



Caregiving and Intellectual and Developmental Disabilities and Dementia:

Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities

August 2017

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

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Notation

This report was prepared at the request of the National Task Group on Intellectual Disabilities and Dementia Practices for submission to the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers.

Summary

This report summarizes the findings and recommendations from a pre-summit activity for the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers. The report was developed by a working group of experts in caregiving, dementia, and intellectual and developmental disabilities (IDD) and organized by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in partnership with the Rehabilitation Research and Training Center in Developmental Disabilities and Health at the University of Illinois at Chicago and the Alzheimer's Association. The purpose was threefold: (1) to assess the current state of research, policy, and practice, and develop recommendations related to caregiving supports for older adults with intellectual and developmental disabilities; (2) to translate the contributions of these findings to the greater dementia care agenda; and (3) to promote inclusion of issues particularly relevant to intellectual disability and dementia concerns as part of the Summit platform. The Report examined the foundational similarities and differences in focal areas affecting people with dementia, both with and absent IDD. Considered were five major areas related to care and caregiving: (1) family caregiving interventions; (2) supportive care settings; (3) effects of diversity; (4) screening and early detection; and (5) bridging service networks. Recommendations are offered in each of these areas, including how funding and actions might be undertaken and by which federal or non-federal organizations

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Background

The Family Caregiver Alliance estimates 65 million people in the US serve as caregivers to older family members or family members with a disability (Alliance, 2016). Among these is an important and often overlooked group, caregivers of older adults with intellectual and developmental disabilities (IDD) and dementia. With an estimated 46.2 million adults ages 65 and older in the US (US Administration on Aging, 2016), there are least 180,000 older adults with ID and, at minimum, 11,000 of these adults will be affected by dementia (Janicki & Dalton, 2000). As the population of older adults in the United States continues to rapidly increase this group will likely need additional services and supports. Caregivers of adults with IDD and dementia have many of the same challenges and stressors as caregivers of older adults with dementia. However, they may have different patterns of caregiving experience, additional challenges and stressors, and access different forms of support and education.

This report summarizes the findings and recommendations from the *Pre-Summit on Caregiving and Intellectual/Developmental Disabilities* for the *National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers*. It was developed from findings and recommendations of a working group of experts in caregiving, dementia, and IDD organized by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in partnership with the Rehabilitation Research and Training Center in Developmental Disabilities and Health at the University of Illinois at Chicago and the Alzheimer's Association.¹ The purpose was threefold:

- 1) To assess the current state of research, policy, and practice, and develop recommendations related to caregiving supports for older adults with intellectual and developmental disabilities;
- 2) translate the contributions of these findings to the greater dementia care agenda; and
- 3) promote inclusion of issues particularly relevant to intellectual disability and dementia concerns as part of the Summit platform.

Commentary on Issues Relevant to the NIH Summit

Similarities and differences in needs and supports

While people with IDD and their caregivers have similar needs for dementia care supports as other adults with dementia and their caregivers, there are also unique aspects for the IDD population. These differences include differences in the trajectory of dementia, often with earlier onset of dementia, a shorter duration of dementia, and greater difficulties in diagnosing dementia given the life-long cognitive limitations. Secondly, individuals with IDD often require life-long services and supports, including family caregiving or supported living outside the family home. An estimated 71% of all individuals with intellectual and developmental disabilities (IDD) live with their family caregiver (Braddock et al., 2015). Of those

¹ The Workgroup worked first *in absentia* and then met on-site on March 22, 2017 at the Headquarters of the Alzheimer's Association in Chicago, Illinois.

living with their family caregiver, 24% are with caregivers aged 60+ (Braddock et al., 2015). A body of research has examined the nature of extended, often life-long caregiving among these caregivers, as well as the different challenges and adaptations experienced by lifelong caregivers when contrasted to late-life caregivers, and the nature of adaptations to caregiving when adults with IDD begin to experience dementia, and then progress through the course of Alzheimer's disease or related dementias. Thirdly, other kin – primarily siblings – play a significant role for adults with IDD when parents are no longer able to provide care (Heller & Kramer, 2009).

Lifelong caregivers experience differences from later life caregivers with respect to adaptation, ascendance to caregiver roles, and via experience, mobilizing and drawing upon networks of support. Financially, many of these caregivers are also more readily able to access public support for extended caregiving and receive assistance with respite, when the adults with IDD are enrolled in community day programs or home-based support services. As many formal providers and governmental agencies exist to aid people with IDD, some educational and support resources have been made available to help orient caregivers to age-related caregiving (e.g., NDSS, 2012), including raising awareness of the symptoms of dementia and being oriented to care practices tailored to caring for someone with dementia (NDSS, 2017).

A critical distinction among caregivers of adults with IDD is that they are often 'career' caregivers, with extensive experience with providing supports and adapting to the ups and downs related to extended caregiving. Many also have extensive experience with social and health care services and advocating on behalf of their relative with IDD. With the onset of dementia many of these caregivers are adapting to new challenges and bring to fore their experience and capacity to continue caregiving. *This rich literature on 'career' caregivers can be of benefit to the Summit – as the findings can translate to increasing our capacity to understand and sustain caregiving among late-life conditions, in particular dementia.*

Findings from aging and IDD research on family caregiving interventions

Family caregivers of older adults and adults with IDD (including dementia) face many challenges including stress, depression, poor health, and financial hardship. However, research on the long-term impact of caregiving on caregivers of individuals with IDD is mixed depending on the characteristic of the adult with disability, the health of the caregiver, life events, the context of care, and the informal and formal supports available. Much research is needed to better understand the impact of caregiving on families and how they are managing the new challenges presented by dementia (Jokinen, 2016; 2017).

Programs and services are available to help families cope with these challenges, but they usually focus on either caregivers for older adults or caregivers for adults with IDD, but not both. A recent scoping review of nearly 70 empirical intervention studies (Heller, Gibbons, & Fisher, 2015) looked at some of the differences and similarities between these programs and what the aging and IDD fields can learn from each other as they develop new interventions to support family caregivers.

The review found several important differences between these two fields. In reviewing the research, there was a difference in semantics, that is, the way each community talked about providing care for a family member. While the aging field referred to providing care as “caregiving,” the IDD field more often referred to it as “family support.” Caregiving programs tended to focus on the person providing care, while family support programs were often directed to the entire family. For both groups, most support programs fell into two broad categories: government programs and small-group interventions that addressed psychological and social issues. Government programs tend to focus on either care coordination and support services or financial and home supports. These include, but are not limited to, case management programs, respite care, consumer-directed services, and in-home medical supports. The psychosocial programs tend to focus on either support and counseling or education and training for the caregivers. Examples of these interventions included future planning programs, support groups, disease-specific education, and counseling sessions, among others.

Both caregiving and family support programs benefited those who participated. Government care coordination and respite programs gave caregivers more access to services and satisfaction with the caregiving role, while psychosocial support programs improved participants’ mental health and attempted to reduce “caregiver burden”. Aging studies focused on ‘self-care’ as caregiving was generally assumed in later age, while disability studies often considered caregiving as lifelong. Some programs also benefitted participants’ physical health, employment, productivity, future planning, and access to supports, and resulted in delayed institutional placement for the care recipient. Few studies in both the aging and disability fields examined the cost of family supports.

However, there was little or no cross-over discussion between the fields of aging and IDD. Only a few articles in the family support literature recognized the intersection of aging and IDD, and no articles in the caregiving literature included people aging with lifelong disabilities like IDD (Heller et al., 2015). This is an important gap to bridge for both groups. The IDD family support literature, while not as developed as the gerontology research, has a greater emphasis on future planning, self-direction and person-centered planning. These types of interventions were assumed to also be useful to older adults and their caregivers, as these interventions were found to empower the person receiving care and often had positive impacts on the caregivers as well. Additionally, among older adults, the IDD interventions featured family peer support and peer leaders as another way to empower and support the independence of people with disabilities. Among older adults the focus was more on adapting to new care capacities and demands as it was assumed the aging caregivers might also benefit from group interaction when the groups are led by their peers with similar lived experience. While both fields were concerned with reducing negative outcomes of caring for a family member, the IDD family support research was more likely to also examine positive outcomes such as evaluating future planning or caregivers’ abilities to maintain employment. Researchers in caregiving may want to seek a similar balance when evaluating the outcomes of their interventions.

As more people are aging with and into disability, collaboration among the aging, dementia care and IDD sectors will be increasingly important. As new programs are developed, these three fields may benefit from each other's efforts. Researchers working on family support interventions for people with IDD may want to incorporate ideas from the aging and dementia care literature, with its broader history and variety of well-researched interventions. Researchers developing programs in caregiving for aging individuals may want to incorporate concepts from the field of IDD on person-centered planning for families and broaden their focus to include both negative and positive aspects in caring for a family member with a disability.

Research dedicated to understanding the course of dementia and the impact of caregiving has mostly excluded people with IDD in their samples. Inclusion of people with IDD and their caregivers into research will increase the breadth and applicability of studies as well as promote full community inclusion. In a similar vein, community organizations that provide education and services to older adults and their caregivers should make a concentrated effort to reach people with IDD and dementia.

Recommendation 1: Better integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusive practices.

- a) Include people with IDD and their supporters in both generic aging and dementia studies
- b) Document the cost of family support programs and how they benefit society and reduce the overall cost of non-family care
- c) Acknowledge positive aspects of caregiving
- d) Incorporate concepts such as future planning, person-centered planning, and supported decision-making in research and practice

Residential services and supports

One housing model extant in both dementia services (van Zadelhoff et al., 2011) and those for persons with IDD (Janicki, 2011) is the use of small group homes. While most states are moving away from using this model for younger adults with ID, some states are returning to its use for aged-care and, more prevalently, for dementia capable care. This model offers one option for alternative care in the community for persons with IDD affected by dementia, who otherwise may be forced to seek institutional admission. As most adults in group homes for dementia may remain in the homes for up to 10 years (Janicki et al. 2005), there is a greater need for more IDD and dementia-capable group homes and research to determine best practice applications.

Existing research has compared dementia special care units (SCUs) to group homes and found that group homes tend to provide higher quality care (because they provided a home-like environment and they operated according to a therapeutic philosophy of care). In addition, costs for caregiving are more economical in group homes (Chaput, 2002; Janicki et al. 2005). As

quality of life and personalization are the underlying foundations for this type of dementia care, such settings can help promote dignity, maintain reasonable levels of autonomy, and continue a relationship with the community, while providing safety and supports for physical and psychological functions.

While the use of small, neighborhood-based group homes is a complement to at-home care and an alternative to institutional care, there still remain some unknowns, which to make this a universal model applicable to all sectors, need resolution. For example, administrators often complain that funders generally did not increase the reimbursement or contract rates for the care provision of people affected by dementia, even when their decline requires more staff-intensive care. While some agencies may be able to absorb this cost differential on the short term, with an increase in the number of older adults with IDD affected by dementia, this may become a significant issue in determining whether aging-in-place and in-place- progression dementia care supports can be viable in the long term.

The research also suggests that care requirement issues arising during early stage dementia are not as problematic from a staff management perspective, but that staff involvement and staff time requirements become more important issues in the mid-stage of dementia when losses of capability and the presence of behavioral and psychological symptoms of dementia (BPSD) become more significant care issues. Understanding how the course of dementia may impact care and continued residence in a group home setting will be important to understand so that policy makers and providers can plan for how to best support people and caregivers in these situations.

Recommendation 2: Increase research and community programming to support people with IDD and dementia living in group home settings.

- a) Examine the benefits of dementia capable communities “Dementia friendly America” with respect to aiding families caring at home for adults with IDD
- b) Develop and test models of residential supports that are dementia capable for both an adult with IDD and other older adults with dementia.
- c) Provide sufficient training and financial supports for dementia capable homes
- d) Examine the degree of family caregiver supports associated with living out-of-home dementia care of adults with IDD

Diversity in population

People with IDD and dementia and their caregivers are far from a homogeneous group, and this diversity impacts caregiving and service access. The issue of caregiving in older age for people with IDD impacts all people of all ethnicities, languages, and socioeconomic classes, as well as people living in a variety of geographic locations with vastly different resources. For example, research indicates that majority of adults with IDD live at home with their families (Braddock, et al., 2015). For racial/ethnic/linguistic minority groups this may be even more common (Heller, Markwardt, Rowitz, & Farber, 1994; Magaña & Smith, 2006a). As a result,

caregivers within minority groups are more likely to experience both the positive and negative effects of continual caregiving, especially when faced with the progression of dementia. Some research has found that Latino mothers experience less caregiver burden and stress than European-heritage mothers; however, mothers who were unable to care for their son or daughter at home experienced high levels of depressive symptoms (Magaña & Smith, 2006a; Magaña & Ghosh, 2010). Culturally in the United States, the push is for independence for adults with IDD. However, this may not fit with the cultural norms of certain minority groups, or even be feasible for some members of minority groups. Further, there is a dearth of research exploring cultural perceptions of dementia among adults with IDD and what norms exist for extended caregiving.

Most studies that examine minority caregivers have found poor health when compared to European-heritage caregivers (Blacher et al., 1997; Magaña, Seltzer, & Krauss, 2004; Miltiades & Pruchno, 2002). This includes more chronic health conditions, limitations due to health conditions, and lack of appropriate health care (Magaña & Smith 2006b; Magaña & Smith 2008). Part of the explanation for these finding may lie with the theory of *cumulative adversity* (Zarit & Pearlin, 2005). Cumulative adversity refers to any combination of three processes: 1) a chain of hardships over the life course; 2) a layering or buildup of hardship effects; and 3) a single hardship that persists over the life course. For many racial/ethnic minority families, the additional strain of providing lifelong care may be an add-on to hardships such as poverty, low education, and discrimination, creating a life-long pattern that may contribute to poor outcomes.

Diversity in geography is also an important fact to consider, as caregivers living in a rural area may experience different supports, stressors, and care aid options. A systematic review of family caregiving for older adults in rural and remote settings across the globe found low use of formal supports, gaps in services, and unmet service needs (Innes, Morgan, & Kostineuk, 2011). Other findings in this area have generally shown that rural caregivers are more likely than those in urban areas to rely on informal supports (Bedard, Koivuranta, & Stuckey, 2004; Montoro-Rodriguez, Kosloski, & Montgomery, 2003). Additional research is needed to discern whether these differences are based on cultural norms or a dearth of services in these areas and also to assess the impact of these differences on outcomes. Focus needs also to be given to the issues faced by caregivers in linguistic isolation situations.

Families who live in rural areas or are members of a minority group may have unique experiences in caregiving that are not generally captured by research and policy. To ensure support, education, and positive outcomes for these families, researchers and policy makers need to be sure to acknowledge the differences that may exist for these groups. Research needs to include all variations of extant minorities as well as people living in rural or remote settings and policy makers and service providers should focus on culturally competent, or culturally aware and sensitive, care.

Recommendation 3: Acknowledge and respect the diversity of family values and caregiving practices.

- a) Develop linguistic and cultural sensitivity among providers based on ethnic and cultural values and practices
- b) Consider the special needs of families living in poverty and families not identified by the service system
- c) Develop methods of reaching families in rural areas and those in linguistic and/or ethnic geographic groupings

Screening and assessment of dementia

People with IDD who are aging face many of the same age-related health issues that people without disabilities face. However, they may develop health issues such as dementia at an earlier age and their initial symptom presentation may differ from that of the general population. In particular, adults with Down syndrome are likely to experience dementia at a much younger age and with greater frequency than would be expected. A systematic review over an 11-year span found a higher prevalence of dementia in persons with Down syndrome. Prevalence was 9% in those under 49 years 5.7–10.3% in for 40–49 years 30.4–40% for 50–59 years, and 41.7–50% for 60–70 years (Strydom et al., 2010).

Additionally, adults with ID may exhibit early symptoms of dementia which are not as easily identifiable to caregivers. One study of over 200 aging adults with IDD found functional decline such as changes in independence with daily living skills was a common early symptom often missed by caregivers and clinicians (Strydom, Livingston, King, & Hassiotis, 2007). These barriers to early clinical diagnosis; differing symptom presentation, lack of appropriate screening tools, and concerns over accuracy of informant reporting may lead to later diagnoses (Sheehan, et al., 2015). Early diagnosis is essential to ensure timely interventions such as medication for symptom management, establishing advance care plans, and psychosocial interventions for both the older adult and their caregiver. Such earlier onset of dementia and elevated need for early diagnosis may be a differentiating feature among persons with IDD.

To combat these barriers and increase timely and accurate diagnosis a push is needed to increase public awareness and improve clinical competence. Researchers have developed and tested instruments to aid in the identification of dementia symptoms in people with IDD, these include the Wolfenbütteler Dementia Test for Individuals with Intellectual Disabilities (WDTIM; Kuske, Wolff, Gövert, & Müller, 2017), and the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID; Deb, Hare, Prior, Bhaumik, 2007). While research has shown promising results on screening in general, the level of adoption of specific screening of persons with IDD by professionals is unknown and warrants greater focus on utility and usage. With respect to screening by caregivers, the National Task Group (NTG) has developed an early detection and screening administrative instrument (the NTG-EDSD [National Task Group-Early Detection and Screening for Dementia]) that has been adopted by many agencies and jurisdictions for use by caregivers, both formal and informal (Esralew, Janicki, & Keller, 2017). Increased training for clinicians and widespread dissemination of instruments specifically applicable for people with IDD may aid in making more early diagnoses. As caregivers and family members are often the first to notice a change in behavior (Jamieson-

Craig et al., 2010), increases in public awareness regarding prevalence and early symptomology may increase referrals for early screenings.

Recommendation 4: Increase early screening and public awareness of dementia and other aging related issues in people with IDD and their caregivers.

- a) Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDD
- b) Help families and other persons who provide support recognize the signs of dementia in people with IDD
- c) Adopt an early detection and screening instrument for persons with IDD as part of the annual wellness visit under the Affordable Care Act.

Bridging the two service networks

While many families and caregivers of people with IDD are familiar with the broader developmental disability service system, accessing and understanding the aging system may present challenges. The need to bridge the fields of aging and disability has been identified and outlined in The Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability (Bickenbach et al., 2012). Despite many of the differences noted between the fields of aging and disability, the NTG has emphasized that adults with IDD require the same community education, and community based supports for themselves, their caregivers, and the organizations working with them as do other adults affected by dementia. For both groups, families do the majority of caregiving and need support, and both need a quality direct support workforce. Hence, in recognition of the importance of family and staff caregivers to community supports offered person with IDD and dementia, the NTG has drawn upon both on the aging and disability fields to develop practice guidelines (Bishop et al., 2015; Jokinen et al., 2013; Moran et al., 2013) and a national training curriculum (Janicki & Keller, 2014; see <http://aadmd.org/ntg/education-and-training>) to enhance caregiving understanding of dementia and strategies for continued care of people with IDD and dementia.

For both the aging and disability fields there is a growing concern about common issues, such as end of life care, abuse and neglect, residential supports, health declines, financial supports, and assistive technology needs. Hence, there are many benefits to bridging between the networks. One issue that particularly illustrates the need for collaborations across systems is the common situation for families of adults with IDD in which aging-related health issues arise for both the adult with IDD and the family members providing support (Haley & Perkins, 2004). Parents and other family members may develop aging related chronic disease and illness (including dementia) that results in caregivers undertaking multiple caregiving roles.

This scenario has been termed “*compound caregiving*” as this additional caregiving responsibility is in addition to a significant lifelong caregiving role that has lasted for decades (Perkins, 2010; Perkins & Haley, 2010). In Perkins and Haley’s (2010) study, 37% of aging caregivers (mean age 61) of co-residing adult children with IDD, were also a compound

caregiver. Sixty-six percent reported they had previously been a compound caregiver, and a further 34% anticipated becoming so in the near future. In the compound caregiving recipient, dementia was the most frequent health condition (21%). Supports (if available) are not assessing the full range of caregiving needs for caregivers of adults with IDD (Williamson & Perkins, 2014).

This is of concern, as compound caregivers reported spending an average of 52 hours per week undertaking their caregiving-related tasks (Perkins & Haley, 2010). Home and Community Based Long-term Services and Supports are based on age eligibility criteria. This may result in the caregiver not having adequate support from either service system (i.e., state developmental disability services for their older child with IDD, or state aging services for their compound caregiving recipient) to fully meet the combined needs.

Some areas of development include finding programmatic solutions that allow for wrap-around supports of both the primary and compound caregiving roles, including effective respite coordination, and programs that are: a) responsive to overall caregiving needs irrespective of caregiver/care recipient age, and b) adaptable to changing caregiver status across the lifespan. For example, the National Family Caregivers Support Program (NFCSP) (OAA Title IIIE) provides information and assistance, caregiver training, respite care, and caregiving related supplies to adults caring for a family member age 60 or older or a family member of any age with dementia, as well as for grandparents age 55 and older caring for grandchildren ages 18 and younger. The NFCSP may also need to adapt program offerings and materials for persons aging with lifelong and/or adult-onset of disability who serve as caregivers to aging parents or older adult spouses as well.

More work is needed in bridging aging and disability to help find solutions to this unique issue. Barriers to collaboration are many and include ideological differences that have notably hindered cross-network collaborations (Putnam & Stoever, 2007). Some research suggests that professionals in the field of aging do not feel adequately prepared to work with and/or meet the needs of persons aging with lifelong disabilities or individuals with early and mid-adulthood onset of disabilities (Putnam, 2011). Over the years, numerous efforts have been undertaken to develop cross-network professional and organizational capacity to support persons aging with lifelong and early and mid-onset disability (see Ansello & Rose, 1989; LePore & Janicki, 1997). However, such efforts have to be repeatedly undertaken due to constantly changing administrative, clinical, and staff cohorts. However, when implemented they are functional and productive, and greatly enhance collaboration among aging and disability service providers and advocates and help to foster bridge-building across aging, disability, and social welfare sectors (Putnam, 2014).

Recommendation 5: Focus on the integration of the aging and developmental disability networks to provide quality continuous care.

- a) Examine the impact of the “Perfect Storm” - an aging population, more numbers of persons with dementia, and diminution of numbers of care workers (i.e., via reductions due to changing policies on immigration)
- b) Fund more research on best practices that apply to dementia caregiving including family support models, relationship-based care, and supported decision-making
- c) Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDD and dementia

Recommendations

In summary, the following are the workgroup recommendations to the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (See Table 1 for recommendations along with potential implementers):

- 1) Better integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusive practices.**
 - a) Include people with IDD and their supporters in both generic aging and dementia studies
 - b) Document the cost of family support programs and how they benefit society and reduce the overall cost of non-family care
 - c) Acknowledge positive aspects of caregiving
 - d) Incorporate concepts such as future planning, person-centered planning, and supported decision-making in research and practice
- 2) Increase research and community programming to support people with IDD and dementia living in group home settings.**
 - a) Examine the benefits of dementia capable communities “Dementia friendly America” with respect to aiding families caring at home for adults with IDD
 - b) Develop and test models of residential supports that are dementia capable for both adult with IDD and other older adults with dementia.
 - c) Provide sufficient training and financial supports for dementia capable homes
 - d) Examine the degree of family caregiver supports associated with living out-of-home dementia care of adults with IDD
- 3) Acknowledge and respect the diversity of family values and caregiving practices.**
 - a) Develop linguistic and cultural sensitivity among providers based on ethnic and cultural values and practices
 - b) Consider the special needs of families living in poverty and families not identified by the service system
 - c) Develop methods of reaching families in rural areas and those in linguistic and/or ethnic geographic groupings

- 4) **Increase early screening and public awareness of dementia and other aging related issues in people with IDD and their caregivers.**
 - a) Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDD
 - b) Help families and other persons who provide support recognize the signs of dementia in people with IDD
 - c) Adopt an early detection and screening instrument for persons with IDD as part of the annual wellness visit under the Affordable Care Act.
- 5) **Focus on the integration of the aging and developmental disability networks to provide quality continuous care.**
 - a) Examine the impact of the “Perfect Storm” - an aging population, more numbers of persons with dementia, and diminution of numbers of care workers (via reductions due to changing policies on immigration)
 - b) Fund more research on best practices that apply to dementia caregiving including family support models, relationship-based care, and supported decision-making
 - c) Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDD and dementia

Table 1 Caregiving and Intellectual and Developmental Disabilities (IDD) and Dementia: Recommendations to the NIH Summit on Dementia Care and Services Research	
Recommendation	Who Could Do It?
1. Better integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusive practices.	
a) Include people with IDD and their supporters in both generic aging and dementia studies	Administration on Community Living (ACL); National Institute on Health (NIH); Foundations
b) Document the cost of family support programs and how they benefit society and reduce overall cost of non-family care	ACL; NIH; Foundations
c) Acknowledge positive aspects of caregiving	ACL; Area Agencies on Aging (AAA); National provider groups
d) Incorporate concepts such as future planning, person-centered planning, and supported decision-making in research and practice	ACL; AAA; National provider groups, State developmental disabilities authorities
2. Increase research and community programming to support people with IDD and dementia living in group home settings.	
a) Examine the benefits of dementia capable communities “Dementia friendly America” with respect to aiding families caring at home for adults with IDD	ACL; Assistant Secretary for Planning and Evaluation (ASPE)
b) Develop and test models of residential supports that are dementia capable for both adults with IDD and other older adults with dementia	NIH; ACL; Centers for Medicare and Medicaid Services (CMS)
c) Provide sufficient training and financial supports for dementia capable homes	CMS; AAA; State developmental disabilities authorities
d) Examine the degree of family caregiver supports associated with living out-of-home dementia care of adults with IDD	ACL
3. Acknowledge and respect the diversity of family values and caregiving practices.	
a) Develop linguistic and cultural sensitivity among providers based on ethnic and cultural values and practices	ACL; National provider groups; Professional organizations; Caregiver associations
b) Consider the special needs of families living in poverty and families not identified by the service system	State Units on Aging (SUAs); State developmental disabilities authorities
c) Develop methods of reaching families in rural areas and those in linguistic and/or ethnic geographic groupings	ACL; CMS

Recommendation	Who Could Do It?
4. Increase early screening and public awareness of dementia and other aging related issues in people with IDD and their caregivers.	
a) Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDD	CMS; Health Resources and Services Administration (HRSA); American Psychological Associations; American Association on Intellectual and Developmental Disabilities; Geriatric Workforce Education Programs (GWEPS); National Task Group on Intellectual Disabilities and Dementia
b) Help families and other persons who provide support recognize the signs of dementia in people with IDD	ACL; GWEPS; AAA; SUAs; State developmental disabilities authorities
c) Adopt an early detection and screening instrument for persons with IDD as part of the annual wellness visit under the Affordable Care Act.	CMS
5. Focus on the integration of the aging and developmental disability networks to provide quality continuous care.	
a) Examine the impact of the “Perfect Storm” - an aging population, more numbers of persons with dementia, and diminution of numbers of care workers (via reductions due to changing policies on immigration)	NIH; ACL; Centers for Disease Control and Prevention (CDC)
b) Fund more research on best practices that apply to dementia caregiving including family support models, relationship-based care, and supported decision-making	NIH; ACL; Foundations
c) Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDD and dementia	ACL; SUAs; State developmental disabilities authorities

ACL: Administration on Community Living; CDC: Centers for Disease Control and Prevention; CMS: Centers for Medicare and Medicaid Services; GWEPS: Geriatric Workforce Education Programs; NIH: National Institute of Health; SUAs: State Units on Aging

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