State Strategic Plan

Alzheimer's Disease & Related Dementias in Iowa

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Message from the Director

Dear Iowans,

Communities statewide are affected by dementia in some way, and most people know someone whose life has been changed because of it. More than 60,000 Iowans have Alzheimer's disease or another type of dementia and over 70,000 unpaid caregivers provide support to them across the state.

With cases expected to keep rising, we must prepare to respond with new resources and strategies for caregiving, increase collaboration among organizations and emphasize building awareness and education around prevention and early diagnosis. This will make Iowa more dementia-capable at all levels.

I am honored to present Iowa's first Strategic Plan for Addressing Alzheimer's Disease and Related Dementias. The Strategic Plan was developed by stakeholders on the ADRD Coalition who shared their lived experiences with dementia. It proposes solutions and focuses on strategies that will help lessen physical, emotional and financial burdens that individuals and families endure through this disease.

The Strategic Plan upholds the Iowa Department of Health and Human Services' guiding principles: data driven, collaboration, communication, equity and integrity. This plan is a blueprint for giving hope, direction and support to anyone affected by dementia. I hope it will become a trusted document for all Iowans including caregivers, policymakers, direct care workers, educators, business owners and those living with the disease. We are stronger when we work together with a common goal, I invite you to join us.

Sincerely,

Kelly Garcia

KELLY GARCIA
Director,
Iowa Department of Health and Human Services

Introduction and Purpose

Alzheimer's disease is responsible for more deaths annually than breast cancer and prostate cancer combined.[1] As the sixth-leading cause of death in the United States, it is a growing concern in Iowa, one that will challenge the state's healthcare systems, community resources and individuals whose lives are impacted by the disease. A multifaceted approach with increased awareness, decreased stigma and improved local dementia-related infrastructure will help reduce the burden in Iowa.[2]

There are over 60,000 Iowans who have Alzheimer's disease or other dementias, and there are over 70,000 people who serve as informal, unpaid caregivers.[3] One in three people over the age of 80 have some form of dementia. Contrary to popular belief, over 70% of persons living with dementia (PLWD) remain in the community.[4] In Iowa, a large percentage live in rural areas away from bigger population centers and resources.[5] A third of PLWD live alone, and another 13% live with a spouse who also requires help with activities of daily living.[6] The burdens PLWD and their care partners feel are numerous, and this disease affects many aspects of communities, workforce, healthcare systems and public health agencies.

To address concerns, the Alzheimer's Disease and Related Dementias (ADRD) Program in the Iowa Department of Health and Human Services (Iowa HHS), in collaboration with a statewide coalition, has created a strategic plan with prioritized recommendations for addressing dementia-related issues in the state.

1 in 3 people

over age 80 have some form of dementia

This plan compiles the latest research, pertinent data and lived experiences from people across Iowa and provides recommendations that can be employed by a variety of decision makers, sectors and individuals.

The recommendations in this plan were developed with a coalition and represent a mix of short- and long-term options that will help create or expand dementia-related infrastructure. The recommendations focus broadly on education and awareness, fostering partnerships, creating policy, building competency and recording data to inform future decisions.

This plan considers recommendations provided by various existing documents focused on addressing dementia-related issues in Iowa. Several documents in the last 15 years list guidelines for state government action to address dementia. While some goals of past plans are achieved, this new plan aims to broaden its scope and reach compared to past plans. To do so, the recommendations appeal to government entities, communities, individuals, businesses, healthcare and more.

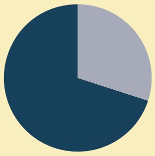
In addition to this strategic plan, the Iowa Department on Aging recently published the Iowa State Plan on Aging, Federal Fiscal Years 2022-2025. The Department on Aging's state plan was developed as required under Title III of the Older Americans Act of 1965. The Iowa State Plan on Aging includes goals, objectives and strategies that relate to and coordinate with some of this plan's recommendations. The Iowa State Plan on Aging can be found at: https://hhs.iowa.gov/media/14251/download?inline.

This ADRD plan is a living document. The ADRD Program intends to update the plan at least every three years to reflect advances in science, changes to prevention and healthcare practice, and new strengths and challenges that may arise. The plan would reflect the current needs of Iowans and assist in the state's response to a growing number of dementia cases.

A Deeper Dive into Alzheimer's Disease and Dementias

Dementias are a class of diseases that affect the brain and its ability to function. Of all types of dementia, Alzheimer's disease is the most common form. Alzheimer's is a progressive disease marked by the loss of brain cells in a part of the brain called the hippocampus (where memories are kept) leading to memory loss and cognitive decline.[7] The disease may start in the memory center up to 20 years before symptoms appear, but it often spreads to nearby centers eventually affecting the brain's ability to manage the functions that keep the body alive.[8] For this reason, Alzheimer's is considered universally fatal.[9] Alzheimer's disease and related dementias are not a normal part of the aging process. While their causes are not entirely known, research shows there are both modifiable and non-modifiable risk factors that can influence a person's likelihood of developing dementia.[10]

More than 70% of persons living with dementia remain in the community.



Age and family history of Alzheimer's are the two biggest indicators of a person's risk for developing dementia, but lifestyle choices play a part as well. These include diet, exercise, keeping the brain active, staying social, managing stress, getting enough sleep and managing coexisting chronic conditions like obesity and diabetes.[11]

While a majority of people affected are persons over age 65, Alzheimer's disease and other dementias can appear significantly earlier with the rarest of cases occurring in people in their 30s.[12] Younger-onset cases are when people develop the disease younger than age 65. While statistically uncommon, these represent massive challenges to care partners and to a health system that is used to older dementia patients. There are also other types of dementia including frontotemporal, vascular, primary progressive aphasia, pseudo-dementias, dementia with Lewy bodies and mixed dementias.[13]

Currently there are no treatments or cures for Alzheimer's disease, although there are a few medications that can treat symptoms for a period of time.[14]

BOLD Act, Healthy Brain Initiative

In an effort to bolster dementia-related public health infrastructure around the country, a new law was passed at the end of 2018 to provide grants and outline activities that states and territories could implement.[15]

The Building Our Largest Dementia Infrastructure for Alzheimer's Act (BOLD Act) was appropriated $20 million annually for four years to provide grant recipients the funds to increase early detection and diagnosis, promote risk reduction, prevent avoidable hospitalizations and support dementia caregiving. The Centers for Disease Control and Prevention (CDC) was tasked with creating three levels of participation in BOLD in addition to awarding funds and monitoring states' progress.[16]

In response, the CDC implemented a programming approach and structure that includes three Centers of Excellence with each center specializing in a different aspect of dementia care and support. The centers and their areas of expertise are:

- Dementia Caregiving – University of Minnesota
- Early Detection – New York University School of Medicine
- Risk Reduction – Alzheimer's Association

State involvement in the implementation of the BOLD Act was offered at two levels, Core and Enhanced, and was supported in varying funding levels between $250,000 and $500,000 annually for each of three years, 2020–2023. States were selected for these awards through a competitive funding opportunity (CDC-RFA-DP20-2004). The Core Capacity states were charged with convening state-wide coalitions, creating a strategic plan or updating existing strategic plans. Enhanced Program recipients were instructed to begin implementation of recommendations from their existing state plans.[17]

To facilitate this, the CDC's Healthy Brain Initiative and the nonprofit Alzheimer's Association created a guiding document for BOLD activities known as State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map (hereafter, 'Road Map'). The Road Map lays out four broad areas from which BOLD grantees can create or customize goals for their state or territory.[18] These areas include:

- Educate and Empower
- Assure a Competent Workforce
- Develop Policy and Mobilize Partnerships
- Monitor and Evaluate

In late 2020, Iowa was awarded a three-year cooperative agreement at the Core level, and Iowa HHS (previously known as the Iowa Department of Public Health) created the new ADRD Program in the Bureau of Chronic Disease Prevention and Management. This temporarily fulfills a common goal in past state-level dementia plans calling for the creation of a permanent dementia-specific position within state government.[19]

Process of Committee, Coalition

For the Core Capacity cooperative agreement, an Advisory Committee was formed to provide input to BOLD activities, assist with early strategic development and help with planning of messaging and awareness.

In addition to ADRD Program staff, representatives on the Advisory Committee include the Alzheimer's Association Iowa Chapter as well as the Iowa Department on

Aging, the Iowa Primary Care Association, the University of Iowa College of Public Health and the University of Iowa School of Social Work.

The Advisory Committee first convened in December 2020 and began meeting monthly after staff were hired in March 2021. The group provided suggestions and contacts to begin building the coalition. The goal was to assemble a statewide coalition of people who have varying connections to Alzheimer's, related dementias, older adults, aging, health systems and more. Program staff began meeting with each potential member individually in summer 2021 before assembling the initial coalition in the fall. Members were added through the strategic plan development process as additional areas of expertise were identified. As of summer 2022, the coalition engaged roughly 50 members.

Following the Healthy Brain Initiative's Road Map, early agendas of the coalition's meetings focused on one Road Map area per month until all four sections had been discussed. From there, the coalition divided into four work groups, each corresponding to a section of the Road Map:

- Educate and Empower
- Assure a Competent Workforce
- Develop Policy and Mobilize Partnerships
- Monitor and Evaluate

These work groups began meeting monthly in spring 2022 in addition to the monthly coalition meetings with the goal of outlining the eventual strategic plan.

As recommendations were created in each group, they were presented to the full coalition each month where discussion and further refinement took place. Progress was reported to the Advisory Committee who also reviewed the finished recommendations in late summer 2022.

Recommendations

The recommendations are broken down into four areas following the Healthy Brain Initiative's Road Map. It should be noted that while ADRD Coalition Work Group members provided a wide-range of valuable insights and feedback, what is included below reflects what Work Group members perceived to be the highest priority areas for future work.

Educate and Empower

Key to any endeavor related to Alzheimer's and other dementias is the ability and willingness to talk and care about this topic. Many individuals are not comfortable discussing Alzheimer's and other dementias, brain health or aging subjects with friends, family or with health care and other professionals. Efforts need to be made to combat stigma and educate individuals from a wide variety of backgrounds about ADRD and what prevention, diagnosis, treatment and caregiving resources are available to support them. Education and awareness efforts should include components that shed light on various forms of ADRD, caregiver burden, build family support networks and aim to decrease elder abuse. Some of this can be achieved through new partnerships and coordination, and others can be done through changes in existing projects.

Recommended Actions:

- **Normalize conversations about cognitive decline by frequently addressing stigma through education and awareness campaigns.** Messages should include clarification on types of dementia, younger-onset, normal aging and other causes of memory issues. Communication efforts should center on health equity and be delivered in plain language and helpful graphics.
- **Increase awareness messaging, education and sharing of resources** for persons living with dementias and their caregivers across the state, and in particular, with disparate populations known to be at increased risk.
- **Use a person-served and family together approach to reduce stigma** for ADRD. Include persons living with dementia and local champions. Include the lived experiences of persons in various communities, persons living with younger-onset dementia, persons living with disabilities and those who speak languages other than English.
- **Encourage stakeholders to use their networks to identify potential partners** in communities of all sizes and within disparate populations to increase the reach of ADRD messaging and educational efforts.
- **Reference dementia care and caregiver services by several names to combat cultural stigma,** and clearly include resources that allow persons living with dementia to access and find supportive care.
- **Implement a statewide No Wrong Door policy for dementia services** where callers can be directly linked to services and supports in real-time or a subsequent, timely referral is provided to the appropriate service.
- **Increase collaboration between older adult-related groups in Iowa who provide dementia resources,** including promoting the creation of an integrated and consistent marketing and communications plan between them to coordinate messaging topics, press releases, and distribution plans.
- **Create targeted, succinct messages for non-prescribing healthcare providers** and others who have patient interactions with information on dementia and cognitive decline, younger-onset dementia, community resources, prevention and ways to seek diagnosis.
- **Promote the expansion of elder abuse penalties in Iowa** and raise awareness of the sanctions placed on perpetrators of various elder abuse behaviors.

Assure a Competent Workforce

The landscape of dementia care is constantly changing, and as an understanding of these diseases improves, those responsible for providing care should have current knowledge of best practices, risk reduction and supportive services. Presently, regulations vary for which paid workers are required to have dementia training and what that training entails. Some workforce requirements are federally mandated, others come from the state, and for some positions in the workforce, there is no guidance or requirements.

In addition, the COVID-19 pandemic caused employment disruptions and exacerbated worker shortages and turnover in direct care fields. As the state began its rebound from this, some workers had completed care delivery and training requirements in one position, but upon losing their job or switching careers (even within similar sectors), they were often required to start from scratch on their dementia training. Certified Nursing Assistants (CNAs) have these requirements logged in the Direct Care Worker Registry, but for other care workers, the training information is kept in records at each facility.

Developing these recommendations, the Competent Workforce Work Group focused on ways to increase knowledge and skills without adding to existing requirements, with an emphasis on encouraging certification portability. The Work Group found that dementia training programs offered to care facilities and others are not standardized nor screened by the Iowa Department of Inspections and Appeals.

One way to establish common baseline training is the creation of a new program that could be updated regularly and include an Iowa-specific component. Other discussion topics included who should be encouraged to receive training outside of professional requirements and how to address worker shortages in the long-term.

Recommended Actions:

- **Require dementia training for any direct care worker or support professional who regularly interacts with persons living with dementia (PLWD).** Encourage training for anyone who interacts with PLWD regardless of setting or population served.
- **Create a standardized core dementia training** and promote the use of this training for new and continuing education anywhere dementia training is required or recommended. This core training should be updated annually with the latest research and best practices. Additionally this training should provide web links and citations to more advanced, elective or sector-specific trainings that are available to anyone.
- **Expand the existing Iowa Department of Inspections and Appeals' Direct Care Worker Registry to include home-based, assisted living and community-based workers** and ensure the registry reflects whether those professionals are up-to-date in each of their respective dementia training requirements.
- **Update training standards to support portability of a worker's existing dementia training** accomplishments when they move to a new place of employment with different dementia training requirements unless the new position requires training on disease-related job-specific skills. Workers would be held to continuing education requirements going forward rather than restarting training.
- **Educate physicians on the latest recommendations regarding cognitive screening practices and tools,** Current Procedural Terminology (CPT) billing codes for dementia care, risk reduction, existing local dementia resources and how to use them via physicians' networks, associations, newsletters and grand rounds.
- **Work with medical schools, nursing schools and other related health professional training** programs to include dementia-related training in their curricula covering risk reduction, types of dementia, strain felt by informal care partners, disease burden on healthcare systems and options for treatment and support.

Develop Policy and Mobilize Partnerships

A recommendation which has the longest-lasting impact is ensuring an ADRD state government position beyond 2023. Nearly every past strategic plan on dementia emphasized the importance of having an ADRD-specific position within state public health.[20] The awarding of BOLD Act funds has temporarily fulfilled that, but in order to implement some of the steps in this plan and to keep Iowa in a strong position to face rising Alzheimer's numbers, a permanent position should be supported within Iowa HHS and regular review and updating of the strategic plan must continue into the future.

Another valuable addition to the state's system would be adding dementia care specialists (DCS) to the Area Agencies on Aging (AAAs) throughout Iowa. This follows the successful pilot program in Wisconsin, a full integration of such specialists where there is now one DCS for every two counties.[21] Other states are implementing this model to great success and community impact. Given Iowa's rurality, teaming up with the six AAAs would be an efficient use of resources while retaining broad geographic coverage. These specialists would be in regular contact with dementia care services in their areas, and conducting screenings could help detect cases early and save on healthcare costs over time.

Creating, fostering and strengthening partnerships is a crucial component of making sure similar interests across the state and in various sectors that work with dementia-related issues and services are communicating and collaborating efficiently. A common complaint among these organizations is feeling like everything operates in a silo; impassioned stakeholders are often unaware of similar work being done around them. This almost guarantees that progress is slowed toward a more efficient statewide network of resources.

Recommended Actions:

- **Station one dementia care specialist at each of the six Area Agencies on Aging in Iowa** who can provide screenings and referrals to local and state resources.
- **Encourage health systems to make use of the CPT billing code** for dementia care planning (99490) and to engage with local at-home caregivers and care partners regarding resources, risk assessment and prevention efforts.
- **Require a review and update of this strategic plan** by a coalition convened by the ADRD Program at least every three years. Publish and distribute yearly progress updates on plan implementation.
- **Identify, increase support and raise awareness for networks, providers, systems and agencies** equipped to carry out dementia-related services for underserved populations.
- **Convene decision-makers, care providers, health systems, physicians etc. for a capacity-building summit** relating to aging and dementia. Topics could include future preparedness for ADRD, reviewing and updating existing dementia-related systems and increasing interdisciplinary collaboration.
- **Focus on building partnerships for informal, at-home caregivers** and care partners with resources in their communities through use of passionate and trusted sources of local information.
- **Increase funding, training and awareness of Adult Day programs and respite care** services in areas that lack these resources in order to decrease caregiver and care partner burden, burnout, preventable hospitalizations and higher healthcare costs.

Monitor and Evaluate

One of the foundational capabilities of public health infrastructure is assessment and surveillance, including the ability to monitor burden, disease incidence and mortality that results. This plan recognizes the importance of tracking the status of Alzheimer's disease and dementias across the state and helping to ensure an adequate response.

Data on Alzheimer's disease and dementias can be difficult to obtain due to multiple barriers, including limited financial and human resources, an inadequate assessment of the full public health burden of ADRD on Iowans and reluctance on families to seek a diagnosis due to stigma.

Data can also be impacted by an unwillingness to talk about care partner burden and the difficulties felt by informal caregivers. Another complicating factor is a past lack of clarity on the differences between Alzheimer's, dementia, subjective cognitive decline and normal aging.

Combined with the efforts of the Educate and Empower section, greater awareness and data collection will lead to a broader understanding of the challenges facing Iowans.

A section of Iowa Code (135.171) was enacted in 2008 to address some of these concerns, but to date no funding has been appropriated to support its implementation. The decade and a half since its enactment coincided with a period when deaths from Alzheimer's have doubled, owing in part to a large population of the Baby Boomer Generation entering a period of higher risk for the disease after turning 65.[22] While data collection during those years would have been valuable, there is still a need to identify gaps in access to resources and regularly collect information that can guide future efforts toward addressing these crucial needs.

Iowa HHS and the Alzheimer's Association have partnered during the past few years to assure the inclusion of question modules on cognitive decline and caregiving on a rotational basis in the state's annual Behavioral Risk Factor Surveillance System (BRFSS) survey. The state has access to data from the annual surveys beginning in 2019. This self-reported information from a broad base of Iowans helps define where gaps currently exist and the extent of the cognitive decline and caregiving burdens over time. This data can be used to capture trends and inform future programmatic and policy decisions.

Recommended Actions:

- **Alternate inclusion of the Cognitive Decline and Caregiver Modules into the yearly Behavioral Risk Factor Surveillance System (BRFSS),** and include state-specific dementia-related questions as the need arises.
- **Monitor trends in Alzheimer's disease, dementias and cognitive decline at the population as well as sub-population levels** to ensure health equity data is available and utilized by ADRD-related stakeholders. Use data collection tools and practices that are inclusive and responsive to assure that data is reflective of all persons living in the state regardless of education level, income, urban or rural status and languages used for communications.
- **Provide a yearly update on strategic plan implementation efforts** and BRFSS module data and include a section on these topics in future strategic plans.
- **Prepare and disseminate informational briefs on the status of Alzheimer's disease, dementias and cognitive decline in Iowa.** Use current burden data to identify populations at increased disease risk, experiencing higher than expected incidence and related mortality in presentations for the public, professionals and decision makers.
- **Identify trusted sources of information and routes of dissemination in underserved populations** and create a dialogue to assist community efforts and form partnerships to increase understanding of those communities' needs.
- **Secure funding to support the data collection requirements** already written into the Iowa Code (135.171) to provide age and county information on Alzheimer's service utilization, availability of caregiver services and future service level needs.
- **Create a publicly-accessible and easy to use online dashboard to highlight statewide Alzheimer's disease,** dementia and cognitive decline incidence, prevalence and county-level trends, or explore adding ADRD information to existing dashboards.
- **Support national data collection on dementia** and caregiving by making data publicly available.
- **Use existing data gleaned to inform public health programming** and policy responses across the ADRD continuum.
- **Embed evaluation into training and caregiving support programs** to determine program accessibility, effectiveness, impact and emerging challenges.
- **Estimate the gap between workforce capacity and anticipated demand for services** to support people with dementia and their care partners.

Priorities

Dementias are complex, often long-term, progressive diseases that interact with communities in a myriad of ways, and they will require a multifaceted approach both in the near-term and in the future. The recommendations put forth in this document are a mix of short-, medium- and long-term activities and initiatives. Regardless of timeframes for implementation, the goal is to improve the quality of life for PLWD and their care partners as well as decrease healthcare and other costs.

While each of the recommendations included in this strategic plan are important, the coalition prioritized several key recommendations that underpin the future success of plan implementation.

First, the work of the ADRD Program within the Iowa HHS public health infrastructure needs to continue and should be supported with resources for implementation of this and subsequent strategic plans. While the initial BOLD Act funding provided an excellent foundation for this, additional mechanisms need to be identified in the event BOLD or other funding is no longer available.

Every one of Iowa's past dementia plans has included this as a recommendation, citing the importance of having a designated position within public health that shows the state's support for Iowans affected by these diseases. Additionally, the prioritized, regular review and update of the strategic plan will help assure its capacity to reflect the needs and interventions that will result in impactful outcomes for Iowans. Using the momentum already generated by this process and other actions of the new ADRD Program, more interventions can be developed and put into practice through partnerships within the existing Coalition and Work Groups.

As Iowans age, more people will be seeking resources that either do not yet exist or are not easily compiled in one location. A state-level ADRD Program within the public health infrastructure emphasizes the necessity to address Alzheimer's disease and dementias and serves as a trusted convener of a wide range of partners.

Second, the goals of reducing stigma and normalizing conversation about ADRD suggested here need to serve as an ongoing foundation to all efforts moving forward.

Without greater willingness to talk about aging and the brain, Iowans with cognitive decline may remain undiagnosed and lose opportunities for prevention and treatment as well as access to appropriate healthcare and other services and supports. Iowans need to hear a wide variety of voices supporting needed change and feeling driven to champion the fight against ADRD.

Advances have been made in normalizing conversations around topics like breast cancer, prostate cancer and HIV, leading to greater public awareness and support for those fighting these conditions. Alzheimer's and other dementias are due for that same level of acceptance and support, but that change only begins when people are no longer afraid to talk about these conditions and drive away stigma.

Third, physicians must play a key role in prevention, early detection and disease management.

Dementia care specialists may not be accessible in every location in Iowa, but most Iowans have access to a healthcare provider. As a result, physicians and other care providers must serve as one of the early lines of defense against these diseases, armed with the tools to assess, diagnose and manage these increasingly common conditions routinely.

They must be encouraged to discuss memory concerns with their patients, be knowledgeable about how community resources work and refer persons to them. They should be aware of the CPT billing codes for dementia care management services, much like they already do with other chronic conditions like diabetes management.

This issue is focused on primary care physicians, small clinics and local hospitals. Using their existing reach, more Iowans will be receiving early, informed care that is crucial to later outcomes in a progressive, incurable disease.

Finally, greater understanding and collaboration are needed regarding the disparities that exist in underserved, disparate populations in Iowa.

People have varying levels of risk for developing Alzheimer's disease based upon a variety of factors, including demographics, and some population groups often lack access to healthcare, dementia care and related resources. Coupled with a variety of other social determinants of health, unfortunately the most at-risk portions of Iowa's population are often the least supported.[23]

Black Iowans are twice as likely, and Hispanic Iowans are 1.5 times more likely to get Alzheimer's than White Iowans, but historically these communities have not been well-served by health care systems and public health messaging.[24] As a result, cases of dementia in these populations are usually caught later in the disease process leading to higher healthcare costs for the PLWD and a heavier toll on care partners.[25]

Partnerships with these communities must be fostered and expanded where they already exist, especially as the other recommended changes begin to take effect and influence statewide dementia infrastructure. The Iowa HHS ADRD Program has begun to learn more about the needs of Iowa's populations who are at greater risk for developing Alzheimer's disease and dementias and will continue to use that understanding to focus its messaging and programming.

Emphasizing actions like these as well as implementing the actions outlined in this plan will not only improve quality of life statewide but can also save financial resources in the state's fight against our nation's costliest disease. Alzheimer's disease and related dementias affect nearly every community in every one of Iowa's 99 counties. For most people, it is not a matter of "if" but "when" they will have some connection to these diseases, either as a family member or a friend. Everyone ages, therefore everyone is at risk. Through Coalition members' combined experience, the recommendations in this document give the state actionable ways to prepare for, combat and manage Alzheimer's disease and related dementias.

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