entirely by the state IDD agency (Larson et al., 2014).

Services and supports that states offer through their Medicaid program or state-only funding to families of adults with IDD include respite services, financial services such as cash subsidies and vouchers, in-home supports such as personal assistance or homemaker services, assistive technology and environmental modification, adaptive medical equipment, health and professional services, family counseling or training, parent support groups, transportation, recreation activities, specialized clothing, and dietary services (NTG, 2012).

Seven percent (\$4.3 billion in FY2013) of total public spending for individuals with IDD went toward supporting family caregivers; 464,043 participants received these services (Braddock et al., 2014). The primary difference between Medicaid and state-only funding for family support programs is that the Medicaid's family support programs must be for the direct benefit of the Medicaid beneficiary. These services generally cover respite and family training services. Medicaid funding has generally allowed states to offer more comprehensive support to families than is typical under state-only funded family support programs (O'Keeffe et al., 2010).

Caregiver training and education services are allowable services under Medicaid HCBS waivers. Training and education can cover a wide range of topics, such as instructions for using equipment specified in a service plan and ensuring compliance with treatment regimens. It may include (a) paying trainers to come into the home to teach skills and techniques for addressing the program participant's needs; (b) paying for caregivers to attend special training and education classes; and (c) paying the expenses associated with caregivers attending workshops and conferences where they learn how to better meet the needs of individuals with disabilities (O'Keeffe et al., 2010).

Individuals with IDD who do not reside in supervised residential settings often receive support and personal assistance services, which include assistance with ADLs and IADLs but not medical or skilled nursing services. These types of services are supplied by direct support workers, direct support professionals (DSPs), home health aides, certified nursing assistants, personal care aides, nurse's aides, homemakers, and companions. Medicaid finances a great deal of these services, often through the Medicaid personal care service state plan option or Medicaid HCBS waivers. In FY2013, 13% (\$8.0 billion) of total public spending on individuals with IDD was for supported living and personal assistance services (Braddock et al., 2014). Just under 300,000 (293,956) individuals with IDD accessed these support services in FY2013 (Braddock et al., 2014). Some states use HCBS waivers, sometimes referred to as "supports waivers," to provide programs intended primarily to provide services and supports to meet the needs of individuals with IDD who live with their families or on their own (O'Keeffe et al., 2010).

5.2.2 Non-Institutional Residential Care Services

As of 2012, almost 450,000 people with IDD lived in non-institutional residential settings other than the home of a family member (Larson et al., 2014). These types of non-institutional settings that serve individuals with IDD provide assistance in acquiring, retaining, and improving

self-help, socialization, and/or adaptive skills by a provider with round-the-clock responsibility for the residents' health and welfare in a residence that is not a single-family home or apartment. Overall, 51% of all people with IDD not living with a family member shared a home with three or fewer people with IDD, and 77% shared a home with six or fewer people. State IDD agencies reported in 2012 that 58,753 people with IDD lived in 35,830 host family or family foster care settings with an average of 1.6 people with IDD living in each host home or family foster care setting (Larson et al., 2014). Adult foster homes are generally single-family residences that offer 24-hour care in a home-like setting. Adult foster home providers commonly provide assistance with ADLs (e.g., eating, bathing, and dressing), household chores, and meal preparation. Other services—such as arranging for transportation or providing social or recreational programming—are also common (Mollica et al., 2009). In a Medicaid HCBS waiver program, adult foster care is often considered a residential habilitation service for individuals with IDD (O'Keeffe et al., 2010). About 58% of total public spending (federal and state Medicaid, state only, and federal only) for individuals with IDD was for smaller residential settings in FY2013 (Braddock et al., 2014).

5.2.3 Community Habilitation or Therapy Services

Community habilitation or therapy services, including occupational, physical, and speech and language therapies, which enable people with IDD to acquire or improve skills to help them become more independent, are used by individuals using in-home care and those in more formal residential care facilities. According to CMS, habilitative services are designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings (Section 1915(c)(5) of the Social Security Act). Habilitation therapists work with individuals with IDD to teach a variety of important skills and improve behavior. These services may include physical and occupational therapy, speech-language pathology, and other services.

5.2.4 Adult Day Services

Adult day service providers are community-based centers that provide an array of LTSS, including structured activities, health monitoring, socialization, and assistance with ADLs, to seniors or younger adults with disabilities on a nonresidential basis (Dwyer et al., 2014). In general, there are three types of adult day centers: (1) social (which provide meals, recreation, and some health-related services); (2) medical/health (which provide social activities and more intensive health and therapeutic services); and (3) specialized (which provide services only to specific types of care recipients, such as those with dementia or developmental disabilities) (National Adult Day Services Association, 2015). For individuals with IDD, adult day service centers provide day habilitation services that focus on enabling the participant to attain or maintain his or her maximum potential and coordinate any needed therapies in the individual's person-centered services and supports plan, such as physical, occupational, or speech therapy (CMS, 2011). In 2011, an estimated 500,000 individuals with IDD received day services and supports (Butterworth et al., 2011). Medicaid covers many of the individuals who receive services from adult day centers in the United States.

5.3 Institutional-Based Services

Although institutional services were historically the dominant type of services for people with IDD, they currently serve a much smaller proportion of the population. Only 13% of all individuals with IDD who used LTSS services in FY2013 resided in intermediate care facilities for individuals with intellectual disabilities (ICF/IDs) (Braddock et al., 2014). ICF/IDs are institutions that provide both medical care and long-term care services to individuals with IDD. Such facilities provide ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each resident function at his or her greatest ability. ICF/IDs (1) are primarily for the diagnosis, treatment, or rehabilitation for individuals with intellectual disabilities; and (2) provide, in protected residential settings, ongoing evaluation, planning, 24-hour supervision, coordination, and integration for health or rehabilitative services to help individuals function at their greatest ability (42 CFR 435.1009) . Medicaid spent \$12.8 billion for ICF/IDs in FY2012 (Eiken et al., 2014a). About 95,500 Medicaid beneficiaries received services in ICF/ID in FY2010 (Eiken et al., 2014b). The number of individuals with IDD served in ICF/IDs has fallen substantially over time. Between 1993 and 2012 the number of people in public ICF/IDs decreased from 147,729 to 86,000 but total Medicaid ICF/ID expenditures increased from \$9.2 billion to \$12.3 billion. Overall ICF/ID expenditures increased 34% but the number of participants declined 42% during this time period (Larson et al., 2014).

5.4 Services for Caregivers of Persons with IDD and Dementia

General information is available for family caregivers from the Alzheimer's Association (2015) and the National Down Syndrome Society (2014). Training programs and educational materials have been developed to help facilitate education and training among family caregivers of individuals with IDD and dementia (McCallion & Janicki, 2002; Watchman, 2007). Family caregivers who must make adaptations to their home to accommodate dementia stage-related changes can access guides to adapting home for dementia, such as those of the Alzheimer's Association (Alzheimer's Association, 2014b,c; Jokinen et al., 2013).

The Administration for Community's National Family Caregiver Support Program (Title III E of the Older Americans Act), provides funding for community-based programs to support the important role of family caregivers, including family caregivers of individuals with IDD and dementia. Although caregiver programs available locally vary, any adult family members or other informal caregivers aged 18 and older providing care to individuals of any age with AD and related disorders may be eligible for services. Although funding is limited, services may include the following:

- Access assistance services to help caregivers locate services from a variety of private and voluntary agencies
- Counseling and training services in the form of counseling, peer support groups, and training to help better cope with the stresses of caregiving
- Respite services for temporary relief—at home or in an adult day care or institutional setting—from caregiving responsibilities (ACL, 2014a)

In a majority of states, the Lifespan Respite Care Programs coordinate systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs (ACL, 2013).

The Administration on Community Living also sponsors the Alzheimer's Disease Supportive Services Program (ADSSP), which provides grants and supports to states in their efforts to expand the availability of community-level supportive services for persons with dementia and their caregivers. In addition, the Alzheimer's Disease Initiative: Specialized Supportive Services (ADI-SSS) project is designed to fill gaps in dementia-capable LTSS for persons living with Alzheimer's disease and related dementias and their caregivers. The ADSSP and ADI-SSS projects fund efforts to ensure that people with dementia of all ages and their family caregivers have access to a sustainable HCBS system that is dementia capable. One area that all grantees participating in the 2014 ADI-SSS projects address is the improvement of the quality and effectiveness of programs and services dedicated to individuals with IDD and dementia, or those at high risk of developing dementia. Grantees funded in 2014 are targeting services to individuals with IDD and dementia and provide training targeted at their caregivers and providers (ACL, 2014b). Grantees funded in 2015 have the option to target services to individuals with IDD and dementia and provide training targeted at their caregivers and providers.

5.5 Services Available for Persons with IDD and Dementia

The amount and type of services that people with IDD and dementia need will change over time as the symptoms become more pronounced (Jokinen et al., 2013). For example, as early stages of dementia develop, adults with IDD living on their own will need additional assistance in coping and adapting to the early changes and decline. Eventually, the person will not be capable of living alone and the demands on housemates sharing an apartment may become too burdensome. Sometimes it is prudent for an adult with IDD affected by early-stage dementia to move to a formal community residential setting, such as a group home, a cluster apartment, or similar supported living arrangement that may have staff who are trained and experienced in working with individuals with dementia (Jokinen et al., 2013).

Group homes are an alternative for long-term care services provided to adults with IDD who have developed dementia (Chaput, 2002; Janicki et al., 2002; McCarron et al., 2002, 2005). Older adults in the general population who have dementia can also reside in residential care settings (Fisher Center for Alzheimer's Research Foundation, 2010). Residential settings for individuals with dementia provide housing and supervision for adults with declining faculties and abilities related to dementia who can no longer live independently and who would otherwise end up living in an institutionalized setting. However, there may be some distinctions between the settings designed primarily to serve individuals with IDD who develop dementia compared to other residential settings that do not serve individuals with IDD, including their sources of financial support and the regulatory authority governing their operation (Janicki, 2011). Despite these differences, the various types of residential care facilities that can serve different populations with dementia have equivalent average annual costs because of care demands; the average annual cost of care for adults with dementia was \$53,320 in IDD group homes in 2010 (Janicki et al., 2005; Janicki, 2010). During the same period the average annual cost in assisted living communities not dedicated to the IDD population was \$57,144 (MetLife, 2010).

For adults with IDD and dementia who live in group homes or other supported living environments, the residential care facilities that focus on individuals with IDD must consider the extent to which they have the policy, staffing, and other resource supports so that residents may remain in place as their functional abilities decline (Janicki et al., 2002, 2005). Staff of group homes that serve individuals with IDD, rather than individuals with dementia, generally focus on young and middle-aged adults, and issues around employment, community participation and independence promotion. When dementia becomes present among some of the residents, the previous staffing approaches and philosophies may not be as appropriate (McCallion & McCarron, 2004). The approaches to care that staff use must reconcile progressive loss of ability and end-of-life care within a system dedicated to skill development and independent living (Janicki et al., 2000). There must also be openness to collaborating with dementia-specific and palliative care resources (McCallion et al., 2012).

With respect to day programs, agencies that focus on individuals with IDD are currently organized for large group activities. When dementia becomes more prominent among some individuals with IDD, adult day programs can be reorganized to better support small group activities and flexibility in hours of involvement for the individual with dementia (e.g., partial versus full days). The activities and services provided in an adult day center can also be offered by staff trained in dementia care practices, including supporting existing skills and memories and rather than teaching new skills (Jokinen et al., 2013).

As mentioned previously, the Home and Community-Based Settings Rule (see Appendix A) promotes the development of services and supports that are person-centered, responsive to specific, assessed needs, and retains a person's right to reside in the setting of their choice. Services and supports should be altered only in response to developing needs, and only by adhering to the requirements for modifying an individual's person-centered service plan. Adhering to the parameters of the rule will ensure that individuals' supports adjust to their cognitive, health and safety needs.

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SECTION 6

INITIATIVES TO IMPROVE COMMUNITY-BASED SERVICES FOR PEOPLE WITH IDD AND DEMENTIA

Dementia care is an area in which the aging and IDD networks systems can collaborate to improve services as their populations face similar needs and, over time, may cross systems (Factor et al., 2012). To meet needs and support adults with IDD affected by dementia as they attempt to remain in their homes and communities, some parts of the aging and IDD networks are developing a system of care that includes support from community care programs. The focus of these efforts has included training staff in aging and dementia care issues for people with intellectual disabilities and ensuring that formal services and family care supports are prepared for dementia (Jokinen et al., 2013).

In recent years, initiatives have sought to formalize dementia-focused cross-network collaboration, such as the National Plan to Address Alzheimer’s Disease (2014) and the state dementia plans of Alaska, Georgia, Hawaii, and New York. For example, the U.S. National Plan implementation includes the development of standardized inter-professional education to address the unique needs of individuals with intellectual disabilities through cross-network collaboration. Professionals from the aging and IDD networks are joining with other disciplines to develop the standardized curriculum. The 2013 Report of the New York State Coordinating Council For Services Related to Alzheimer’s Disease and Other Dementias (2013), in its issues and recommendations for individuals with IDD and AD, states that the Department of Health and partners should train professionals and paraprofessionals who work with individuals with developmental disabilities to be aware of the connection between Down syndrome and AD and to identify indicators of AD.

6.1 Training

Successful cross-network collaboration begins with a shared understanding of the nature and scope of the needs of adults with IDD affected by dementia. To accomplish this, several initiatives to provide cross-network training have been developed for IDD and aging services providers.

6.1.1 Aging and Disability Resource Centers (ADRCs)

ADRCs serve as a visible and trusted resource for all populations, regardless of age, income or disability, for objective information on their long-term services and support options and their Medicare benefits. While ADRCs vary in their capacity and relationship with the IDD network, the vision is to achieve a system that can serve all populations (J. Lugo, Office of Consumer Access and Self-Determination, U.S. Administration for Community Living, personal communication, July 7, 2015). Dementia-specific content with a focus on persons with IDD has been incorporated into staff training in some ADRCs.

6.1.2 The Florida Department of Elder Affairs (DOEA)

DOEA developed “Meeting the Needs of Aging Persons with Developmental Disabilities: Cross Network Collaboration for Florida,” a five-module training for ADRC staff which describes the differences, commonalities, barriers, and similarities between the two

networks and how to overcome the barriers or enhance similarities (R. Lucchino, Emeritus Professor Utica College, President of the Board, Area Agency on Aging for South West Florida, personal communication, March 8, 2015). The training materials are available through the DOEA.

6.1.3 National Task Group on Intellectual Disability and Dementia Practices (NTG)

NTG has developed a multipurpose universal education and training curriculum on dementia and intellectual disability (NTG, 2015). The NTG Education and Training Curriculum on Dementia and Intellectual & Developmental Disabilities is a two-day in-person training. The curriculum covers an introduction to aging with IDD, IDD and dementia, dementia versus Alzheimer's, screening and early detection of dementia, health care advocacy, steps to getting a proper diagnosis, stages of dementia and associated caregiver tips and strategies, non-pharmacologic management of difficult behaviors, communication, programmatic issues and considerations, supporting staff and family caregivers and bridging the aging and IDD networks (K. Bishop and K. Pears, National Task Group, personal communication, January 7, 2015).

A 3-day format includes a Train-the-Trainer day and prepares local trainers in the core concepts of the curriculum, implementation strategies, workshop logistics, curriculum materials and how to use them, and fidelity maintenance. The Train-the-Trainer model goal is to develop a cadre of NTG regional trainers who will then be available with ongoing support from the NTG and NTG master trainers to provide ongoing training to their own organizations and to outside agencies on a fee-for-service basis.

6.2 IDD and Aging Systems Integration with a Dementia Focus

Care for persons with dementia is often fragmented both within and between aging and developmental disabilities services systems. Although coordination between these systems is an ever-evolving process, at present, aging and disability systems collaboration is guided by the ideological convergence of their interest in supporting community living in the least restrictive settings for all populations (Putnam, 2014). Integration at the systems level with a dementia focus is being fostered by both federal and state support through programs such as the Alzheimer's Disease Supportive Services Programs and ADRC (Administration on Aging, 2015a, 2015b).

6.2.1 New York

Although many initiatives to integrate the aging and IDD service networks have been limited and short-term (Factor et al., 2012), efforts to integrate these systems in New York State have been ongoing for nearly 30 years (K. Bishop, National Task Group, personal communication, March, 10 2015; T. Galbier, Alzheimer's Association Rochester & Finger Lakes Region Chapter, personal communication, March 2, 2015; M. Romano, Oneida County Office for the Aging/Continuing Care, personal communication, March 13, 2015). A focal point for this integration has been to ensure that formal services and family care supports are prepared for the growth in need for dementia care by persons with IDD and their caregivers.

6.2.2 Oneida County Office for the Aging/Continuing Care Advisory Council's Special Populations Subcommittee

In 1986, the Oneida County Aging and Mental Retardation and Developmental Disabilities Coalition was formed by the Oneida County Area Agency on Aging, other aging community-based organizations and developmental disabilities providers (e.g., The Arc, Oneida-Lewis Chapter). Their focus was to bridge the aging and IDD networks, beginning with identifying and assisting elderly caregivers of adult children with developmental disabilities who had not previously received any network services. The caregivers were connected to support services, including Medicaid waiver programs and adult day services. As early as 1991, the coalition created resources on aging and developmental disabilities, including dementia. Today this group is an active, formal standing committee of the Oneida County Office for the Aging/Continuing Care with a broad membership of long-term care facilities, developmental service providers, senior centers, Alzheimer's Association Chapters, and other aging services providers who continue to focus on ways to improve the systems of care for all persons aging with developmental disabilities (M. Romano, Oneida County Office for the Aging/Continuing Care, personal communication, March 13, 2015).

6.2.3 Alzheimer's Disease Demonstration Grants to States (ADDGS) Grant

From 2002 to 2006, with funding from the U.S. Administration on Aging, the New York State Office on Aging (NYSOFA) implemented its first ADDGS grant designed to increase the ability of persons with developmental disabilities and AD to age in place in spite of their disease progression (Osber et al., 2007). NYSOFA and its partners created and implemented replicable methods for (1) delivering dementia services for persons with developmental disabilities which allow people to age in place; and (2) incorporating dementia services into a dementia-capable single point of entry system. The grant also established a network of local aging and IDD service providers offering dementia-appropriate direct services and a technical assistance center at the University at Albany. In support of the ADDGS activities, statewide trainings on intellectual disabilities and dementia were supported by the New York State Developmental Disabilities Council and by New York State ARC, and collaborative training with the New York State Hospice Association.

6.2.4 Assistive Support: Dementia Supports Program (ASDSP)

In 2006, the Alzheimer's Association Rochester & Finger Lakes Region Chapter developed the ASDSP for individuals with developmental disabilities and dementia. The program, which grew out of their involvement in the ADDGS project, is structured around the "aging in place" model, which emphasizes helping individuals to remain in their community, in familiar surroundings, and close to family and friends for as long as possible (Dixon, 2008).

The ASDSP is part of an interdisciplinary team approach to community-based care coordination for persons with developmental disabilities. ASDSP care consultants are part of the interdisciplinary team, which includes representatives from provider organizations that have a relationship with the participant, including the service coordinator, clinicians, social workers, medical staff, managers and advocates. Community partners include Lifetime Assistance, Inc.; Arc of Monroe; and Continuing Developmental Services.

The team develops and implements an individualized service plan (ISP) with the individual and his or her caregiver(s). An ISP is a written document that typically lays out when and where services will be provided and what goals those services will help the individual and his or her caregiver(s) attain. ASDSP care consultants lead ongoing, comprehensive assessments of the participant's dementia-specific needs. Semi-annual ISP review meetings take place with the consumer, family members, and other caregivers (T. Galbier, Alzheimer's Association Rochester & Finger Lakes Region Chapter, personal communication, March 2, 2015). In addition to ISP development, service options for participants include home safety assessments by an occupational therapist with specialized training in dementia care; oversight through monthly face-to-face contact and phone consultation with ASDSP care consultants to ensure that dementia-specific needs outlined in the ISP are addressed; participant-driven, on-site guided education and discussion on dementia-related issues are offered by day service staff; and informal peer discussion groups meetings with other participants to develop a greater sensitivity to the changes observed in their peer.

Although the program was originally funded through an agreement with the New York State Office for Persons with Developmental Disabilities (NYS OPWDD) to provide services to consumers enrolled in the Options for Persons through Services program, the Alzheimer's Association Chapter now works with consumers and IDD network care providers as a certified NYS OPWDD Medicaid provider. The program director reports that participants have shown improvements in their ADLs and reductions in behavioral disturbances (T. Galbier, Alzheimer's Association Rochester & Finger Lakes Region Chapter, personal communication, March 2, 2015).

6.2.5 Dementia Capable Systems Integration Grant Program

In 2011, the New York State Office for Aging was awarded a U.S. Administration on Aging Systems Integration Programs to Create Dementia Capable, Sustainable Service Systems for Persons with Dementia and Their Family Caregivers grant. This grant focuses on integration of statewide programs, using a Single Entry Point/No Wrong Door, for people of all ages in need of long-term care services regardless of income levels, including persons with intellectual disabilities and dementia. In New York, NY CONNECTS is an ADRC and serves as the state's Single Entry Point/No Wrong Door.

The Systems Integration grant program has a goal of improving the dementia capability of all community-based long-term care services. This grant includes seven multicounty/regional local partners consisting of NY CONNECTS, six Alzheimer's Association Chapters, and one community-based nonprofit dementia services organization in Long Island. These partners routinely engage in cross-referrals and cross-training with a goal of formalizing their relationships.

6.2.6 Systems Integration Dementia Workgroups

As part of the Systems Integration grant, two workgroups have been formed to address dementia, including issues specific to persons with intellectual disabilities (M. Romano, Oneida County Office for the Aging/Continuing Care, personal communication, March 13, 2015). A Dementia Screening Work Group will recommend what dementia screening elements should be incorporated into entry-level consumer intake process through the local NY CONNECTS (Lines

et al., 2015). The Dementia Screening Work Group will review available tools and instruments, including those specific to the IDD population, to develop the best approach for New York. In addition, a Dementia Capable Work Group is defining protocols for NY CONNECTS to address dementia services across all populations, including those specific to persons with IDD and dementia.

6.2.7 Guidelines for Structuring Community Care and Supports

Community care and supports for people with IDD have not historically planned for the long-term, high-level needs of persons with dementia, leaving them unprepared for the changes in the needs of the adults they serve (R. Lucchino, Emeritus Professor Utica College, President of the Board, Area Agency on Aging for South West Florida, personal communication, March 8, 2015). To assist agencies supporting families or other in-home caregivers providing dementia care to adults with an intellectual disability or agencies developing and operating residential settings for persons with an intellectual disability affected by dementia, the NTG developed “Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia” (Jokinen et al., 2013).

This model provides recommendations for care management and services for people with IDD in the pre- and post-diagnosis stages, including early, mid-, late, and end-stage of the disease progression. In the pre-diagnosis stage, the emphasis is on the early recognition of first signs and symptoms of dementia, which can often go unnoticed or be simply ignored by caregivers. Any suspicions of dementia based on changes in behavior should be validated by the use of an early detection screening tool (such as those mentioned previously in this paper), followed by a formal assessment and diagnosis. In post-diagnosis stages of dementia, the focus is on care planning, training and outcomes, and appropriate actions are recommended for each stage.

In addition to recommendations for each stage of dementia, the guidelines provide setting-specific recommendations for individuals living in a private home with a family member or a caregiver, living alone, living in group homes, and for those living in residencies that specialize in dementia care and those attending adult day services. Other issues covered in this publication include abuse, financial management, nutrition, medications, and managing personal choice and liability.

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SECTION 7 CONCLUSIONS

Aging and IDD service networks enable people of all ages who have chronic conditions and disabilities to remain in their homes. With number of adults with IDD aged 60 years and older projected to nearly double between 2000 and 2030, people served through IDD networks will increasingly be at risk for developing dementia (Heller et al., 2010). Aging and disability service systems will need to build greater capacity to provide services to an increasing number of persons with lifelong disabilities who are aging, including older individuals with disabilities who will increasingly need more services and supports to maintain their health and independence. Cross-network collaboration may advance dementia-capability across these systems. Their populations face similar needs and, over time, both systems may serve the same people as persons with IDD and/or their caregivers become eligible for aging services.

This paper provides an overview of issues faced by persons with IDD affected by dementia and their caregivers, the resources available to them, examples of cross-network initiatives, and resources for improving dementia care across agencies and organizations that serve this population.

Future development of community-based services for adults with IDD affected by dementia through shared initiatives across agencies and organizations that involve the aging and IDD networks need to consider the following issues:

- *Is dementia awareness education available to the IDD population and service providers?* This includes information about the risk factors associated with developing dementia, first signs of cognitive problems, management of symptoms if individuals have dementia, support programs, and opportunities to participate in IDD-focused dementia research.
- *Do the information and assistance services in both the aging and IDD networks identify those individuals with IDD and dementia and their caregivers who contact them?* Strategies to ensure that persons are identified include adding dementia-specific questions to information gathering and assessment forms; training to recognize possible cognitive impairment in conversations with clients and their caregivers and in other interactions; and partnering with organizations specializing in dementia. Identifying individuals with possible dementia is only the beginning of the dementia care process.
- *Are persons with IDD and dementia being referred for appropriate diagnosis?* Obtaining and documenting an individual's baseline level of performance over time in adulthood is optimal to accurately assess for dementia-related decline. Observer rated scales appear to be most useful for the screening of possible dementia in people with IDD. Once a possible dementia is detected, adherence to a formalized referral process for a comprehensive dementia evaluation by a trained specialist who understands assessment procedures for persons with IDD is ideal.

- *Are program eligibility and resource allocations taking into account the impact of cognitive disabilities on an aging population of persons with IDD?* Dementia-capable home and community-based resources are needed by persons with IDD and their caregivers beginning when suspicions of a possible dementia arise to when care ends with eventual death. Individuals' needs change and become more intense over time. The number of older persons with IDD will increase significantly over the next 20 years as the prevalence rates of dementia in all populations increase with age. Assessing and addressing program eligibility and resource allocations may help better prepare for current and future needs of persons with IDD and dementia and their caregivers.
- *Are the dementia-capable home and community-based services available to the general population capable of serving persons with IDD and dementia?* Although some people with IDD experience neurological symptoms, such as seizures, the majority of the dementia symptoms and the stage-based losses in capacity mirror those of the general population. The services and supports needed by the general population and dementia are the same as those needed by persons with IDD. Understanding the nature of the person with IDD's non-dementia-related lifelong disability is necessary to provide person-centered services and supports, but this process is the same as in the general population.

Resources are available to help systems address the needs of persons with IDD and dementia and their caregivers. As highlighted in this paper, The Administration on Community Living's National Alzheimer's and Dementia Resource Center, the National Task Group on Intellectual Disabilities and Dementia Practice, the Florida Department on Elderly Affairs and the Oneida County Office for the Aging/Continuing Care are just a few of the examples of sources for information on new and emerging practices in dementia-capable home and community-based services for persons with IDD and dementia.

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SECTION 8 APPENDIX A

In January 2014, after a series of Notice for Public Rule Making, the Centers for Medicare and Medicaid promulgated a rule, *1915(i) State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915(c) Home and Community-Based Services Waivers - CMS 2249-F and 2296-F*, now referred to as “the home and community-based settings rule” (CMS, 2014). The purpose of the rule was to establish a definition for settings in Medicaid funding authorities that qualify as home and community-based for reimbursement purposes. Five main tenets of the rule are:

- The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
- Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
- Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- Facilitates individual choice regarding services and supports, and who provides them.

The rule is more focused on “the nature and quality of the individual’s experience” rather than what the setting is not. The rule also establishes a set of qualities that provider controlled settings must adhere to in order to keep their HCBS funding status (441.301(c)(4)(A) through (E)). Because this is the most significant change to the waiver programs since they were established in 1982, states have five years, until March 2019, to implement the requirements of the rule. All states were required to submit transition plans describing their current array of residential and day services and the extent to which the settings comport with the rule, and if they do not, the changes the state would make to bring the settings into compliance.

The rule does not establish separate requirements for older or younger beneficiaries. Settings are to accommodate the individual needs and preferences of Medicaid beneficiaries and these preferences are determined through a person-centered service planning process, the structure of which is also described in the rule (441.301(1)(i) through (v) and 441.301(2)(i) through (xiii)).

An additional aspect of the person-centered planning requirement which is significant in the context of services for individuals of any age with dementia or Alzheimer's disease is eight required elements for modifying an individual's person entered service plan for a "specific, assessed need" (441.301(2)(xiii)(A) through (G). An example of how this section might be applied is establishing protections for individuals who experience wandering behavior. In an assisted living environment or adult day setting serving seniors or younger individuals with IDD, the provider must tailor restrictions or safety protections in response to individual behaviors, and not lock an entire unit or section, thereby restricting several beneficiaries' movements whose needs and behaviors are different.

The settings rule is important in the context of this discussion because some current services and day services in particular may not meet the requirements of the rule, particularly for younger individuals with IDD. For example, nationally there is a concerted effort to improve the employment outcomes for individuals with disabilities, and current day settings do not provide the supported employment services that enable people to work in the community in typical jobs. Likewise, there are seniors who may also want to continue working though they reside in an assisted living facility or attend a day service to have medical or therapy needs met. The implication for day services is that in order to meet the requirements of the rule for continued reimbursement, providers may need to retool some of their practices toward greater flexibility and more varied supports that enable beneficiaries to be more integrated in their communities.

Source: Patricia D. Nobbie, Ph.D., Program Specialist, Office of Policy Analysis and Development, Administration for Community Living (2015)

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