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Perspective

Caregiving, intellectual disability, and dementia: Report of the Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities

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Abstract

Introduction: A specially commissioned working group produced a report on caregiving, intellectual and developmental disabilities (IDDs), and dementia for the National Institutes of Health–located National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers.

Methods: Experts in caregiving, dementia, and IDDs examined the current state of research, policy, and practice related to caregiving and supports; identified the similarities and dissimilarities between IDD-related care and services and the general population affected by dementia; and considered how these findings might contribute to the conversation on developing a dementia care research and services development agenda.

Results: Five major areas related to programs and caregiving were assessed: (1) challenges of dementia; (2) family caregiving interventions; (3) supportive care settings; (4) effects of diversity; and (5) bridging service networks of aging and disability.

Discussion: Recommendations included increasing supports for caregivers of adults with IDDs and dementia; increasing research on community living settings and including caregivers of persons with IDDs in dementia research; acknowledging cultural values and practice diversity in caregiving; increasing screening for dementia and raising awareness; and leveraging integration of aging and disability networks.

Keywords: Alzheimer's disease; Caregiving; Dementia; Intellectual disability; Public policy

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1. Background

The Family Caregiver Alliance [1] estimated that some 65 million people in the United States serve as caregivers to older family members or family members with a disability. Among these is an important and often overlooked group: caregivers of older adults with intellectual and developmental disabilities (IDDs) who are diagnosed with dementia. Of some estimated 46.2 million adults aged 65 years and older in the United States [2], it is estimated that there are least 180,000 older adults with IDDs of which an estimated 11,000 will be affected by dementia [3]. 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 IDDs and dementia face many of the same challenges as do caregivers of other older adults with dementia; however, they often experience unique patterns of caregiving, face additional challenges and stressors, and benefit from different sources of support and education. Given the rich base of literature on caregiving within the IDD field, it was deemed beneficial to examine key issues that are distinct within IDD caregiving as compared with that in the generic dementia field and propose applications of the findings to the research and care agenda of the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (Research Summit) [4,5]. As a prelude to the Summit, various organizations were invited to form pre-Summit activities and submit reports encapsulating the concerns, issues, and recommendations related to their topic and germane to the Research Summit. This article summarizes the findings and recommendations of a report produced by the Working Group on Caregiving and Intellectual/Developmental Disabilities and submitted as a pre–Research Summit activity [6] to the 2017 National Institutes of Health–located Research Summit (A full version of the report "Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities" can be accessed from https://aspe.hhs.gov/pdf-report/caregiving-and-intellectual-and-developmental-disabilities-and-dementia-report-pre-summit-workgroup-caregiving-and-intellectual-and-developmental-disabilities and http://rrtcadd.org/2017/08/11/caregiving-and-intellectual-and-developmental-disabilities-and-dementia-report-of-the-pre-summit-workgroup-on-caregiving-and-idd/). The Working Group's effort was commissioned by the National Task Group (NTG) on Intellectual Disabilities and Dementia Practices 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 of this effort was threefold: (1) to assess the current state of research, policy, and practice and develop recommendations related to caregiving supports for older adults with IDDs; (2) to translate the contributions of these findings to the greater dementia care agenda; and (c) to promote inclusion of issues particularly relevant to IDDs and dementia as part of the Summit platform.

2. Methodology

After the NTG's designation request as an official pre–Research Summit activity was approved, it worked with the working group's chair, Dr. Tamar Heller of the University of Illinois at Chicago, to organize the membership of the group. Key researchers and others from across the United States concerned with caregiving, IDDs (Note: The National Task Group on Intellectual Disabilities and Dementia Practices' [7] definition of intellectual disability was used in this article; this includes adults affected by dementia who have intellectual limitations that significantly limit the person's ability to successfully participate in normal day-to-day activities, such as self-care, communication, work, or going to school, and developed the intellectual limitation during the "developmental period" (before approximately the age of 22 years), and the limitation is anticipated to result in long-term adaptive or functional support needs and/or are eligible for state or federal public support programs because they have been diagnosed as having an intellectual disability and are affected by dementia and meet the criteria of having been diagnosed with possible, probable, or definitive dementia or have mild cognitive impairment, as defined by the World Health Organization's International Classification of Diseases or meet the diagnostic criteria of the American Psychiatric Association's Diagnostic and Statistical Manual. The Centers for Disease Control and Prevention [8] definition of developmental disabilities was also used; these are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. In most instances, dementia has an elevated risk to some people with intellectual disability while risk among adults with developmental disabilities is generally not documented or at norm with the general population. In this article, although we include both consideration of intellectual and developmental disabilities, most of the dementia-related research literature concerns adults with intellectual disability.), and dementia and IDD were identified and invited to become part of the working group. Each was asked to submit a background review and synopsis of his or her key research or policy publications related to the three key issues noted above. These were then synthesized, by core members of the working group, into a draft document that was then passed around to the working group members for further input and comment. A meeting of the group was then held at the Alzheimer's Association in Chicago, Illinois,

(with members attending both in person and telephonically) to further discuss the draft document and gain consensus. Following the meeting, a revised draft was circulated for comment and for input into forming a series of draft recommendations. This version then was updated and recirculated for further comment and consensus. Following receipt of comments, a final report was assembled and with concurrence of the working group submitted to the organizers of the Research Summit.

3. Commentary on issues relevant to the Summit

3.1. Special considerations related to dementia among persons with intellectual disability

Dementia is a condition that has an inordinate impact on some adults with intellectual disability and their caregivers. In general, aging adults with IDDs face as many of the same age-related health issues as do other aging people [9]. However, differences are noted in that some conditions are chronic, affected by aging, and may compound caregiving challenges in older age. With dementia, the age of onset may be earlier and its initial symptom presentation may differ from that of the general population, particularly among adults with Down syndrome (one form of ID). Although among adults with ID in general, the risk for dementia is not abnormal, it is generally recognized that having Down syndrome is a significant risk factor for Alzheimer's disease. One systematic review over an 11-year span verified a higher prevalence of dementia in persons with Down syndrome. Prevalence was 9% in those under 49 years, 5.7%–10.3% for 40–49 years, 30.4%–40% for 50–59 years, and 41.7%–50% for 60–70 years [10]. Research also has revealed that the average age of onset is in the early 50s among persons with Down syndrome, and the average age among other forms of ID is more consistent with that of the general population [11,12]. The combination of earlier onset among adults with Down syndrome and diagnostic overshadowing masking early symptom presentation poses a unique challenge for caregivers. Furthermore, these unique aspects, coupled with lower life expectancy, result in many older adults with Down syndrome continuing to reside with kin and thus leading to primary caregivers having to face new, and often more challenging, demands in caregiving.

Underrecognition of mild cognitive impairment or dementia is an issue in the ID field and may delay timely interventions that may aid in caregiving. For all adults with ID, the exhibition of early symptoms of dementia is often not easily identifiable by caregivers due to symptom masking by lifelong neurocognitive deficits. One study of over 200 aging adults with ID found functional decline, such as changes in independence with daily living skills, was a common early symptom often missed by caregivers and clinicians [13]. Barriers to early clinical diagnosis, differing symptom presentation, lack of appropriate screening tools, and concerns over accuracy of informant reporting may result in later diagnoses [14]. Early diagnosis is essential to ensure timely interventions, such as medication for symptom management, establishing advance care plans, and psychosocial interventions for both the adult and his or her caregiver. The masking of features of onset of dementia and dearth of diagnosticians experienced with differentiating dementia from ID is a primary barrier to timely diagnosis among some persons with ID, particularly in nonurban areas. The working group noted that research would be beneficial to examine these factors and empirically determine what role variations in geographic resources availability play.

To address these barriers and increase timely and accurate diagnosis, there is a need for increased diagnostic competency among diagnosticians, more public awareness in general, and accessible information designed to raise the "index of suspicion" for caregivers. One barrier to early detection is the lack of inclusion of specialty tools in recently issued guidelines that can be useful in assessment [15,16]. Within the field of ID, researchers have developed and tested specialized instruments to aid in the identification of dementia symptoms in people with ID [17,18]. Although research has shown promising results for screening in general, the level of adoption of specific screening efforts of persons with ID warrants greater focus on utility and usage. The NTG's early detection and dementia screening administrative instrument (the NTG-Early Detection and Screening for Dementia) has been adopted by many agencies and jurisdictions for use by paid staff and family caregivers [19]. As caregivers and family members are often the first to notice a change in behavior [20], increases in public awareness regarding prevalence and early symptomology may increase referrals for early screenings. The working group noted that increased training for clinicians and widespread dissemination of information about instruments developed specifically applicable for people with ID is warranted and would aid in determining earlier diagnoses.

Dementia-related caregiving in this group poses idiosyncratic challenges and manifests special demands, as caregivers need to be more alert to subtle changes in function due to the presence of lifelong impairment and confront the need to transition from routine care—on the presence of an ID—to specialty care and adapt to stage-related changes when dementia becomes evident. Further research is needed to address issues related to underrecognition, adaptation to special challenges, noninclusion in mainstream dementia caregiving studies, and the impact of exclusionary criteria that deny participation of adults with Down syndrome in general dementia studies.

3.2. Similarities and differences in needs and supports for ID-related caregiving

Although people with IDDs and their caregivers have needs for dementia care supports in line with those of other

adults with dementia and their caregivers, there are also some unique and contrasting aspects. These aspects include differences among the adults in the trajectory of dementia (often with earlier onset of dementia), a shorter duration of dementia, and diagnostic difficulties given lifelong neurocognitive limitations [10]. Furthermore, some adults with IDDs require lifelong services and supports, including family caregiving or supported living outside the family home. Based on 2015 data, an estimated 71% of all individuals with IDDs live with their family caregiver; of these 24% reside with caregivers aged 60 years and older [21]. Research has examined the nature of extended and specialized lifelong 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 IDDs begin to experience dementia and its progression. Another contrasting feature is that in many instances, other kin—primarily siblings—play a significant supportive role for adults with IDDs when their parents are no longer able to provide care [22].

Lifelong caregivers often have different experiences from later-life caregivers with respect to adaptation, ascendance to caregiver roles, and with mobilizing and drawing on networks of support. Also, many of these caregivers are also more readily able to access public support for extended caregiving and receive assistance with respite, especially when the adults with IDDs are eligible for disability-related state funded services or are already enrolled in community day programs or home-based support services. As many formal providers and governmental agencies exist to aid people with IDDs, educational and support resources generally are available to help orient caregivers to age-related caregiving [23], including raising awareness of the symptoms of dementia, and being oriented to care practices tailored to caring at home for someone with dementia [24].

Another critical distinction among caregivers of adults with IDDs is that they are often "career" caregivers, with extensive experience of providing supports and adapting to the daily "ups and downs" resulting from extended caregiving. Many caregivers also have extensive experience with public, social, and health care services stemming from advocating for their relative with IDDs at various life stages. With the onset of dementia, many of these caregivers do adapt to new challenges and bring to the fore their experience and capacity for continued caregiving; but not in all instances, particularly, if the caregivers are themselves aging, the dementia-related functional and behavioral changes are physically challenging, or when the dementia compounds the existing restrictions in function due to the severity of the IDD.

Notwithstanding these notable differences, there are still many similarities in caregiving aspects to other caregivers. Like other caregivers, caregivers of adults with IDDs and dementia have to cope with changing behavior and associated declines, have to seek out information and resources to help with sustaining caregiving, must obtain help with diagnostics and advice on interventions, contend with financial and residential care planning, and seek counsel in dealing with advanced dementia and end-of-life care. Given these similarities, the working group noted that this extensive literature on "career" caregivers can be of benefit to increasing the capacity of understanding and sustaining caregiving among late-life conditions, such as dementia.

3.3. Findings from aging and IDD research on family caregiving interventions

Family caregivers of older adults and adults with IDDs (including dementia) face many challenges including stress, depression, poor health, and financial hardship (Although some relevant studies from the general comparative caregiving literature were included in the Report, the working group did not undertake an extensive review of the dementia-related family caregiving literature as that was not within the remit of this group.). However, research on the long-term impact of caregiving on caregivers of individuals with IDDs is mixed depending on the characteristics of the adult with a disability, the health of the caregiver, life events, the context of care, and the informal and formal supports available [25]. Research is now emerging that can enable a better understanding of the dynamics of caregiving on families and how they are managing the new challenges presented by dementia [26]. Studies have shown that available programs and services are useful in helping families cope with these challenges; however, these usually focus on either caregivers for older adults or caregivers for adults with IDDs, but not both. The working group noted that there is a dearth of comparative studies on caregiving by conditions, and this detracts from the broader generalizability of findings.

In a scoping review of nearly 70 empirical intervention studies examining 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, Heller, Gibbons, and Fisher [27] found several important differences between these two fields. One key difference revealed by the study is that there was a difference in semantics (i.e., 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, whereas family support programs were often directed to the entire family. The study showed that for both groups, most support programs fell into one of two broad categories: government programs and small-group psychosocial interventions. Government programs tended to focus on care coordination and support services or financial and home supports (examples included case management

programs, respite care, consumer-directed services, and in-home medical supports). The psychosocial programs tended to focus on either support and counseling or education and training for caregivers (examples of these interventions included future planning programs, support groups, disease-specific education, and counseling sessions, among others). Research has demonstrated benefits for those who participated in either type of support program. Government care coordination and respite programs gave caregivers more access to services and increased satisfaction with the caregiving role, whereas psychosocial support programs improved participants' mental health and reduced perceived "caregiver burden." 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. Understudied in both fields were examinations of the financial impact of such programs or the costs of family supports.

With respect to cross-over dialog between the fields of aging and IDDs, the literature was sparse. Only a few articles in the family support literature recognized the intersection of aging and IDDs, and no articles in the caregiving literature included people aging with lifelong disabilities, such as IDDs [27]. This is an important gap to bridge for both groups [28]. The IDD family support literature, while not as developed as the aging research literature, gives a greater emphasis to future planning, self-direction, and person-centered planning. These types of interventions were assumed to be useful to older adults and their caregivers, as they were found to empower the person receiving care and often had positive impact on the caregivers as well. In addition, 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. Generally, the working group observed that although 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 disability and/or experiencing new impairments or significant comorbidities, collaboration among the aging, dementia care, and IDD sectors will be increasingly important to both caregiver sustenance and direct support for persons with IDDs affected by dementia, and system-based program development and research. Researchers examining family support interventions for people with IDDs could incorporate ideas from the aging and dementia care literature, with its broader history and variety of well-researched interventions. Conversely, researchers developing programs in caregiving for aging individuals could incorporate concepts from the field of IDDs on person-centered planning for families and broaden their focus to include both negative and positive aspects in caring long term for a family member with a disability.

A further consideration is that research dedicated to understanding the course of dementia and the impact of caregiving has in large part excluded (or not actively included) people with IDDs in their samples. A position of the working group is that inclusion of people with IDDs, and their caregivers into relevant research will increase the breadth and applicability of studies and produce generalizable value as well as promote full community inclusion. In a similar vein, the working group noted that a concentrated effort by community organizations that provide education and services to older adults and their caregivers to reach out to people with IDDs and dementia will broaden the research base and contribute positively to new program development.

3.4. Residential services and supports

Out-of-home residential care is evolving in the general dementia care field, where reliance on institutional admission (primarily skilled nursing care) is deferring to alternative care models, such as residential memory centers, Alzheimer's care centers, and assisted living. One community housing model extant in both dementia services [29] (but to a lesser degree) and in those for persons with IDDs (to a higher degree) is the use of small group homes [30], which in the IDD system are generally publicly funded. Although the research literature on the application of this model in the general public is sparse, there is a significant amount of it with application to adults with IDDs. In the IDD field, this model offers an option for alternative care in the community for persons with IDDs affected by dementia, who otherwise may be forced to seek institutional admission, and its financial underwriting is generally part of the IDD long-term care system in each state. As research shows that most adults in such homes for dementia care often transition from regular group homes or from living with their family and may remain in the dementia homes for up to 10 years [31], this would call for greater investment in research on community dementia-capable care and the identification of best practice applications geared to stage-related functional decline.

Research that compared dementia special care units to group homes 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) [32]. In addition, costs of care are more economical in group homes [31,32]. 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—all values associated with promotion of quality care in dementia [33]. The use of neighborhood-based group homes can benefit most persons affected by dementia; however, one consideration is financial, as there is generally no dedicated public financing available for such specialty homes for the general population. Within the IDD system, although dedicated funding is available, one complaint is that government oversight agencies generally do not increase the reimbursement or contract rates for the group home care provision of people when they become affected by dementia, even when their decline requires more staff-intensive care. With a projected increase in the number of older adults with IDDs affected by dementia, this is an issue that warrants further policy research and examination.

The IDD research also suggests that care requirement issues arising during early-stage dementia are not as problematic from a care management perspective, but that staff involvement and staff time requirements become more important issues in the mid-stage of dementia when ambulation remains, but losses of capability and the presence of behavioral and psychological symptoms of dementia become more significant care issues. The working group noted that understanding how the course of dementia may impact care and continued residence in a group home setting is important so that policy makers and providers can determine optimal admission policies and plan for how to best provide long-term supports to people and caregivers in these situations. The same question applies to other living settings, including examining the triggers that compromise continued family home–based care.

3.5. Population diversity and caregiving factors

People with IDDs and dementia and their caregivers are far from a homogeneous group, and this diversity impacts caregiving and service access. The provision of caregiving in older age for people with IDDs impacts 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 most adults with IDDs live at home with their families [21]. For racially, ethnically, and linguistically diverse groups, this may be even more common [34,35]. As a result, caregivers within such diverse 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, Latino mothers who are unable to care for their son or daughter at home experience high levels of depressive symptoms [35,36]. Culturally in the United States, the push is for greater autonomy and self-direction for maturing adults with IDDs, and this is generally the basis for many state supportive care policies. However, this may not fit with the cultural norms of certain groups or even be feasible for some members of these groups. The working group noted that there is a dearth of research exploring cultural perceptions of dementia among adults with IDDs and what norms exist for extended caregiving. This may lead to a misalignment between state services policies and meeting family caregiving needs in some groups.

Most studies that examine minority group caregivers have found poor health when compared with certain European-heritage caregivers [37-40]. This includes more chronic health conditions, limitations due to health complications, and lack of appropriate health care [40,41]. Part of the explanation for these findings may lie with the theory of *cumulative adversity* [42]. 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/language minority group families, the additional strain of providing lifelong care may be an add-on to hardships, such as deprivation/poverty, low education, and discrimination, creating a lifelong pattern that may contribute to poor outcomes.

Diversity in geography is also an important fact to consider, as caregivers of persons with IDDs living in a rural area may experience different supports, stressors, and care aid options [43] 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 [44]. Other findings in this area have generally showed that rural caregivers are more likely than those in urban areas to rely on informal supports [45,46]. Additional research is needed to discern whether these differences are based on cultural norms, economic status, or public policies resulting in a dearth of services in these areas. Also, research should be undertaken to examine issues faced by caregivers in linguistic isolation situations. Finally, research also should assess the impact of these differences on outcomes.

Families that 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 found differences that may exist for these groups. The working group noted that 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.

3.6. Bridging the service networks of aging and disability

Although many families and caregivers of people with IDDs 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* [47]. Despite many of the differences noted between the fields of aging and disability, the working group emphasized that adults with IDDs 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 [48]. Hence, in recognition of the importance of family and staff caregivers to community supports offered person with IDDs and dementia, one United States organization, the NTG, has drawn on both the aging and disability fields to develop practice guidelines [18,47,48] and a national training curriculum [49] (see http://aadmd.org/ntg/education-and-training) to enhance caregiving understanding of dementia and strategies for continued care of people with IDDs and dementia. In 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 the networks. One issue that particularly illustrates the need for collaboration across systems is a common situation for families of adults with IDDs, in which aging-related health issues arise for both the adult with IDDs and the family members providing support [50]. 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 caregiving responsibility is in addition to a significant lifelong caregiving role that has lasted for decades [51,52]. Perkins and Haley [51] found that 37% of aging caregivers (mean age 61 years) of coresiding adult offspring with IDDs were also a compound caregiver. Sixty-six percent reported they had been 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) often are not assessing the full range of caregiving needs for caregivers of adults with IDDs [53]. This is of concern, as compound caregivers reported spending an average of 52 hours per week undertaking their caregiving-related tasks [52]. As 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 IDDs, or state aging services for their compound caregiving recipient) to fully meet the combined needs.

Some areas of development and focused research 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 (1) responsive to overall caregiving needs irrespective of caregiver/care recipient age and (2) adaptable to changing caregiver status across the life span. For example, the National Family Caregivers Support Program [54] provides information and assistance, caregiver training, respite care, and caregiving-related supplies to adults caring for a family member aged 60 years or older or a family member of any age with dementia, as well as for grandparents aged 55 years and older caring for children with IDDs up the age of 18 years. The National Family Caregivers Support Program 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. The working group recommended that research examine the extent of IDD-related applications under the National Family Caregivers Support Program that are extant in each state.

The working group noted that more work is needed in bridging aging and disability services to help find solutions to this unique issue. Barriers to collaboration are many and include ideological differences that have notably hindered cross-network collaborations [55]. Professionals in the field of aging often 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 [56]. The working group recommended that efforts be undertaken to develop professional and organizational capacity to support persons aging with lifelong and early- and mid-onset disability with the supposition that these efforts could be enhanced through collaborations involving disability service providers and advocates that would foster bridge-building across aging and disability sectors [57–59].

4. Conclusions and recommendations

The workgroup examined a number of research gaps pertaining to older adults with IDDs with implications for the Research Summit's greater dementia care agenda. The key question was what was extant in the IDD literature related to caregiving, programs, and dementia that could be applied to a greater dementia care planning and research agenda. The workgroup found that although adults with IDDs face many of the same aging-related health issues that do adults without lifelong disability, they may develop neurocognitive complications, such as dementia, at an earlier age and that the early signs are more difficult to register, and that some of these adults have a shorter period of debilitation. This is particularly true for adults with some ID conditions, such as Down syndrome.

The workgroup also found that most adults with IDDs, including those with dementia, live with parents—many of

Table 1
Caregiving and intellectual and developmental disabilities (IDDs) 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 IDDs and dementia to capitalize on the strengths of both programs and promote inclusive practices.	
a) Include people with IDDs and their supporters in both generic aging and dementia studies	Administration on Community Living (ACL); National Institutes of Health (NIH); foundations
b) Document the cost of family support programs and how they benefit society and reduce overall cost of nonfamily care	ACL; NIH; foundations
c) Acknowledge positive aspects of caregiving	ACL; Area Agencies on Aging (AAA); national provider groups and associations
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 IDDs 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 IDDs	ACL; Assistant Secretary for Planning and Evaluation (ASPE)
b) Develop and test models of residential supports that are dementia capable for both adults with IDDs 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 IDDs	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
4. Increase early screening and public awareness of dementia and other aging-related issues in people with IDDs and their caregivers.	
a) Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDDs	CMS; Health Resources and Services Administration (HRSA); American Psychological Association; American Association on Intellectual and Developmental Disabilities; Geriatric Workforce Education Programs (GWEPs); National Task Group on Intellectual Disabilities and Dementia Practices
b) Help families and other persons who provide support recognize the signs of dementia in people with IDDs	ACL; GWEPS; AAA; SUAs; state developmental disabilities authorities
c) Adopt an early detection and screening instrument for persons with IDDs 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 IDDs and dementia	ACL; SUAs; state developmental disabilities authorities

whom provide lifelong caregiving. These caregivers are usually experienced with accessing long-term services and supports, including family supports and various models of residential supports (e.g., group homes, supported living); however, they may not always find that public services are adapted for dementia care. Despite their expertise and common concerns about end-of-life care, abuse and neglect, residential supports, health decline, financial supports, and uses of assistive technology, rarely are people (or their family caregivers) included in general studies of dementia care.

The working group noted the need to include people with IDDs in various mainstream dementia-related activities because some of them have an elevated risk for dementia; earlier onset and compounding impairments have a deleterious effect that can compromise living arrangements and the unique situations faced by their caregivers. Adults with IDDs, suspected of neurocognitive decline, are also excluded from mainstream assessment and diagnostic resources, generally available to other people affected by dementia. Some specialty instruments have been developed

for use with this group but have not yet been readily integrated into general use by mainstream clinical services. One organization, the NTG, has taken the leadership to make information on dementia and ID more readily available. It has developed various practice guidelines [18,47], a national training curriculum [49], and a dedicated screening and early detection instrument, useful to both IDD and aging fields.

Efforts to bridge the aging and disability service sectors, as exemplified by the Administration on Community Living's inclusion of IDDs in funding dementia care innovation projects, are expanding and warrant more extensive efforts by other federal agencies and national organizations. The rich literature on "career caregivers" and family support models in aging and IDDs can prove useful to general dementia care practices, and extensive research on general dementia caregiving can also inform practices in IDDs. The integration and exchange of information is highly warranted.

The workgroup recommended conducting comparative effectiveness research to study different integrative support models involving aging and IDD networks to provide quality continuous care; increasing research on community programming that supports people living with family caregivers, as well as those living in a variety of supported living and group settings; and including persons with IDDs and dementia and their families in general research on dementia care. The workgroup's specific recommendations to the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers are outlined in Table 1, along with potential implementers.

RESEARCH IN CONTEXT

1. Systematic review: Experts in caregiving, dementia, and IDD examined the current state of research, policy, and practice related to caregiving and supports.
2. Interpretation: Five major areas related to programs and caregiving were assessed: (1) family caregiving interventions; (2) supportive care settings; (3) effects of diversity; (4) screening and early detection; and (5) bridging service networks.
3. Future directions: The article recommends the following; conducting comparative effectiveness research; increasing research on community programming; and including persons with IDD and dementia and their families in research on dementia care.

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