

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.

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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,

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