

# Persons Living with Dementia in the Criminal Legal System

American Bar Association

Commission on Law and Aging

in collaboration with

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## Comments from the Director:

Thank you to the research team and nearly 400 respondents that made this project possible, and the RRF Foundation for funding. Thanks, you to the respondents who completed surveys and participated in interviews, giving generously of their time. We couldn't have completed this project without them. The research team gave their time and expertise generously to this project that lasted months longer than anticipated and filled many more hours than any of us imagined. We found a way around the roadblocks, changed directions, and found common ground in the data and information on this important issue.

We especially thank the RRF Foundation for Aging for their financial support and encouragement on this project. Without outside support, projects like this would not be possible.

The terms of the consent to participate in the surveys and interviews as approved by the Institutional Review Board (IRB) at the University of Virginia, and corresponding IRBs, limited access to the original data to members of the IRB approved research team. This assured privacy and confidentiality to those who agreed to share their experiences. The assurance of privacy and confidentiality allowed participants to say things that they might not otherwise be comfortable saying. Most of the participants are still employed in the criminal legal system. The information that appears here has been de-identified. We have included references to publicly available resources that were identified in the interviews and surveys.

The sections of this report were written by several members of the research team. The reader will notice differences in style and word usage from one section to another. Rather than risk changing the intended meaning of the author, as editor I have chosen to leave those differences in place, editing only for typos or clarity and not for differences in style or terminology.

Lastly, I say thanks to Charlie Sabatino who spearheaded the ABA Commission on Law and Aging's role in this project, secured funding from the RRF Foundation, and wrote a huge section of this report after his refocus, as he calls it – aka retirement. We know you will never stop advocating for a better life for us as we age.

David Godfrey, JD, Director ABA Commission on Law and Aging

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## Executive Summary

Currently an estimated 6.2 million Americans age 65 and older have dementia, and, parallel to the trend of aging Americans, the number with dementia is predicted to increase to 12.7 million by 2050. As the US population ages and rates of dementia increase, the prevalence of dementia among those involved in the criminal legal system can also be expected to increase. Indeed, these demographic trends as well as a substantial increase in average sentence length over the past 25 years have had a marked effect on the age of the prison population: the number of state prisoners age 55 and older has increased by 400% from 1993 to 2013, and it is predicted that by 2030, this age group will account for one-third of the US prison population. Unfortunately, a lack of data and information on justice-involved adults with dementia significantly impairs our ability to set a policy agenda that addresses the unique needs of this population across the justice intercept points. To help fill the gap, this mixed-method, cross-collaborative research effort collected survey data and conducted interviews with a variety of correctional health and legal field stakeholders to learn about their experiences working or interacting with people with dementia in the criminal legal system.

### Action Steps

- Building on the neuro-developmental jurisprudence that has reshaped juvenile justice in the 21<sup>st</sup> century, laws and practices governing administration of criminal justice should be revised to take account of the degeneration of brain function that occurs later in life, including its effect on culpability, in decisions about diversion, sentencing and placement.
- End the pointless practice of committing people with dementia for restoration of competence after they have been adjudicated incompetent to stand trial,<sup>1</sup> and develop alternative strategies for protecting the defendant and the public.
- Create new care placements within the civil or criminal systems, as appropriate, for people with dementia who are considered “high risk.”
- When consistent with public safety, transfer people with dementia out of the traditional correctional system.
- Provide system-wide training for participants in the criminal system on the impact of dementia on a person, and how to respond to unexpected behaviors.

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<sup>1</sup> “Incompetent” is the term most commonly used in criminal law and procedure when a person is found mentally unable to assist counsel in their defense. Some states use unable to assist counsel, or unable to stand trial.

## Report Summary

This project looked at unique issues for individuals with neurocognitive disorders—specifically those commonly referred to as dementias. The project team examined data from five sources— a review of case law, a survey of peer reviewed publications, online surveys of relevant professionals, individual interviews, and a review of statistical data from South Carolina comparing the state dementia registry with correctional records. A core finding that emerges is that training is needed for law enforcement and other community-based frontline first responders, providers, lawyers, judges, and correctional staff on the ways that thought processes and behaviors change as individuals begin to experience more significant dementia. In many criminal legal systems, dementia is included within the general term ‘mental illness’, resulting in commitment to mental hospitals for hopeless attempts at restoration of capacity (especially competence to stand trial). Traditional correctional facilities are dangerous and inappropriate for a person with dementia, and placement options for people with dementia and a history of violence are nearly impossible to find in most communities.

There is widespread agreement that correctional systems are by and large unprepared or unable to provide a safe and caring environment for people living with neurocognitive conditions. The typical correctional setting relies on a person understanding, remembering, and learning rules and tasks that are difficult or impossible for a person with dementia. People with dementia in a correctional system are often placed in special housing: either as punishment for behavioral dysregulation, or in an effort to increase security and protection of vulnerable populations. Those settings often result in isolation that may worsen an individual’s condition— though there is a need for research in this area as well. There are some innovative efforts to train companion caregivers for people with dementia in the correctional system. These efforts merit study— but at best, the person is in a correctional environment that is designed more for security than for therapeutic well-being.

People living with dementia become involved in the criminal legal system either as new arrestees, or as people who experience cognitive decline while in the correctional system. Data is limited on the number of people aging into dementia in the correctional system and the number of people entering the criminal legal system with existing dementia. The South Carolina data indicates that many more people are aging in correctional environments than are entering new into these systems, but it is important to attend to both groups.

The criminal legal system is ill equipped to respond effectively and humanely to people with dementia who commit crimes. While there are pioneering efforts at training and community-based diversion from the criminal legal system, many frontline responders are not trained to recognize that people with dementia have cognitive and neuropsychiatric deficits that impair their ability to form intent or change their behavior. Those that are arrested need defense attorneys that recognize the impact of neurocognitive decline on a person’s ability to form intent, to control behavior and to make choices. As one respondent put it, “You have to be naked and baying at the moon in order for most lawyers to recognize that they have a mental health problem before

them.” Training is needed on how to recognize and understand dementia: from the frontline, to the court room, to corrections.

Neurocognitive decline and conditions do not fit the legal model for mental illness in that there are no effective cures, treatments or therapies to restore fading capacities. This creates a challenge in pre-trial determinations of fitness to stand trial. It also creates challenges in correctional health care, which often has resources to care for physical or mental illness, but not for long-term cognitive decline.

The standard procedure in many Courts when a defendant is found unable to stand trial is a commitment to a mental hospital for “restoration of competence to stand trial.” Restoration is impossible for a person with a progressive dementia whose deficits are the cause of the finding of incompetence. We have heard repeatedly about the vicious cycle: being found unable to stand trial, being committed to a mental hospital for restoration, unsuccessful restoration resulting in being sent back before the judge, then often yet again being sent back to a psychiatric hospital (not designed to treat dementia) for further treatment, until it is finally decided it won’t help. New laws and standards of practice are desperately needed to break this cycle. Although solutions would require careful development and funding, a diagnosis of dementia should result in placement in an appropriate care setting and may require a new form of civil commitment where necessary to assure safety. Some mental health laws exclude dementia as a qualifying condition for civil commitment and may leave few options for proper placement after a criminal arrest. This can be especially problematic when the underlying offenses are violent in nature. Professionals who assess capacity lack data on recidivism and other risks for people with dementia, but the answer is likely dependent on the environment the person is released to, with a need for care in a safe and controlled environment being paramount.

It is often impossible to find memory care, skilled nursing care, or Alzheimer’s care for a person with dementia and a history of violent or sexual acts even without a prior conviction. Most community-based long term care providers refuse to admit and will discharge these patients. Even medical or compassionate parole or release programs, seeking placement of people who are very sick and very near the end of life, commented that unless there is a family member willing to become a caregiver, the person often dies before a placement can be found. A few innovative programs are developing specialized care settings for people who are considered “high risk.” Some care facilities are a part of correctional health care, others are community-based facilities focused on care for people who are otherwise hard to place. These models need to be studied, and where they are producing good results, potentially should be replicated.

With the completion of this report, we are just beginning the dissemination process. We believe the findings and recommendations need to be heard by law and policy makers, community advocates, law enforcement agencies, attorneys, judges, forensic mental health professionals, correctional services, correctional health officials, mental health agencies, and long-term care providers.

# Report

## I. Background

The Abstract created when this project was proposed, provides a meaningful background for framing the research and findings. The abstract reads:

Criminal Justice and the Policy and Practice Challenges of Dementia:  
A Research and Policy Development Initiative

For older persons, there has been no systematic effort to understand the impact of age-related brain changes in criminal prosecution or the corrections system. As our population ages and the prevalence of cognitive impairments among older persons increases, multiple issues related to the interface between persons with aging-related cognitive impairment (i.e., dementia) and the criminal justice system need to be addressed.

Dementia syndromes sometimes result in deviant or criminal behavior, leading to involvement with the criminal justice system, or dementia may result long after initial involvement during incarceration. This raises fundamental legal and moral challenges in ensuring fair punishment, protecting public safety, and delivering appropriate healthcare services to the incarcerated person. There is an acute need to develop an understanding of how the impact of dementia should be taken into account in both prosecution and corrections so that a framework for policy and practice can be established.

This project is examining the nature, frequency, and challenges faced by the criminal justice system in dealing with arrestees, defendants, and inmates with dementia. We hope to establish a framework to organize the key issues, solution options, and policy and practice recommendations. Key to this objective is identifying needed collaborations and resources that can work with law enforcement, the courts, and corrections facilities. From this framework, the project will explore policy, practice, education, and/or research recommendations related to screening and identification of dementia, diversion, prosecution, adjudication, sentencing, and management in correctional facilities, including compassionate release.

The research design has three components:

- I. Literature review, gap analysis, and key indicator development, led by Jennifer Bronson of the National Research Institute.
- II. An online survey and exploratory virtual focus groups and interviews with law enforcement/first responders, judges, prosecutors, defense attorneys, jail personnel, and correctional health care personnel and administrators.
- III. Consensus building for developing recommendations using the input of the focus groups organized around stakeholder groups and key issues.

The project will develop findings and recommendations regarding policy, practice, education, and/or research. The primary deliverable of the project will be a published White Paper with a set of findings and recommendations, along with the publishing of short summaries and commentaries on the report in a variety of mainstream neurology, gerontology, and psychiatry journals. However, the real impact of this kind of initiative is realized years beyond the project term, because the evolution and assimilation of policies and practices by organizations and professional groups is a multi-year process.

## II. Methods and Obstacles

The research process was shaped and reformed into a virtual format at the time of COVID-19. The research included a review of published literature, a review of reported case law, a review of statistical data from South Carolina that compared the state dementia registry with criminal arrest records, a survey with over 300 substantive responses, and interviews with 45 key respondents.

The case law review was done by the University of Virginia, with initial research by Kevin Bui, a law student, and reviewed by Professor Richard Bonnie and Sarah Leser, M.P.H., M.P.P.. This involved a search of all state and federal reported cases on issues of dementia in criminal appeals. There was a specific search for cases on ability to stand trial, on criminal responsibility including not guilty by reason of mental disease or defect, on ability to form intent, and on mitigation in sentencing or release based on diminished mental capacity.

A comprehensive literature review was done looking at peer reviewed publications by a research team that included Kristen Hellebust, M.D., Debra A. Pinals, M.D., from the University of Michigan Medical School and Jennifer Bronson from NRI. This has been revised and supplemented based on additional resources found through the surveys and interviews.

South Carolina was able to compare data in a statewide dementia database, with a statewide corrections database to reveal information about dementia and incarceration.

A survey was developed to collect a broad sample of responses, and to identify people interested in participating in interviews or focus groups. The survey data was made available to all research team members, the narrative data was 68 pages single spaced. It was sorted into categories and reviewed by research team members. The narrative report on the surveys was written by one team member.

The survey raised a couple of challenges. The original research plan relied on the general exemption of legal research from the requirement for an institutional research board review and approval. As we progressed, it became apparent that many of the respondents would not be legally trained, and some areas of inquiry could potentially reveal confidential or sensitive information or carry a risk of trauma for respondents. The University of Virginia asked for an IRB review and approval. The IRB process required specialized training for research team members, limited interaction with respondents, and limited access to all identifiable information (accessible only by researchers approved to be part of the IRB team). The application, training and approval for the IRB took several weeks.

We knew going into the project that gathering input from law enforcement is often difficult. Part of the original research team included a senior leader at a law enforcement trade organization who planned to disseminate the survey to the association members. For unclear reasons, the organization was unable to distribute the survey to law enforcement. Efforts to connect with other law enforcement groups failed and groups expressed that they were unable to

ask their members to participate in the survey; based on what we had heard before starting, we expected this response. The result was only a handful of responses from law enforcement on the surveys and interviews. We did collect a lot of secondary input on the role of law enforcement through the surveys and interviews.

Our model called for both individual interviews and focus groups. We found that in a virtual world, focus groups proved very difficult or impossible to put together. In the past, at conferences or with tightly affiliated groups of people, focus groups had worked well. The few virtual groups that we managed to arrange lacked a common sense of interest or commitment, and participants dropped off. On several occasions we scheduled a small group, and only one respondent participated. In the end, we decided to code the focus groups as interviews, separating out the participants where possible. Interview answers were coded by two or more research team members. The interview summary and narrative with selected quotes was compiled by one member of the team.

Why surveys and interviews? The surveys allowed us to gather input from over 300 respondents, a much larger number than we could have interviewed. The surveys also offered a greater level of anonymity, and allowed for narrative answers — some respondents were able to make comments that they would be unlikely to make in an interview or focus group. The interviews allowed the researchers to ask follow-up or probing questions—impossible in an online survey. Interviews prompted longer verbal answers than written surveys, often revealing more complex thoughts.

Reviewing the data from all sources, it was reassuring to see that the same issues and concerns appeared across multiple sources.

### III. Demographic Trends and Social Science Research

#### ***Abstract***

As the US population ages and rates of dementia increase, the prevalence of dementia among those involved in the criminal legal system can be expected to increase. However, a lack of data and information on justice-involved adults with dementia significantly impairs the field's ability to set a policy agenda that addresses the unique needs of this population across the justice intercept points. To help fill the gap, this mixed-method, cross-collaborative research effort collected survey data and conducted interviews with a variety of correctional health and legal field stakeholders to learn about their experiences working or interacting with people with dementia in the criminal legal system.

#### ***Introduction***

The American population is “graying” as the Baby Boomer generation ages. The US Census projects that by 2035, there will be more older adults than children for the first time (Census, 2018). In 2020, there were 56 million Americans age 65 and older, or about 1 in 6 people, and this number is expected to increase to 73 million (FIFARS, 2020). These demographic changes have led to corresponding increases in health conditions for which older age is a risk factor, such as dementia. Currently an estimated 6.2 million Americans age 65 and older have dementia, and, parallel to the trend of aging Americans, the number with dementia is predicted to increase to 12.7 million by 2050 (Alzheimer's Association, 2022 see <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>).

Dementia is a general term used to describe a person's cognitive decline and impaired ability to remember, think, make decisions, or care for themselves in a way that interferes with everyday activities (CDC, 2019). Although aging is a known risk factor for dementia and the prevalence of dementia is higher among older adults, it is important to note that dementia is not a natural part of aging (CDC, 2019). People younger than 65 can also develop dementia, although it is less common and the prevalence is unknown (Alzheimer's Association, 2020, <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>). The most common forms of dementia are Alzheimer's disease, frontotemporal dementia, vascular dementia, and Lewy body dementia (NIA, 2021). Dementia symptoms vary from person to person and by type of dementia, but typically include memory loss and confusion, poor judgment, difficulty communicating with and understanding others, wandering and getting lost in familiar places, mishandling of money and finances, impulsivity, aggression, hallucinating or experiencing paranoia or delusion, and repeating questions (NIA, 2021). As dementia progresses, an individual's ability to live independently and perform self-care tasks, such as feeding and dressing themselves, typically becomes impaired and they will require more medical and support services.

An overlooked group of people with dementia are those who are involved in the criminal legal system. This is an important subgroup, because the prison population is also aging. The

number of state prisoners age 55 and older has increased by 400% from 1993 to 2013, and it is predicted that by 2030, this age group will account for one-third of the US prison population (Carson and Sabol, 2016; Osbourne Association, 2018). The incarceration of people with dementia poses a unique set of legal, ethical, and healthcare-related questions that impact multiple social systems and demand attention. Common challenges associated with dementia in the general population, such as timely and accurate assessment and access to appropriate care, are often magnified and more complex for individuals in the criminal legal system.

Criminal justice involvement among people with dementia can be conceptualized with the sequential intercept model (SIM). Initially designed for people with mental illness, the SIM offers a framework to understand the different points at which a person can be diverted out of the justice system, or a point at which their involvement shifts and an opportunity for services can be established (see Figure 1 below) (Munetz and Griffin, 2006). Although dementia is not a mental illness, the SIM can guide the identification of intervention and solution points to better address justice-involved adults with dementia.

See Figure 1. The Sequential Intercept Model at <https://www.prainc.com/curesact-sim/>

### ***Prevalence of dementia among justice-involved adults***

The prevalence of dementia among people in prison and jail is largely unknown. In addition, there is virtually no data on the prevalence of dementia among people along other points in the justice system, from contact with law enforcement and arrests to probation and parole. These data gaps make it difficult to know the extent of the problem, including its scale, scope. It also makes it difficult to identify points for intervention or diversion to a more appropriate placement.

The lack of information is a barrier to providing recommendations and implementing programs and practices to improve the correctional care and treatment of individuals with dementia.

Prevalence data on dementia among people in prison and jail is challenging to collect and there is currently no evidence of a national survey that captures it (Cipriani et al., 2017; Moll, 2013). While the Bureau of Justice Statistics (BJS) periodically collects correctional health data through its national-level inmate surveys, dementia is not included. However, BJS does ask about having a cognitive disability, defined as serious difficulty concentrating, remembering, or making decisions because of a physical, mental or emotional problem. An estimated 20% of people in prison and 33.5% of those in jail age 50 or older reported a cognitive disability (Bronson, Maruschak, and Berzofsky, 2015). Data also show that when compared to the general population, people in prison and jail have significantly worse health outcomes, which has led correctional health scholars to posit that inmates over 50 have health profiles similar to those of adults outside of prison who are over 65 (Maruschak, Berzofsky, & Unangst, 2015; Dulisse, Fitch, & Logan, 2020). For example, 38.4% of adults in prison versus 15.4% of adults in the general population report

having a disability (Maruschak, Bronson, and Alper, 2021).

### ***Entry pathways for people with dementia in the criminal legal system***

Incarceration of people with dementia follows one of two general pathways. On the first, a person develops dementia during the course of their sentence. On the second pathway, an older adult with symptoms of neurocognitive decline becomes a first-time arrestee in their 70s or 80s. Cognitive impairments have been noted to be a significant cause of first-time criminal offenses by older adults (Miller, 2011). Individuals with dementia may exhibit behavioral problems that cause safety concerns and warrant police involvement, such as wandering, indecent exposure, shoplifting, traffic violations, or violence towards others (Sun et al., 2019). Cognitive and sensory impairment in dementia patients may escalate police involvement during crisis, and police are often not properly trained to identify and address these health-related issues (Moll, 2013). On both of these pathways, the timely identification of dementia is essential to understanding the person's behaviors as related to neurocognitive decline, provide treatment and services to delay the progression of dementia and address existing symptoms, and consider alternative placements that offer the appropriate level of care.

### ***Competency to stand trial and criminal responsibility***

Dementia researchers and criminal justice practitioners agree that the scope and articulation of criminal responsibility for those with dementia needs to be clearly defined. At a minimum, a diagnosis of dementia should call into question an individual's competency to stand trial and criminal liability, as dementia may impair one's ability to provide informed consent for their legal defense strategy and understand court proceedings (Padama, 2018). In a study of those age 60 or older among the forensic population, defendants with Alzheimer's Disease were found to be incompetent to stand trial at a rate of 30 to 50% (Sfera et al., 2014). Determining competency is a critical psycholegal factor during the adjudication process; however, there is a lack of clarity regarding how neurocognitive impairments potentially affect functional abilities related to competency to stand trial (Miller, 2020). State definitions vary, but generally a defendant is deemed incompetent to stand trial if, as a result of mental disorder or disability, they are unable to understand the criminal proceedings and assist in their defense (Bartos et al., 2017). However, unlike many mental health disorders for which the appropriate treatment can mitigate symptoms and restoration is possible, dementia is both progressive and irreversible. This complicates restoration. One study found that, while restoration is possible for some people with dementia, the likelihood of successful restoration decreased by 10% per five-year increase in age (Morris & Parker, 2009).

If competent and taken to trial, the availability of an insanity defense to people with dementia is dependent upon how a state defines insanity. Twenty-five states use the M'Naghten test to determine legal insanity, which requires an individual to be incapable of understanding the nature or wrongness of their criminal act to qualify as insane. This test excludes individuals with frontotemporal dementia from using the insanity defense, as early frontotemporal dementia does

not affect cognitive capacity or cause impairment to rationality (Mendez, 2010; Sfera et al., 2014). Twenty-one states use the American Law Institute (A.L.I.) test to determine legal insanity. This test differs from the M’Naghten test in that, in addition to evaluating a defendant’s capacity to understand the wrongfulness of their act, it also considers whether mental “defect” may compromise ability to conform one’s behavior to the requirements of the law (American Law Institute, 1962). Therefore, because symptoms of frontotemporal dementia may render an individual incapable of controlling their behavior even when they understand that an action is wrong, an individual with this dementia may qualify as legally insane in states that use the A.L.I. test but not the M’Naghten test (Berryessa, 2016).

People with dementia may constitute a special population requiring categorical or systematic protections to mitigate criminal culpability or restrict sentencing (Arias & Flicker, 2020). Though little research has focused specifically on dementia patients and categorical protections, parallels can be drawn between other analogous populations in which assignment of liability must be given special consideration, including juveniles and individuals with psychiatric illness. Categorical protections concede that a crime has occurred but allow for special treatment within the criminal legal system on grounds that the individual did not have the requisite mental status necessary to be criminally liable (Arias and Flicker, 2020). However, the progressive nature of dementia may limit applicability of categorical protections. Individuals often display symptoms of dementia before they meet clinical criteria for diagnosis, raising questions about the diagnostic criteria threshold an individual must meet to qualify for categorical protections, and unlike juveniles and individuals with mental illness, individuals with dementia are unlikely to benefit from rehabilitative programs that could serve as alternatives to sentencing (Arias & Flicker, 2020).

### ***Dementia and the correctional environment***

In most cases, incarceration is not the right placement for people with dementia, particularly as the condition progresses. Individuals with dementia experience unique health risks, have high service needs, and may benefit from diversion from incarceration to treatment-based alternatives (Ahalt & Williams, 2016). They are also at significant risk for victimization from other inmates, injuries from falls, declining physical and emotional wellbeing, and placements in restrictive housing units particularly for those who are undiagnosed (Davies, 2011; Moll, 2013; Garavito, 2019). Early symptoms of dementia, appearing before memory loss, typically include disinhibition, emotional shifts, irritability, and violent outbursts. These symptoms are overlooked, dismissed, or classified as bad behavior by correctional personnel who are not trained to recognize or respond to signs of dementia (Garavito, 2019; Miller, 2011). Furthermore, symptoms of dementia often go unnoticed by the individual themselves, meaning they are unable to advocate for themselves and are unlikely to receive healthcare until the symptoms are noticed by staff or another inmate (Garavito, 2019).

However, even when there is a desire to remove the person from jail or prison, this population is difficult to place in alternative settings, as there are few to no community placement options for adults with dementia and a criminal record. Furthermore, for those who commit

violent crimes, even as a symptom of cognitive impairment and with no prior history, probation or intermediate sanctions are unlikely to be considered viable sentencing options (Yates & Gillespie, 2000). One option for diversion is the establishment of dementia courts, which could be modeled after other established diversion courts which exist in every state (Strong, 2016). Existing diversion courts are specific to people with behavioral health challenges. Like these courts, a dementia court would be comprised of defendants with dementia or degenerative neurocognitive impairment. A collaborative, non-adversarial team would link the defendant with a suitable local treatment provider and sanctions for failure to comply with the court's requirements (Dubljevic, 2020). However, because dementia is progressive and incurable, treatment options the court may impose are limited, and how to finance alternative dispositions must be considered (Kapp, 2020).

### ***Best practices, recommendations, and interventions in the literature***

There is very limited research in the literature regarding best practices or even recommendations for people with dementia in the justice system, particularly those in prison and for whom a community placement cannot be found or is not suitable. Recommendations include screening people in prison for dementia, developing specialized units inside prison facilities, utilizing volunteer inmates to aid the person with dementia, improving the physical environment, developing pathways for compassionate or medical release, and training justice actors about dementia.

Scholars and stakeholders in the field have identified early and regular screening for dementia as a priority need for all older prisoners, especially first-time offenders, and annually for those who turn 55 during incarceration (Williams et al., 2012; Garavito, 2019; Dulisse, Fitch, & Logan, 2020; Sfera et al., 2014). Dementia screening results can be used for decisions related to classification and housing assignments, programming, treatment of chronic conditions, and discharge planning and parole supervision (Williams et al., 2012). However, currently available cognitive screening tools are designed for community populations and may not perform as well in prison settings; an improved comprehensive assessment that measures the unique challenges of this population should be created (Williams et al., 2012; Dulisse, Fitch, & Logan, 2020).

There are also recommendations for creating palliative, hospice, or specialized geriatric units within prisons that can house prisoners (Ahlat & Williams, 2015; Lyon, 2019). An example of this is the Memory Disorder Unit located in the Federal Medical Center (Massachusetts) that is modeled after nursing home memory care units (Bollinger et al., 2019). The unit houses 36 inmates with middle stage dementia, and the staff is certified in dementia care (Bollinger et al., 2019).

Specialized units, however, are expensive to operate; this likely contributes to their rarity (Maschi et al., 2011). Even in the absence of specialized programs, research suggests some relatively inexpensive and easy-to-implement structural changes may be helpful in maintaining independence and dignity for those with dementia in prisons. These changes could include marking cell doors with different colors, installing handrails and non-slippery floors, placing older

inmates in lower bunks, and allowing for more time to respond to stimuli such as drills (Mistry & Muhammad, 2015). Inmate peer programs have also been used to positively support the person with dementia, such as California's Gold Coats program and California Men's Colony, which utilizes a peer support program in which volunteer inmates provide protection and facilitate social integration for those with dementia in the correctional setting (Garavito, 2019; Maschi et al., 2011).

Compassionate release or medical parole are also discussed by scholars in the field as a means to provide individuals with dementia to more appropriate healthcare in the community (Garavito, 2019; Pro & Marzell, 2017). Whether released after completing their sentence or through a compassionate or medical release program, there is a scarcity of geriatric-focused reentry programs, especially those specialized for individuals with dementia (Ahalt & Williams, 2016). Additionally, justice-involved individuals are often stigmatized; this impacts their ability to be placed in nursing homes or long-term care facilities, which are often hesitant to accept patients with a criminal record (Pro & Marzell, 2017). For those who were convicted of sexual offenses or who are perceived to pose a threat to care staff, it is nearly impossible to find community placements (Mistry & Muhammad, 2015). Connecticut developed a nursing home specifically to accept patients from the Department of Corrections, but the facility has faced many setbacks including ineligibility for Medicare and lawsuits from the community (Garavito, 2019).

Training on dementia is recommended for those in the justice system who could come into contact with people with dementia, but few dementia-related training programs currently exist for law enforcement and correctional officers (Moll, 2013). Evidence shows that individuals with dementia can become violent during crisis events, so proper training in addressing dementia symptoms and de-escalation techniques are crucial (Moll, 2013). Trainings for police officers should also include information about community resources that can be utilized to divert the person from further involvement in the criminal legal system (Sun et al., 2019). Attorneys and prosecutors would also benefit from training—cases involving people with dementia need not reach a point where affirmative defenses and sentencing options become relevant, as prosecutors are allowed to practice discretion regarding the bringing of criminal charges, and the deposition of any charges filed (Kapp, 2020). Efforts should be made to inform prosecutors about the nature and consequences of dementia, including resources available, so that they may use their discretion to handle incidents involving individuals with dementia outside of the criminal legal system (Kapp, 2020).

In light of the knowledge gaps and the need to identify interventions for people with dementia in the criminal legal system, this mixed-method, cross-collaborative research effort collected survey data and conducted interviews with a variety of correctional health and legal field stakeholders. The purpose was to learn about their experiences working or interacting with people with dementia in the criminal legal system in order to better understand how and why these individuals are behind bars, and make recommendations to improve policy, data collection, and treatment.

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## IV. Summary of Relevant Case Law

A summary of major areas of interest – full review in appendix A.

### ***Competence to Stand Trial***

Case law regarding dementia is sparse, and most that exists centers on the adjudication of competence to stand trial. The first important issue regarding competency is whether there were adequate procedures to protect a defendant's right not to be tried or convicted while incompetent to stand trial. In some cases, defendants have alleged that a court deprived them of due process by refusing to authorize a competence assessment or hold a competency hearing upon the defendant's explicit request – or to order an evaluation *sua sponte* (on its own motion) even if the defendant did not raise a request. The alleged error in these cases is not that the court has incorrectly adjudicated the defendant as competent, but that the court erred in failing to order a hearing to determine competency in the first place, given the defendant's apparent impairments. Non-dementia case law suggests that the bar for raising a successful due process challenge on appeal may be high. By contrast, dementia-related case law suggests that the bar may be particularly difficult to meet for those with dementia due to the subtle presentation of symptoms and variability in behavior found in dementia-related diseases. Other recurrent issues in the adjudication of competence include: (i) whether behaviors exhibited in the competency assessment are consistent with test results and physiological indicators; (ii) the continuity and length of observation of the defendant; (iii) whether symptoms at any given time are consistent with the rate of a disease's projected progression and purported onset of disease; and (iv) whether retroactive extrapolation of the defendant's mental state at time of trial is feasible in a particular case given individualized rates of disease progression and other pertinent variables, such as presence of other co-occurring mental conditions.

If an individual with dementia is found incompetent to stand trial, the question of how to proceed with that person and their criminal charges arises. Although those with dementia are unlikely to recover the necessary capacities to stand trial due to the progressive nature of the disease, most state statutes automatically commit incompetent defendants to state psychiatric hospitals for purposes of competency restoration, even in cases involving dementia. Many defendants, afflicted with conditions that appear to be irreversible have understandably alleged due process violations when faced with statutes that automatically commit defendants without any individualized determination of whether competency can realistically be restored. Many states have laws that allow for community-based restoration, or even considerations for the least restrictive environment. However, nearly all of claims regarding sending individuals to state hospitals for restoration have failed. While courts may be reluctant to strike down automatic inpatient commitment statutes, legislatures may be motivated to revise them because of a different kind of due process challenge. Defendants may successfully allege a due process violation if they are forced to wait too long in a jail cell before entering inpatient treatment. Limited availability of inpatient beds and resources along with a high number of incompetent defendants have made such due process violations a real and frequent possibility. In fact, many

states have faced and lost lawsuits regarding this issue, and the problem is likely to be exacerbated as the elderly population increases. At the same time, the notion of dementia requiring the same treatment service as serious mental illness ignores the differences in these conditions.

### ***Criminal Responsibility***

As with the adjudication of competence, dementia is clearly relevant to the adjudication of criminal responsibility. A diagnosis of dementia could result in a successful affirmative “insanity defense,” where the defendant may receive no conviction if the disease renders one unable to appreciate the nature/wrongfulness of the crime or conform one’s conduct to the law. States vary in how and whether they contemplate such defense strategies. Dementia at the time of crime could also bear on whether or not the defendant had the particular mental state required to satisfy the elements of a given crime (e.g. the requisite mental state of “malice” or “recklessness”).

Relatedly, courts may also grapple with the feasibility of retrospective determination of mental state at the time of a crime when there were no diagnostic evaluations prior to when the crime or indictment occurred. Case law is limited but suggests that courts are likely to be highly skeptical of retrospective inquiries. Skepticism towards retrospective inquiries may be especially problematic if a disease alters cognition such that one commits crimes but does not notice the symptoms and seek medical attention. In such circumstances, there will be no formal medical history or diagnostic imaging or evaluation available to build an argument that the defendant had dementia when the crime occurred, so a defendant may have to rely on retrospective arguments instead. Moreover, dementia itself may not qualify a defendant for the insanity defense in those jurisdictions that require a more narrowly defined mental illness or intellectual disability for this type of adjudication.

Even if defendants with dementia are found not guilty by reason of insanity (NGRI), the prospects of liberty and release may be particularly low because of the irreversibility and gradually worsening nature of the disease. All defendants found NGRI may be automatically and involuntarily committed to a state psychiatric hospital for purposes of ameliorating the mental condition that led to the crime. NGRI commitment statutes generally provide periodic release hearings that mandate the NGRI patient to be released if the patient is no longer dangerous or mentally ill. However, commitment laws often exclude dementia as a sole reason for psychiatric involuntary treatment. Thus, a person with dementia found NGRI may be caught between statutes, leaving systems to sort through options for placement or ways to allow hospitalization to proceed when there are no other options. There appears to be no case law directly addressing dementia in the context of NGRI commitment, but relevant case law suggests that the irreversibility and gradual worsening of the condition may lead to courts finding that patients are too dangerous to be released.

## ***Sentencing and Punishment***

Criminal litigation involving people with dementia in the criminal process often addresses severity of punishment. When cases actually proceed (since many are diverted to forensic processes related to competence to stand trial) cases are of two types: (1) mitigation claims pertaining to sentencing based on the argument that severe punishment is disproportionate to the defendant's *culpability at the time of the offense*; and (2) claims arising after imprisonment, arguing the prisoner's *current mental condition* (relating to onset and symptoms of dementia) warrant mitigation of the previously prescribed punishment.

At the time of sentencing, the judge can decide to reduce an otherwise applicable prison sentence. Dementia may establish the criteria of what is often called "diminished responsibility" – mitigating factors that echo the exculpatory criteria of the insanity defense but do not amount to an absolute affirmative defense and a finding of non-culpability. For example, the court may find that the defendant's dementia establishes the mitigating factor of being unable to conform one's conduct to the law such that it warrants a lesser sentence than what might be given to an individual without dementia. However, case law on dementia-related mitigation is extremely limited, and thus the degree to which courts will consider dementia as a mitigating factor is unknown. Clinical input may be helpful as mitigation cases utilizing a mental health condition generally require the determination of a defendant's mental state at the time of crime or examination of vulnerabilities at the time of the alleged offense.

Cases in which an individual has dementia at the time of sentencing or develops dementia while in prison may invoke questions regarding the Eighth Amendment, which prohibits "cruel and unusual punishment." Prisons often lack the ability to provide healthcare to prisoners with dementia, and individuals with dementia are vulnerable to abuse and victimization from other prisoners. It is possible that someone with dementia may petition for compassionate release, which allows for a prisoner's early release from prison if there are extraordinary and compelling reasons to warrant release, such as terminal illness or debilitating illness that prevents self-care.

Compassionate release is rarely used, though, and there is no dementia-related case law pertaining to compassionate release. However, as the elderly population in prisons increases, claims are likely to arise. Medical parole and compassionate release laws and policies often lack criteria for dementia to be considered.

## **V. Findings and Recommendations**

There is growing concern about people living with neurocognitive conditions (colloquially referred to as dementia) who have become involved with the criminal legal system. Specifically, this project sought to establish an evidence-based framework for the treatment of people with dementia in the criminal justice<sup>2</sup> system. Information is needed to understand the problem, organize the key issues, identify solution options, and develop policy and practice recommendations. Key to this goal is the identification of needed collaborations and resources that can work with law enforcement agencies, the courts, and prisons. The findings from this research will heighten awareness of the issue within the criminal legal system and the community. Key stakeholders will need to develop organizational policies and legislation, standards of practice for prosecutors, defense attorneys, judges, clinicians, prison management and correctional healthcare.

### **A. Scope of Problem**

#### **Findings**

- There is a widespread need for training on how to identify, assess, and manage people with dementia across the spectrum— from law enforcement to lawyers, judges, court personnel, and correctional personnel in order to ensure that people with dementia receive the most appropriate treatment and supports.
- Aside from correctional health care and professionals conducting assessments, there is widespread misunderstanding of the nature and effects of dementia. There were repeated comments about needing to know about effective treatments, and about how to make people with dementia remember and follow rules.

#### **Recommendations**

Mandatory training on the ways dementia changes behavior and on identifying, assessing, managing, treating, and caring for people with dementia should be provided to officials in the criminal legal system, including law enforcement officers, lawyers, judges, court personnel, and correctional personnel.

### **B. Initial Contact with Law Enforcement**

#### **Findings**

People with dementia need help and care. Arresting, prosecuting, and punishing them

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<sup>2</sup> The initial proposal uses the terms criminal “justice” system, researchers and respondents urged using criminal “legal” system, as many advocates find there is insufficient “justice” in the system.

does not benefit society. The most promising practices train first responders and offer community-based responses to keep people with dementia and with serious mental illness out of the criminal legal system. Many respondents in our survey put the point simply – people with dementia don't belong in the correctional system.

### **Recommendations**

- Extensive training is needed for first responders to recognize that a person's actions may be the result of dementia and to call in appropriate community resources for proper assessment and care.
- The model of community mental health response needs to be studied, best practices developed, and positive efforts replicated.

## **C. Assessment**

### **Findings**

Effective assessment of arrestees with signs of dementia is essential in every jurisdiction. Limited compensation and other barriers make a complete assessment impossible and delays in scheduling assessments place people with dementia at risk of harm. Jail and prison personnel carrying out health screenings need training and resources to identify those who may have dementia and who need further assessment. They also need the authority to divert those arrestees to a safe care environment while assessment takes place.

### **Recommendations**

- Adequate resources are needed for timely professional assessment of arrestees with signs of dementia.
- Intake personnel need training and resources to screen for dementia. Where legally appropriate, they should also have the authority to divert for additional assessment and safe and appropriate care.

## **D. Commitment for Restoration of Competence to Stand Trial**

### **Findings**

Many courts automatically refer or commit people with dementia to a state psychiatric hospital after adjudicating them as incompetent to stand trial. Commitment to a psychiatric hospital for restoration of competence to stand trial has little chance of success, may be harmful, and sometimes results in a person with dementia spending more time detained than they would have had they pled guilty. The current standards for competence to stand trial are often effective in halting the prosecution of people living with dementia— but commitment for mental health treatment is inappropriate for those with dementia, as there is currently no effective treatment or

therapy to restore cognitive ability.

### **Recommendations**

- People with dementia who have been found incompetent to stand trial should no longer be committed for restoration of capacity. If the person poses a danger to self or others, a civil pathway for protective custody should be invoked.

## **E. Diversion from Prosecution**

### **Findings**

Diversion of people with dementia is further impeded by lack of specialized community resources and lack of clear legal authority and processes for establishing protective placements that provide safety for the community and appropriate care for people with dementia.

### **Recommendations**

- Communities need to develop care models for people living with dementia that focus on safety of the person and others using behavior management and other care models.
- Development of a civil statute that authorizes protective custody and care of people with dementia who pose a risk of causing harm to themselves or others.
  - Criteria: The person has experienced such severe and irreversible deterioration of brain function as to pose a serious danger to himself or others for the foreseeable future and, as a result, requires protective residential custody and care.
  - Upon placement of the person in a suitable residential facility for protective custody and care, the responsible custodian shall assure that the person receives services in the least restrictive setting compatible with the person's health, safety and wellbeing.
  - Possible legal pathways for placement in such a facility:
    - Family (through guardianship).
    - Family or other "responsible person" (by civil petition).
    - Dismissal of criminal charges to allow for civil pathways to care.
    - State official with formal custody of the person (administrator of prison or psychiatric hospital) [This will deal with the cases involving prisoners with dementia].

## **F. Corrections**

### **Findings**

- The punitive and rehabilitative goals of criminal justice are unattainable in the case of people with dementia. Moreover, the goal of protecting society is attainable in settings outside the prison system.
- Very few correctional settings can provide dementia-focused resources to meet the safety and care needs of people living with dementia. Isolation in special units can worsen symptoms of people with dementia, and people with dementia are easily abused and exploited by other inmates in the general population.
- People with dementia are often unable to understand, remember or follow rules, and non-compliance with correctional rules and directions is often treated as a disciplinary issue rather than a medical issue. This often results in punishment or loss of privileges, including social isolation and restrictive housing placements that can be harmful to a person with dementia.
- Safe care placements for people living with dementia and a history of violent acts are very difficult to find and, in many communities, long-term care and memory care providers refuse admission to these patients. Specialized care facilities are in desperately short supply.
- Unsurprisingly, the aging of the prison population – due in large part to the increasing number of inmates serving long sentences – is resulting in an increasing number of people living with dementia in the correctional system.
- The data from South Carolina show that most people identified with dementia developed it during their incarceration (as opposed to entering the system with it).
- Efforts to use medical parole or compassionate release to help people with dementia often encounter difficulties with securing a community placement when the release is approved.
- Dementia in the correctional population often co-occurs with brain injury, mental illness, and/or substance use disorders which are disproportionately high among justice-involved adults and can advance aging. For this reason, correctional health scholars recommend screening for dementia among justice-involved people starting at age 50.

### **Recommendations**

- Dementia care facilities must balance residents' care needs with public safety.
- Models of dementia care for people with a history or propensity for violence should be studied, best practices should be developed, and compliant facilities should be funded and implemented.

- Laws and policies that prohibit placement in otherwise appropriate care settings need to be changed.
- A civil path for diversion or release as outlined above needs to be developed.
- Care facilities need to be developed, ideally through public-private partnerships, and funded to care for people with dementia who are perceived to present a threat to public safety.
- Standards and processes for medical release, conditional release, and compassionate release should expressly include dementia as a qualifying condition.

## **G. Correctional Health care**

### **Findings**

- People living with dementia have unique medical and psychiatric needs and very few correctional systems are currently able to provide appropriate care for them.
- There are currently no therapies or medications to cure dementia, although some medications can slow its progression.
- While the physical health of the person may remain stable until very late in the illness, many people with dementia may have complex co-morbidities.
- Correctional health care professionals often have difficulty obtaining medical history from inmates with dementia and, as a result, often lack information needed for a complete assessment and care plan.
- Models have been developed in which qualified inmates are trained to provide care and support to inmates with dementia. These models should be studied and potentially replicated, but cannot replace a more comprehensive approach to supporting individuals with dementia in a medically appropriate manner.

### **Recommendations**

- The diversion of people with dementia from jails and prisons is of utmost importance, especially as the disease progresses and individuals' awareness of their situation and surroundings becomes impaired. Efforts to place these people in non-correctional settings should be a high priority along with the creation and expansion of placement options. Until such placement options become available, facilities or correctional systems should consider a host of policies related to the provision of long-term care to aging inmates with complex health needs, including staffing, trainings, and screening policies.
- The care of people with dementia needs to occur outside of the correctional health care

system, with specialized care settings designed to meet their needs.

- When release is not possible, state prison systems and large jails should consider designating specialized long-term care nursing units with particular facilities that can house and care for aging inmates with complex health needs.
- Establish a facility-based geriatric care team (larger facilities) or identify and train a key facility person who can provide legal advocacy and manage the care of inmates with dementia.
- Institute “dementia friendly” environmental design elements that are relatively quick and inexpensive, such as adding more and clear signage, improving lighting, installing handrails, and different paint colors, and moving dementia patients to lower bunks.

## **H. Research**

### **Recommendations**

- Research is needed on the diversion models used by courts to assess their effectiveness in identifying, assessing, and promoting appropriate dispositions of criminal cases involving arrestees with dementia.
- All stakeholder entities should collaborate on funding and implementing public and public-private research and demonstration projects to establish and test the use of memory-care and other long-term care facilities and supportive services for the optimal care of people with dementia diverted or released from the criminal legal system, including those with hard-to-manage behaviors.
- Correctional health care professionals and other professional groups should collaborate on developing consensus methods and tools for screening and assessing people with dementia who interact with the criminal legal system.

## **I. Coda**

### **Fair and Compassionate Dispositions for Persons with Dementia in the Criminal Justice System**

Anglo-American jurisprudence has undergone a sea-change in the 21<sup>st</sup> century in the rules governing criminal prosecution of adolescents based on evolving knowledge about the developing brain, particularly impulsivity and susceptibility to peer influence. (Luna B. The Relevance of Immaturities in the Juvenile Brain to Culpability and Rehabilitation. *Hastings Law J.* 2012;63(6):1469-1486.) Indeed, the Supreme Court has invalidated severe mandatory sentences for youth, declaring adolescents to be “constitutionally different” from adults for these reasons. More broadly, state legislatures have revised their governing statutes to “raise the age” of criminal court jurisdiction so that youth who may have committed delinquency offenses are dealt

with in a way that incorporates better understanding of the developing brain.

[\(https://www.sentencingproject.org/publications/bringing-more-teens-home-raising-the-age-without-expanding-secure-confinement-in-the-youth-justice-system/\)](https://www.sentencingproject.org/publications/bringing-more-teens-home-raising-the-age-without-expanding-secure-confinement-in-the-youth-justice-system/)

This report makes the case for extending this developing “adolescent jurisprudence” to defendants with dementia, thereby reflecting the impact of the deteriorating brain on fair and humane punishment. Profound advances in neuroscience show that dementia can cause changes in personality, judgment, capacity to plan, and ability to exercise self-restraint. The evidence assembled in this report indicates that tens of thousands of defendants with dementia are confined in jails and prisons – and even in psychiatric hospitals that are not designed to care for them. The data and research reviewed in this report highlight the critical need to develop suitable placements at every stage of the criminal process and to take due account of the impact of dementia as a mitigating factor.

This report is rooted in two ethical aims: compassionate care and fair punishment:

- Regardless of the offense committed, a person who develops dementia while in the criminal justice system should receive humane and protective care and treatment in a clinically suitable setting.
- Persons who commit offenses while afflicted with dementia should be assessed to ascertain whether and how this condition might have affected their mental and emotional functioning at the time of the offense. If punishment is legally and morally warranted, it should be proportionate to the prisoner’s mitigated culpability.

In summary, building on the jurisprudence that has reshaped juvenile justice in the 21<sup>st</sup> century, laws and practices governing administration of criminal justice should be revised to take account of degeneration of brain function, including its effect on culpability, in decisions about diversion, sentencing and placement.

## VI. South Carolina Alzheimer's Registry and Criminal Records Data Base: The Prevalence of ADRD among People in South Carolina Prisons from 1992 - 2016

South Carolina is able to link data from the South Carolina Alzheimer's Disease and Related Dementias (ADRD) Registry with data from the South Carolina Department of Corrections (SCDOC) to identify persons who appeared in both data sets. The South Carolina researchers provided the project team with de-identified data and analyses of the prevalence of people with ADRD and a history of incarceration in the South Carolina Prison system during the period 1992- 2016. There are two major findings:

First, the ADRD Registry contains 279,085 persons who were diagnosed with ADRD from 1992-2016. There was a total of 2,171 persons who were on both the ADRD and SCDOC registries, or about 1%. This means that approximately 1% of South Carolinians known to have been diagnosed with dementia between 1992 and 2016 also had a history of incarceration in a South Carolina prison sometime during this period. (It is important to emphasize that this finding focuses only on the prison population; it therefore does not tell us anything about the number of persons with dementia that were arrested or detained in jail during the target period.)

Second, among the 2,171 persons on both the ADRD and SCDOC registries, 241 (~11%) were diagnosed with dementia *before* being incarcerated and 1,930 (~89%) were diagnosed during the period of incarceration or after they were released. (Unfortunately, further analyses are necessary to extract the people who were diagnosed after they had been released from prison.)

These findings are intriguing. Presumably, many of the prisoners diagnosed before imprisonment committed their offenses and were convicted while they were significantly impaired, raising many of the concerns discussed in this report. However, it is difficult to interpret the post-incarceration diagnoses without distinguishing clearly between those diagnosed in prison and those diagnosed after release. (Further analyses are underway as this report is being published). Whatever the actual figure, however, it appears that a significant number of prisoners were first diagnosed as having dementia while they were in prison. That finding highlights the need to find alternatives to imprisonment for inmates who become significantly impaired while incarcerated.

## VII. Online Surveys of Relevant Professionals

Online surveys using the Qualtrics platform were used to gather input from as many people as possible on the issue of people with dementia in the criminal legal system. The survey was limited to 11 questions, plus an introduction and the required consent-to-participate steps from the Institutional Research board approval by the University of Virginia. There were five questions on demographics and frequency of encounters with people with dementia, followed by six questions that allowed open-ended narrative answers. The platform was set to allow respondents to respond or skip any question except the consent-to-participate question. The number of responses predictably declines in later questions. A challenge in designing this type of a survey is gathering useful information without over-burdening the respondents with details.

The surveys were distributed to 9 groups. Additional groups were asked to distribute the survey, but did not do so for various reasons: some explained and some not. A few groups reported that they were limiting surveys and other emails to their networks, as network members reported being overwhelmed. The distributions varied from fewer than ten people to organizational listservs with a thousand or more email addresses. Because of the nature of the dissemination plan, it has proven impossible to calculate a response rate. The response rate on this type of an entirely voluntary survey is generally in very low single digits. The respondents were all volunteers, with no incentive other than wanting to share their experience and be a part of this research project.

The number of responses to the demographic questions ranged from 312 to 352.

The first demographic question was about primary work role and received 312 responses.

Primary work roll classification	Number of responses	% of responses
Adult protective services, social worker, aging services professional	8	.25%
First Responder excluding law enforcement	2	.64%
Health care provider, including hospital staff (not in prison or jail systems)	21	6.7%
Law enforcement	4	.128
Prosecutor or district attorney	5	.16
Defense attorneys, including public defenders	10	.32
Judge	0	0

Other Court Personnel	1	.003
Jail Personnel	14	.448
Prison personnel	9	.288
Prison and Jail Healthcare Staff	186	59.61
State Hospital management	4	.0128
Forensic Evaluators	37	11.85
Other	46	14.75

Nearly 60% of responses were from people who work in correctional health care. The remaining 40% represent a broad spectrum of professionals who interact with people with dementia in the criminal legal system.

The second demographic question asked about the size of the organization or entity that the person works in, with answer options of 1-30, 31-100, 101 or more.

How Many Employees		
1- 30	31-100	101 +
69	60	221
0.1971	0.1714	0.6314

Larger employer slightly dominates. This was as expected as nearly 60% of respondents work in correctional health care, and correctional facilities tend to have large staffs.

The next two demographic questions asked about the setting and the reach of the respondent's work. The respondents represent a nice mix of geography reflecting population distribution, and the reach appears to represent all expected groups.

Setting				Reach				
Urban	Suburban	Rural	Frontier	Local	Regional	Tribal	Statewide	National
124	101	121	3	114	52	3	145	38
0.3553	0.2893	0.3457	0.0085	0.3238	0.1477	0.0085	0.4119	0.1079

Frequency of dementia case encounters			
Never	1 -5 times per year	6-10 times per year	11 or more
33	136	68	112
0.0945	0.3896	0.1948	0.3209

The majority of respondents did interact with people with dementia. The weighting here is seldom and frequent, with a lower level of encounters between 6 and 10 times per year. Importantly this indicates that over 9 in 10 respondents encounter people with dementia in the criminal legal system.

The first substantive narrative question was question 8, and yielded the most responses, about 20 pages, single spaced of narrative responses.

**Q8 - Please share with us examples of the kinds of cases you have seen involving people with dementia who may have committed a crime. To the extent you know: what was the nature of the act, what was the outcome, or what is the status?"**

There were 237 classifiable responses about the nature of the offense:

Aged in	53	22.36%
Sex crimes	36	15.18%
Trespass, shoplifting	30	12.65%
Assault	30	12.65%
Murder	25	10.5%
DV	25	10.5%
Traffic / DUI / drugs	20	8.43%
Theft / financial crime	19	8.01%
Assault in health care/SNF	17	7.17%
Threatening	7	2.95%
Arson	5	2.10%

Sex crimes are the second most reported, followed by trespass, assault, murder, traffic-driving under the influence, drugs, theft, assault in health care, threatening and arson.

Reports of assaults committed in health care facilities included striking both health care staff and other patients or residents in long-term care. While not a huge number, it raises two questions: 1) what can be done to increase safety in health care settings, and 2) should striking

out by a person with dementia in a health care setting result in arrest?

The grouping on trespass and shoplifting drew several peripheral comments about the person with dementia being homeless. One memorable quote:

“Due to lack of access to basic needs, they (homeless) were arrested for "indecent exposure" while toileting, "arson" for making fire during winter," or "resisting arrest" while not being able to understand the simple command of the arresting officer.”

Another comment mentioned an increase in arrests for trespassing by people with dementia on cold nights. A couple of the arson arrests were directly related to a homeless person with dementia trying to stay warm. This indicates an overlap between needed dementia resources and needed homeless services. A jail should not become a default homeless shelter for a person with dementia.

The murder cases described tended to focus on murder of family members, often in a state of confusion and disorientation. However, one person was reported as arrested for attempted murder when a social worker came to remove a person from their home to a nursing home, and the person shot at and grazed the head of the social worker.

Overall, this data is heavy on serious crimes. Sex crimes, assault and murder account for almost 40% of the events cited by the respondents to this question. Those are acts for which the criminal legal system struggles to balance culpability with diminished capacity. The laws on diminished capacity and the defenses that are available have been written to make it very difficult to mount a successful defense for these crimes based on lack of capacity if the person is found able to assist counsel and stand trial. For minor crimes it was common to hear that charges were not pursued. For serious violent crimes, some were found unable to stand trial (unable to assist counsel in defense). Some are convicted, then the challenge begins in the corrections system of providing appropriate services and custody.

Additional details in the responses talked about when the person developed dementia. There are two populations of people with dementia in the criminal legal system: those who have dementia at the time the crime is committed, and those who develop dementia while in the corrections system. The largest number of respondents to this survey primarily had experience with those who were “aging in” (who developed dementia while incarcerated).

### **Q9 - For your office, what are current practices and what resources do you have available for working with people with dementia who may have committed a crime?**

There were 185 classifiable responses in four general categories, dementia care (14.5%), health and medical care (27.56%), corrections resources (49.18%) and legal options (8.6%.) The heavy response of issues in correctional resources is proportional to over half of all respondents

working in correctional health care.

## Dementia Care

The responses relating to resource dementia care fall into two general categories: 1) release and community placement, and 2) care inside correctional facilities. At the arrest stage, release can sometimes be arranged within a few days. Up to a week may be needed to confirm an assessment that the person has dementia and make plans for a release either to family or community-based placement. If charges are not dismissed, care inside of correctional facilities or release from correctional facilities becomes challenging. A few respondents (5 out of 27) reported correctional facilities that have specialized care units for geriatric patients or people with dementia. Sometimes this care is provided in the infirmary. Several reported that no appropriate care is available within the correctional facilities they work in. A couple of noteworthy comments:

“Zero. None. No programming. No policies. No special unit to accommodate. Administration has been talking about building/designating an elderly unit for years, but IT HAS NEVER HAPPENED.”

“A 12-person Dementia unit is planned, but this has been discussed for years and never realized.”

Probably most disturbing was this comment:

“Not a lot. Already in prison, offer medications to treat behaviors, such as Haldol or Ativan.”

These are sedatives used as chemical restraints. Chemical restraints should only be used as a last resort when they are the only way to assure the person’s safety, not as a primary tool to control behaviors.

## Health Care

The responses on available or needed health care resources show a genuine concern for the care of people living with dementia, and at the same time a general frustration by most at how limited the ability of resources to provide appropriate dementia care is. Most are cared for in settings for acute mental illness or general medical needs, but dementia is different in two primary ways, it is “incurable”, there is no effective treatment to eliminate the symptoms, and the person's body may remain otherwise healthy until the very late stages of Alzheimer’s or other causes of dementia. The sentiment is probably best summed up in this long comment:

“In our prison setting we are very limited with what we can provide to demented patients. We offer supportive services and psychiatric and medical services. We usually house them in an infirmary setting, but they have no activities, they spend day and night in the same cell with very little interaction, no entertainment, no stimulating games or work that might help them cope with the time. They lay in their beds, doing nothing. Most do not have TV's or music of any kind. They rarely go outside and do not have any cues to keep them

oriented. I (am) always astound at the idea that we ask them if they know the day of the week, the date, the month, the year, but we give them nothing that would help them orient from day to day. Each day is exactly the same and there are no calendars, no clocks in their cell. As I write, this I am realizing more and more how awful it is. If the idea of prison is to punish and rehabilitate, they cannot.”

### **Resources available and needed in correctional facilities**

This group of responses shows a great deal of inconsistency in correctional facilities being prepared to provide appropriate care for people with dementia. Some respondents reported models of good care (or, the best care possible in the setting), while others expressed dismay at the overall lack of ability to assess and provide care or safety to people living with dementia.

### **Model practices**

A few correctional systems have specialized nursing or dementia care facilities. To be effective, these facilities would provide assisted living memory care, or skilled nursing care in the community, but in a secure setting. This level of care is essential to avoid cruel and unusual punishment for people with dementia, who are determined to be a safety risk in other settings.

Every state needs the ability to provide this level of care, either in the corrections system, or in community-based facilities that are equipped and trained to care for “high risk” residents.

### **A few relevant responses:**

- Specialized "sheltered housing" or other protected units are available in a number of DOCs for this population
- Our prison has an extensive dementia training program for any staff who will work in the dementia unit. All staff receive training on older adults in prison upon hire and yearly.
- Patients have access to several types of higher-level care including assisted living and inpatient setting.

A promising practice that was also mentioned in the interviews, is training inmates to be caregivers of inmates living with dementia.

“We have a dorm where vulnerable adults are frequently helped by other willing inmates but it's not an official program.” “We have one barracks that is used for elderly patients who require more assistance. There is one nurse who does the pill pass and there are a few inmate assistants that help with showers and ADLs.”

The good reports are more than offset by the negative comments. Most would agree that the general population in a correctional facility is not an appropriate place to care for a person living with dementia. The lack of resources and capability is reflected in these comments:

- We have no policy, protocol, or procedure. A majority of the time, these inmates are placed

in an infirmary setting. They live there until time to release or die.

- Only the Mental Health associates are available. They feel our prison has inadequate resources for inmates with dementia.
- If the person's ability to function is significantly compromised, we will house the patient in the mental health unit. However, there isn't really a treatment for dementia, so we mostly keep them in the mental health unit to monitor them and keep them safe from other inmates who may want to take advantage of the patient's disability.
- There are no resources. Medical team and Mental Health team cannot agree who is responsible for their care.
- We only provide evaluation, so no other services are offered.
- We don't have many resources or guidance regarding dementia.
- She was (in my opinion,) overmedicated. No special consideration for her advanced age and physical issues. Very overweight. Had both knees replaced! Chronic diarrhea! Issued one pull-up per shift! One day her daughter came to visit and since she did not have approval for a wheelchair, she had to walk the equivalent of 3 city blocks and could barely make it! Not a good situation. I hate to be so negative, but Corrections has minimal training with mental health or dementia issues, and I am also sad to say that most of the nurses didn't give a hoot! If anyone buck's the system, management finds a way to get you fired!
- Our facility is not designed to deal with patients with this condition, and we are not designed to care for patients needing assistance with ADLs.
- No true current practices. They are pushed under the rug.
- Very few get tested for dementia, and when they do, services are not readily available.
- Working in a county jail setting, resources, and accommodations to work with people with dementia are limited. When behavior is unpredictable or in past, violent, the person is typically segregated from the general population. The isolation tends to worsen their fears, anxiousness and sometimes paranoid thoughts.

There were some mentions of legal resources available. A couple of comments mentioned working with the legal system to seek dismissal of charges or appropriate placements. There was a comment on working in medical parole or compassionate release. That concept also came up in the individual interviews. A few respondents mentioned people living with dementia needing guardians and one talked about working with the prosecutor's office in seeking guardianship. The number of survey responses from attorneys was low; this data seems proportional to the sample demographics.

## Q10 - What training is available or is needed?

A theme running throughout the survey data is that dementia is different. It is not an illness that can be treated medically, and it is not a mental illness – there are no therapies or medications to treat dementia. The science and neuropsychology of dementia is also a rapidly developing area of knowledge. Both basic and ongoing training is needed by health care and mental health care staff to understand assessment, diagnosis, and how to care for and manage behaviors of people with dementia. In the correctional population there are frequent reports of co-existing conditions such as mental illness and dementia or brain injury and dementia further complicating the need for advance training of all health care staff.

“Police and non-police first responders need training.”

“Training for police on how to spot, handle and DE-ESCALATE patients with degenerative neurocognitive disease (emphasis in original.)”

These two survey responses really encapsulate the responses about the training needed by police and other first responders. A promising practice is the development of mental health response teams. These include both law enforcement and trained professionals to assess people who are not responding in a rational or understandable way, to assist with a response that meets the needs of the person (often in crisis.)

Another emerging practice is training inmates to provide companion care for people with dementia. To be successful this requires selecting people who are likely to be good caregivers and then providing training. The comments in this section included: “Training for other patients to work as companions. For being a companion to a fellow inmate/patient, we offer training. Training for inmates to help elderly such as a CNA course or something similar.”

The largest grouping of responses asked for broad and across the board training for staff in all capacities in correctional facilities. One particularly strong comment was:

“Bring the dementia care training we used in home health and assisted living into the jails for both medical and security. Security personnel treat dementia-related behavioral issues the same as they would from a rational, volitional behavioral inmate so would benefit from more re- direction techniques, etc. Our officers all get an 8-hour Mental Health First Aid training but nothing specific to dementia care. Prosecutors and defense attorneys need more training to recognize organic cognitive issues earlier in the prosecution process. Jurisdictions need faster alternatives to their competency processes involved with criminal cases particularly when the defendant is incarcerated.”

The training comments for professionals who carry out screening, assessment, and forensic evaluation show a need for specialized training in dementia.

There were nine comments specific to the training of judges and lawyers in dementia. Comments specifically called out the need for dementia and mental illness as defense strategies,

and the need for prosecutors and judges to understand that a person with dementia probably lacks understanding needed to form intent. One comment that stands out:

Courts need training in what to do with inmates that have been charged with a crime not only for those that are incarcerated in a jail but those that are not. Once the individual is charged with a crime and summoned to court, but fails to attend their hearing, a warrant is issued and then they are incarcerated because of the warrant.

About 2 in 10 comments indicated that no or nearly no training is currently provided in dementia cases.

### **Q11 - What resources, or processes would improve your ability to address these cases?**

There were about 211 relevant responses to the question on resources. Of those, the need for training was cited by about 1 in 3 (71 33.64%). Challenges with placement were also in about 1 in 3 (70 33.17%). Generalized resources were mentioned by just under 1 in 5 (35 16.68%). Assessment resources were mentioned by about 1 in 10 (20 9.47%). A need for legal resources was mentioned by about 7% (15 7.10 %.)

Training was the most requested resource for improving the treatment of people with dementia. Training was asked for in specialized assessment, diagnosis, and treatment of dementia. Training is needed for correctional staff in recognizing and providing appropriate response to dementia. Training is also needed for lawyers and judges.

Responses on placement fell into three categories: 1) the need to divert from the criminal legal system to community-based care, 2) the challenges of community-based placements for people with dementia who are being released from correctional facilities, and 3) the need for dementia appropriate care facilities within the criminal legal system.

In keeping with the first category of diversion and the central tenant of the Hippocrates – first do no harm – one comment said, “First of all, DO NOT ARREST those with dementia, as the county jail is NOT the place to care for these fragile individuals.” Another simply said, “Diversion opportunities.”

Across the research project there were repeated comments on the general lack of care facilities for people with dementia, especially those with a history of violent acts, or serious mental illness. This lack of placements makes it harder to divert, harder to release these individuals when charges are dismissed, or the decision is made to not prosecute, or when the decision is made that release is the humane option or the person has completed their sentence. Medical parole or compassionate release fails when there is not a viable discharge option.

There is a wide-ranging need for community based long term care facilities with the capacity to provide memory care, and with the willingness to admit “high risk” residents.

The responses specify the need for dementia care inside the correctional system. Some people living with dementia, until the very last stages of the illness, present a risk to the safety of others. Almost one in three respondents to this question mentioned the need for appropriate dementia care within the correctional system. This can take the form of specialized units, or prison-based nursing homes.

The generalized grouping of resources included:

- Information on understanding dementia
- Additional staff across correctional settings
- Increased interaction with other professionals, networking, and information exchange opportunities
- Specialized expertise including discharge planner

The comments on needed resources for assessment focus on the ability to do complex and time-consuming evaluations and advanced medical testing. Several responses mentioned the time needed to do a proper assessment (several hours, often spread over several days). Recent developments in medical imaging make it possible to detect amyloid plaques in the brain, the presence of which in combination of cognitive decline are diagnosable as Alzheimer's, the most common cause of dementia. And resources are needed for that kind of state-of-the-art testing.

Several comments mentioned the need to work with prosecutors, defense attorneys and judges to streamline the process of releasing people with dementia whenever possible.

## **Q12 - What data point related to people with dementia would be helpful to your work?**

A data point is a discrete unit of information. In a general sense, any single fact is a data point. In a statistical or analytical context, a data point is usually derived from a measurement or research and can be represented numerically and/or graphically.

This question was less understood, with about 68 classifiable responses. These fell into three natural groupings: basic information needs of competency, such as signs of dementia, stages of the illness, and best practices and standards. The next grouping was the largest and asked for data on dementia in the community, in correctional settings, data on recidivism by people with dementia who are not charged, or who are released post-conviction, general statistics on dementia by age groupings, and how training improves care.

Though drawing the fewest responses, this question yielded valuable insight.

- I would be interested to know how many people have been incarcerated and had a diagnosis as well as how many have acquired a diagnosis since being incarcerated.
- Recidivism / relapses in behaviors from when folks were younger
- Better statistics on numbers of dementia patients who are incarcerated and dispositions.
- Accurate statistics on causes of dementia in incarcerated population.

- Cost of putting them through competency restoration and recidivism rates vs cost of SNF locked facility.
- Number of those incarcerated with severe dementia.
- Prevalence among US incarcerated populations with dementia and in custody deaths of dementia patients.
- Estimated number of dementia patients found in metropolitan jails.
- Anything that shows the need for placement and/or housing of individuals released from the criminal legal system.
- How many prisons and jails have special units for inmates with dementia?
- Having yearly screenings to see if dementia progresses
- The acceptable number of nursing staff needed to care for one patient with dementia.
- Numbers incarcerated and recidivism once they are released to return to custody. Also, number of incidents within facility where inmate with dementia requires medical attention from physical conflict incidents.
- The number of offenders with dementia currently incarcerated who could be eligible for compassionate release.
- Length of time from incarceration to release or disposition.
- Numbers of people with dementia that commit or are thought to commit crimes.
- How often police encounter a person with dementia or Alzheimer's.
- Specifically, information about how various conditions/diagnoses may vary in presentation, ways to differentiate between these categories, and functional deficits that are typical observed. As my work is related to competency, knowledge about functional deficits, ways to improve or stabilize deficits, and likelihood of these areas improving.
- As noted above, the likelihood that individuals with dementia are restored to competency would be helpful in determining when to opine someone as unrestorable.
- How often inmates with dementia go unnoticed in the system.
- Projections for number of people who will be incarcerated and living with dementia in coming years.

### **Q13 - What else do we need to know, what else were you hoping I'd ask?**

Sometimes the most important thing we learn is what we should have asked. This question was included as a catchall to look for insights we might have missed. Noteworthy responses include:

- Very few practicing lawyers have exposure to the neuroscience literature, and current discussions in neuroscience that are focused on conditions related to aging.
- Law Enforcement has introduced a new model to have a mental health person ride along to provide intercession with people who struggle with mental health issues that include dementia. They act as a liaison to assisting people to obtain necessary

services to remain stable in the community. We work as a multidisciplinary group to identify gaps in our system to address mental health issues (not limited to those who have dementia.) We have social workers who go into the community to work with folks to ensure the information/applications are completed to allow for continued benefits. We do outreach to our pastoral community to discuss resources and connecting people to support in the community.

- I would be clear that dementia is an umbrella term that is not just relevant to older individuals. Cases of dementia that could be related to TBI or other causes are often overlooked.
- Prison and jails cannot help these patients.
- <https://nicic.gov/managing-elderly-corrections> what is best practice in supporting/caring for incarcerated people with dementia?
- In my experience, after just 2.5 years working as a prison psychiatrist, but with a background including earning a JD prior to going to medical school and working as a psychiatrist for 15 years before working in this setting, I have been appalled at the lack of acknowledgement of cognitive limitations in several cases I have been involved with. Without having access to all the relevant background information, the best I can gather is that a defendant who does not bring attention to their dementia may get to prison without anyone else having noticed their impairments.
- I suspect many people are dying on the street due to untreated dementia. I believe homeless people and people with criminal history deserves access to testing, basic needs and care
- Mandatory reporting/arrest for domestic violence inadvertently and detrimentally affects the elderly especially those with dementia.
- I would be willing to join a discussion to look at the challenges inherent in care for dementia prisoners, and how best to train others.
- Need for state and national policies on compassionate release.
- What is the frequency of use of force, segregation, physical restraints, and other control related means utilized with individuals with dementia in the prison system? Frequently I only see an individual with dementia after a period of frequent and high intensity infraction and custody use of force. The infraction records usually state that the individual was not complying with commands or directs from the officer and then force is used. Many reports show some form of lack of comprehension or lack of understanding.
- Security often restrains patients even when medical is asking for them to stop.
- I am just grateful someone is asking.
- I am just happy someone is addressing this issue! We have to start somewhere.
- Where were you all at 10 years ago! (These guys need help!)

## VIII. Interviews of Selected Professionals

The summary and analysis of the interviews was done in two groups: legal professionals and health care professionals. The groupings were made because there was enough difference in responses to make the categorization meaningful. Interview responses were coded and reviewed. If there were two research team members involved in the interview, the team members cross-checked answers. If the interviews were done by just one team member, another team member reviewed the coding with reference to the interview notes, transcript, or in many cases a video recording.

### A. Jail and Correctional Health Care Personnel

The project interviewed 39 individuals who worked in jail and correctional health care settings, spread across the following professions:

- 12 Psychologists
- 6 RNs
- 6 Mental Health Counselors
- 4 Neurologists (one specialized in geriatrics)
- 3 Psychiatrists
- 2 Social Workers
- 1 Geriatric Specialist
- 1 Medical Director
- 1 Medical Administrator
- 1 Case Manager/Program Manager
- 1 Medical Parole Reviewer
- 1 Prisoner Advocate/Former Prisoner

About half the interviewees worked primarily at the pre-conviction stage in jails or as contractors with jails and the other half in post-conviction prison settings, although some jails also house post-conviction prisoners with shorter sentences.

#### ***1. Frequency/Age/Type of Crime***

Most interviewees say they encounter dementia cases either rarely or only a few time per year, although those who worked in a state hospital or a jail medical unit have more frequent encounters, including daily encounters in a rare, dedicated dementia unit where one clinician worked. About 20 percent of interviewees see an upward trend in cases, while the majority had no impression on the subject.

Three general dementia scenarios were identified: (1) first arrest of older individuals with dementia; (2) younger people, mostly male, with dementia-like neurocognitive impairments from traumatic brain injury (TBI,) drug use, or other cognitive impairment; and (3) long-termers who

have developed age-related dementia. Frontotemporal dementia cases tend to fall on the early side of the old age spectrum and are particularly difficult. In the words of one interviewee, “It often starts when the person is in their 50s. By the time they get properly evaluated, everyone has already wrongly concluded the person is a complete jerk.” Interviewees commonly shared the perception that old age begins chronologically about 10 years earlier in correctional settings because of adverse social and environmental stressors: poverty, poor diet, lack of safety, trauma, drugs and violence, and the stresses of incarceration.

Most respondents could not identify any particular pattern with respect to the types of crimes committed by people with dementia. They represented a broad range of crimes, including an example of a sophisticated fraud scheme by a defendant diagnosed with frontotemporal dementia. However, examples of cases actually recalled most frequently involved sex offenses and domestic violence. A few interviewees identified aggressive actions by nursing home residents as a typical cause of police response.

## **2. Diversion**

Most interviewees described diversion as haphazard, without a formal program or protocol for dementia. Almost no one was aware of a formal diversion program in their setting; and less than a third said that, while cases are diverted, there is no formal process for it. A few interviewees pointed to the existence of Crisis Intervention Teams (CITs) in their state to defuse mental health related situations at initial contact and divert them to appropriate community resources. However, they added that those kinds of teams are not necessarily trained to respond to dementia cases. Such teams were less likely to be available in more rural areas.

Even without CITs, interviewees acknowledged that police and other first responders sometimes perform ad hoc diversion, putting an individual on a psychiatric hold or sending them home. The lack of training of police and first responders in dealing with these kinds of cases was identified as a major barrier.

Diversion to community resources also requires the existence of appropriate community resources for these kinds of cases. Every interviewee who addressed this lamented the lack of sufficient community resources capable of and willing to accept people with hard-to-manage behaviors, especially if they had any criminal record of violence or a sex offense. If the individual is a recidivist, diversion becomes even harder, as interviewees felt that the courts and prosecutors tend to dig in their heels in favor of punishment.

Several interviewees identified the need for some kind of facility for temporary placement of people with dementia and mental health issues after arrest to keep them out of jails. The most successful diversions tended to depend on the availability of a family support system. In some cases, families were said to use civil guardianship as a means to manage the family member’s dementia. Without family supports, most acknowledged a high risk of the individual getting placed indefinitely in institutional settings.

About a fifth of the interviewees cited criminal referrals of nursing home residents as a concern, since aggressive and uninhibited behavior can be common in Alzheimer's disease, at least during certain stages. They felt that these cases could be better managed in nursing homes. A neuropsychologist who was interviewed stated, "I was shocked by the zero-tolerance policy in nursing homes... although it's mostly zero tolerance for Medicaid patients! Not private pay – there was more tolerance for those folks."

After arrest, diversion depended heavily upon the views of local prosecutors, many of whom were characterized as very law-and-order oriented, interested in high conviction rates, and unwilling to drop or suspend charges where the alleged crimes are serious. Most commonly voiced was the recommendation for better screening post-arrest, before one falls further into the prison system. Given the inadequacies of diversion, interviewees commonly characterized jails as the default psychiatric institutions of their states that have also become the default for people with dementia whose behaviors cause disruption or injury.

### **3. Assessment & Restoration**

Most of the interviewees in jail and prison health settings considered assessment resources to be lacking or less than ideal. In almost 40 percent of the interviews, assessments were said to be conducted by a psychologist who may be either within the jail system, contracted by the jail, or took place very often in a state hospital where assessments, primarily for capacity to stand trial, are conducted. In only a couple instances did interviewees say they were part of a well-staffed mental health team including psychologists, psychiatrists, nurses and social workers that could provide quality assessments. Most pointed to a need for well-trained neuropsychologists or geropsychologists to properly evaluate cases exhibiting dementias. However, such specialized resources were generally lacking. One interviewee noted that it is impossible to get a neuropsychological evaluation unless you can pay for a private evaluation.

The quality of professionals doing assessments was noted as a problem in several cases. One forensic evaluator noted that once an "expert" meets their state's qualifications (i.e., an 8-hour course), there is no ongoing reassessment or requirement of ongoing training to keep skills current. As a consequence, this interviewee sees reports from other evaluators that are of poor quality. Also identified as a barrier was the limited payment – only \$300 for a forensic evaluation in the state. Interviewees also identified instances where a proper physical exam diagnosed causes of dementia that were easily reversible, such as UTI, uncontrolled diabetes, substance abuse, or medication interactions.

Even with the right professionals, another barrier identified was the difficulty in accessing prior medical records or collateral evidence of the individual's normal level of functioning. This kind of evidence was seen as important for proper diagnosis. People being assessed often don't know or recall their prior history accurately or are not able to identify family or other community

contacts. In addition, getting proper consents to meet HIPAA requirements can be a challenge.

Some interviewees pointed to the fact that there is no recognized protocol for how such assessments of dementia should be conducted in criminal justice settings. Tests used were sometimes limited to preliminary screening tests, such as the MMSE or the Mini-cog. Testing for malingering, such as the TOMM, also appeared to be used often, since there was a commonly held concern that arrestees may feign incapacity. Complicating matters is the fact that much of the testing during the pandemic has been done remotely via telemedicine. This adds additional challenges to accurate testing.

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*An 82 year-old was charged with attempted murder for stabbing his son. The family called the cops but didn't want him arrested, and the cops weren't trained to recognize dementia as a factor in violent behavior. He was sent for three restorations, and it took three years to resolve the charge that could have been resolved in 11 months. He should have gone to the hospital. He is now finally in a Veterans nursing home now.*

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By far, the most common institutional problem identified by interviewees related to dementia is the almost unbending insistence of the courts to seek restoration when individuals are found to be incompetent to stand trial (IST). All interviewees recognized that dementias, other than those caused by reversible acute medical conditions, are quite different from mental health conditions in that they inevitably, progressively decline. Yet, continuing restoration attempts may be insisted upon by the courts even when the clinical experts have already concluded that restoration is not possible.

One interviewee said that unrestorable people in the state may languish in hospitals for decades. A neuropsychologist interviewee stated, "So they end up at state hospitals for long periods of time and get "fake restored" and coached on how to answer the exams. But they fail anyway, and this process repeats 3-4 times. And they don't get time served for time spent in state hospitals." A few interviewees described civil commitment as a disposition sometimes used, especially when the person is found incapacitated to stand trial; but given the time duration limits of civil commitment, these people often returned to the streets only to clash with law enforcement again.

#### **4. Trial and Sentencing**

When a defendant with dementia is deemed to have the capacity to assist in their defense and go to trial, similar assessment issues affect the ability to evaluate the defendant for purposes of a Not Guilty by Reason of Insanity Defense (NGRI). Interviewees often felt that the standard for NGRI in their state was ill-suited for recognizing dementia as qualifying. For example, in states where the NGRI standard focused primarily on the ability to distinguish right from wrong: a person with dementia with the ability to distinguish right from wrong, may still be unable to remember

an event that happened 10 minutes ago or to distinguish an intruder from their spouse.

*Refer to the interview summary of legal informants for additional perspectives of dementia issues at the trial and sentencing stages.*

Where an NGRI defense is successful, interviewees were very consistent in characterizing the prison systems and state hospitals as ill-equipped to manage and care for older people with dementia.

## **5. Incarceration**

Interviewees who worked in post-conviction prison settings identified the physical and mental decline of those individuals with long-term sentences as a major problem. Virtually all also commented on the accelerated aging of the prison population such that old age functionally appears around a decade earlier than in the community at large.

A majority noted a need for dementia-focused training of correctional officers and mental health staff for dementia that gradually develops in prison and is often not diagnosed early enough nor treated properly. “The system is reactive,” stated one interviewee, “only providing a high level of treatment or care when a person goes off the deep end or is seriously suicidal or likely to harm self.”

Similar to what was stated by health professionals in jails, prisons were seen as lacking the neuropsychologist and geropsychologist resources needed to identify dementia early and accurately. Nearly one-third commented on the downward spiral of dementia in prison due in large part to behavioral aberrations being viewed as a disciplinary problem rather than as symptoms of a medical condition. Their experience was that misbehavior is routinely seen by correctional officers as intentional and results in limitations of privileges or punishment such as transfer to special lockups for short or long terms. As one interviewee noted, “If there are lines on the floor that you’re not supposed to cross, and you cross the line, you are disciplined or worse.”

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*“These people are easily victimized ...money, stealing- threatened. Any self-care issues are difficult and other inmates will beat them up if they pee on themselves because they don't want to be around it.” A Prison geriatrician.*

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Problems of victimization by other prisoners were also identified by roughly 10 percent of the interviewees. It was said that old people and those with diminished abilities are viewed as weak, and prisoners come after them. They are exposed to theft, physical harm, or intimidation. In the last two years, the impact of the pandemic has resulted in a reduction of the prison populations according to most interviewees, but it has also resulted in shortages in staffing, further exacerbating prisons’ ability to properly manage dementia.

This dismal picture of dementia in prison was common but not at all universal. It was clear

from the range of interviewee responses that the operation and culture of prisons vary widely between and within states. The resources available to prisons varied dramatically. One professional in a women’s prison noted that the prison has a very robust mental health staff capable of doing assessments, including several psychiatrists, psychologists, social workers, and a medical director. However, these resources were not the norm in most prisons. One interviewee in a rural western state noted that their prison lacked even sufficient physician back-up for medical care, much less resources to deal with mental health conditions and dementia.

One interviewee noted that the highly structured environment, consistency, routines, and predictable activities of their prison provided stability for people with dementia and enabled some inmates to function better than they would in any other setting. Some 5 percent of interviewees reported that their state’s system had special programs such as trained inmate helpers or units for older and medically impaired individuals, including those with dementia. One interviewee successfully developed a specialized unit in a state prison specifically for people with dementia. Another interviewee felt that younger residents were generally kind to older residents with dementia, unless their behavior was aggressive. If behavior became unmanageable, they were then transferred to the state mental hospital.

## **6. Specialized Units**

One need most consistently identified by interviewees was for skilled nursing/memory care units for people diagnosed with dementia and other chronic conditions needing 24/7 care. The issue of whether those units should be within the prison system or outside the prison system and in the community generated differing views, based more on interviewee’s assessment of political, financial, and social realities in their states.

The cost of such care provided within the prison system must be borne by the prison system, since Medicare and Medicaid generally do not cover that care for inmates. A few interviewees described such specialized units within their system, though even in those cases, limited capacity posed challenges.

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### ***A Public Private Partnership Example***

*In 2013, Connecticut contracted with a private nursing home company to operate the state's first long term care nursing center for the justice-involved population and individuals who are otherwise challenging to transition and place in an appropriate site of care in the community. The 95-bed facility, named 60 West is a Medicare/Medicaid certified and state licensed Long Term Care Facility. Individuals referred for potential admission to the facility receive an onsite comprehensive assessment, including a risk review, in addition to the standard nursing home pre-admission screening. A committee comprised of Department of Mental Health and Addiction Services, the Department of Corrections, and 60 West staff approves admissions. The referral process reviews eight questions assessing the individual's*

*needs and safety risk. Generally, admission candidates have a chronic degenerative condition such as dementia, requiring skilled nursing care. The facility has a secured a cognitive impairment unit and an open long- term care unit.*

See: <https://www.cga.ct.gov/2020/rpt/pdf/2020-R-0092.pdf>.

Many interviewees felt that such care would be better provided in secure, forensically focused private nursing homes in the community, and a couple of rare examples of such facilities were identified. Such care would be covered in most instances by Medicaid, given the generally low income and resources of this population. More commonly, interviewees spoke of major barriers in placing incarcerated people in community facilities, because of nursing home and community resistance to accepting felons, and in particular, those with any kind of history of violence or sexual offenses. Nursing homes have a financial disincentive too, since the staffing and training needs of a forensically focused nursing home would likely be greater than other nursing homes. A preferable solution, according to one interviewee, would be a public-private partnership between the prison system and private nursing homes that also have the ability to draw upon Medicare and Medicaid to cover the cost of care.

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#### ***A Federal Memory Disorder Unit***

In 2019, an innovative Memory Disorder Unit opened at FMC Devens, a federal medical center adjacent to a minimum-security prison in Massachusetts. The unit is staffed by inmates who are Certified Nursing Assistants and have completed the Massachusetts state required nursing assistant course and meet state requirements for certification. The staff nurse educators are certified as Certified Correctional Personnel Dementia Trainers and the correctional guards are certified as Certified Dementia Trained Correctional Personnel, after completion of the Alzheimer's Disease and Dementia Care curriculum developed specifically for correctional facilities by the National Council of Certified Dementia Practitioners.

See <https://www.nccdp.org/resources/caring-for-inmates-in-a-specialized-dementia-unit-in-a-correctional-setting.pdf>.

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#### ***The Gold Coat Program***

The Gold Coat Program began in 2009 at the California Men's Colony State Prison in San Luis Obispo, to train healthy inmates to care for those with dementia and other cognitive impairments. The name comes from the gold smocks they wear. The inmates have life or very long sentences, no recent disciplinary violations, no history of mental, emotional, or cognitive issues and impairments, and a commitment to in-prison community services. The inmates must complete a 12- month training course given by the Alzheimer's Association.

See <https://www.marshallproject.org/2015/08/27/when-prisons-need-to-be-more-like-nursing-homes>.

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### ***A Prison Hospice Example***

Louisiana State Penitentiary (Angola) has a large population of aging men serving long sentences with little hope of reprieve. Eighty-five percent of the inmates incarcerated in Angola are expected to die there.

The prison, in 1998, in partnership with University Hospital Community Hospice in New Orleans, created a hospice, with care provided within the prison infirmary by prison staff and trained inmate volunteers. Inmate volunteers in Angola sign up for 40 hours of training before they can become a part of a patient's four-person rotation and perform hospice duties. The hospice was developed and services are delivered without additional cost to the prison. Consultation, training, and support was provided by the community hospice. See Carol Evans, Ronda Herzog, Tanya Tillman, "The Louisiana State Penitentiary: Angola Prison Hospice," *S(4)J. Palliat. Med.*,553-5 (August 2002).

See <https://pubmed.ncbi.nlm.nih.gov/12243680/>

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Many interviewees also identified long-term supportive services in the community as the preferable option for many in the prison system whose dementia no longer made incarceration appropriate or safe, but rarely were such services accessible. Programs such as adult day care were identified as sorely needed by inmates, but prisons have little capacity to create such programs internally, and accessing them in the community is nearly impossible.

Given the community opposition to placing or serving people with serious criminal records in the community, many felt that the only real option was to create special nursing home-like units in the prison system.

### ***7. Release and Reentry***

For incarcerated people with dementia who become eligible for parole or who complete their sentences, interviewees voiced similar challenges to those discussed under "Diversion" above. Success in returning to the community often depended primarily on the availability and support of family members. The lack of community services geared to this population and the resistance of care facilities to take people with serious criminal records poses sometimes insurmountable barriers. Reentry resources were commonly described as temporary assistance with prescriptions, transportation, and housing.

For people with dementia, especially when family caregivers are unavailable, finding housing and community services placements was seen as most difficult. One interviewee identified a need for some sort of quasi-inpatient, secure, long-term care facility in community with specially trained staff.

Interviewees also pointed to barriers in the process itself, noting inadequate discharge planning resources and poor coordination in handoffs to probation and parole. In the words of one prison psychologist, “There’s not enough housing, not enough social workers, and not enough case management and supervision.” The level of effort and coordination needed to reestablish benefits such as Medicare and Medicaid or Veterans benefits, and coordinate medical care and social services, and help the individual transition into supportive housing or a care facility is substantial.

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### A Placement Success Story

*"Most nursing homes won't take people with felony charges. We had one older individual with arson charges who really needed a nursing home level of care. It took a ton of extra work with our prison hospital staff meeting with the nursing home to persuade them. We finally agreed on an acceptable behavior management plan (e.g., how we will prevent this person from burning down the nursing home), but it worked out well. The case was a rare success."*

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Interviewees who worked at higher levels in the system emphasized a need more broadly for better communication and coordination efforts between courts and communities, community facilities and services, and families, as well as the community at large to improve reentry. Huge attitudinal barriers are difficult to overcome and triggered by labels such as felon, predator, sexual offender, violent offender, murderer.

The lack of resources butts up against what one interviewee described as so much pressure to get people out that there is corresponding pressure to accept any placement that says “yes,” even if it’s not that appropriate. Group homes tended to be the default, despite that they were plagued by a multitude of problems. They were described by one interviewee as “People being paid very little to manage very sick and complex individuals. They are quick to call police if behavior gets hard to handle.”

Alongside the parolees being pushed into the community are people incarcerated for life or longer durations without the availability of parole and who suffer from dementia or other serious chronic conditions. Interviewees were asked about the possibility of medical parole or compassionate release. The criteria for both of these were viewed as unreasonably high by many interviewees. Unless in an advanced stage, dementia was not deemed a serious medical condition eligible for medical release; and the criteria for compassionate release according to several interviewees required the existence of a terminal condition. The fate of these long termers was often to remain in the general prison population. The prisons of some interviewees had medical units to which they would be transferred. A very few, as noted earlier, had more specialized units or inmate volunteer caregiver programs (such as California “Gold Coats” or Louisiana’s Angola

Prison Hospice), but the default in a number of states for handling difficult behavior was a state hospital.

## **8. Training**

Every interviewee, without exception, identified the need for specialized training in dementia, as well as more and better training in behavioral health conditions across the board. The majority targeted mental health staff and corrections officers as the foremost priority, followed by lawyers and judges. Also identified were law enforcement, crisis intervention teams, other first responders, probation and parole officers, and nursing home staff.

One interviewee extended the need for training to families, stating, “Families need more training to understand the trajectory of dementia and know how to communicate it to 911. Instead of ‘Father’s running around with a knife,’ they need to say, ‘Father’s having a breakdown.’”

It was noteworthy that many of the interviewees, all health care professionals, pointed out that even mental health staff generally get little or no specialized training in dementia/neurocognitive issues. One interviewee stated that in her state’s system, “Most training at all levels is about serious mental illness, not cognitive or intellectual impairments. Dementia often flies under the radar, because of so many co-morbidities.” One substance abuse counselor noted that counselors must take 40 hours of continuing education per year, but none on dementia. In commenting on training, a number of interviewees reiterated the need for dementia specialists such as neuropsychologists and geropsychologists.

A veteran public defender was pleased to report that in his state, indigent defense services has run many trainings on dementia, and it has made a difference. He reported that prosecutors used to pushback intensely against considering dementia and routinely pushed these cases to trial. Today, they are more likely to dismiss the charges: “It changed because of more mental health training, use of testimony, and awareness in general.”

One interviewee with extensive training experience emphasized that training must be more than sitting through an online module. Rather, it should be interactive with an adult level of engagement. For law enforcement, video and body cam footage is helpful. First responders need to learn the skills to slow down and diffuse a situation. This would include more verbal de-escalation training, as well as appropriate holds and physical maneuvers.

One neuropsychologist interviewed stressed that, in the end, training for all stakeholders needs to involve a fundamental rethinking of the goals and processes of the criminal legal system with respect to neurocognitive disorders of aging:

“Criminal justice needs to catch up with neuroscience... Just as a juvenile may be deemed not criminally culpable because of their brain development, adults with a variety of brain impairments should not be found culpable.”

## B. Legal Professionals

Thirteen interviewees representing various legal perspectives and consisted of:

- 7 Defense Attorneys
- 2 Correctional Practitioners
- 1 Police Officer
- 1 Attorney who Works in Medical Parole
- 2 Judges

Interviewees were all highly experienced in their positions with many collateral accomplishments and credentials.

The survey of police was not able to be implemented, but one interviewee who had many years of experience as a police commander in a large city noted that police officers for the city, as part of their initial training, receive training on social conflicts such as domestic violence as well as some mental health training, but no training on dementia. Officers receive annual training related to firearms, but not on mental health needs. The cases that stood out most for the commander were those in which police were called because the person with dementia had wandered and was missing or was otherwise creating a behavioral problem and appearing very confused. The commander's city has adopted the practice of using crisis response teams (CRTs) which help divert cases from criminal processing to medical settings. However, a shortage of clinicians and social workers limits this kind of support to the police on the street. The commander advocated the need to identify these cases even prior to a first encounter by having 911 operators and dispatchers trained to ask initial screening questions and to convey that information not only to police but to Fire and EMS.

The attorneys interviewed included both private practitioners and public defenders. The following summarizes the experience of all but the judges with people exhibiting symptoms of dementia in the criminal legal system. The judges' input is separately described below.

### **Frequency**

Interviewees reported encountering dementia cases infrequently. Most did not perceive an increase in older defendants or more cases with signs of dementia, although in many cases, dementia is mixed with mental health problems and therefore, may not receive attention. The dementia cases they encountered did not trend toward any particular types of crime.

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### ***The Downward Spiral***

*Attorney LM had a client in his 50s with both schizophrenia and dementia symptoms, and who had a serious criminal charge. He was determined incompetent to stand trial and sent to the state psychiatric hospital for restoration. The state hospital will hold someone only for a few months and, in his case, concluded that he was not restorable. He was eventually let back out on the street and got arrested again after stabbing a person in the neck, almost*

*killing the person. The prosecutor this time opposed the motion to find him incompetent to stand trial and won. Yet, there was no way for defense counsel to represent the individual at trial. The only option he had was to work out a plea deal despite that the defendant really didn't have the capacity to consent.*

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One attorney acknowledged that he probably had a hundred dementia cases in his career but never recognized it until he had personal experience with his mother and a colleague both, suffering from dementia. He added that lawyers and judges don't see dementia because they are not trained to see dementia. Indeed, for mental health issues in general, including dementia, the attorney put it this way, "You have to be naked and baying at the moon in order for most lawyers to recognize that they have a mental health problem before them."

### ***Assessment and Diversion***

Only one of the interviewees had any kind of formal diversion programs in their jurisdiction, but it was quite limited. Prosecutors have the discretion to refer arrestees to the program – called the pretrial intervention program - if the person has nothing serious on their past record. The program requires the individual to participate in therapy and to take classes in topics such as anger management, and to perform a certain number of hours of community service. It clearly would not be appropriate for someone with dementia.

Assessment at the pre-trial stage was generally considered inadequate by all except one interviewee, who noted that his county provides good evaluations and good medical care, but that there is no unit available to properly care for dementia. In one case described, the person is either kept in the jail infirmary in isolation, or, if released to the community, there are few if any reentry type support services. In this jurisdiction, the person can be sent to a psychiatric hospital; but that is not ideal, and they can not be held for more than 90 days.

What constitutes a good assessment in the first place is not something well-defined. One interviewee highlighted the fact that there is no standard that prisons conform to for assessing dementia. Getting outside medical records can be vital for assessments, but interviewees described difficulties in getting medical records from providers, because of HIPAA regulations and the challenge of getting authorizations from people with decisional capacity issues.

The interviewees reported that attitudes of prosecutors vary by county. Law and order prosecutors tend to prosecute, not divert. In one of the attorney's words, "Mental health defenses are generally held in low regard in the criminal justice system; it's like an excuse."

Arrestees with minor, non-violent charges will often get dismissed. A typical pattern noted was dismissal of minor crimes, returning the defendant to the community, where supportive resources are generally lacking unless the person has family willing to help. These cases have a fairly high likelihood of recidivism, until a more serious incident results in prosecution.

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*Public defender: I have a client, a defendant in a homicide case, sitting in the state hospital for almost a decade, because he was found not competent to stand trial; but restoration is not possible, so he may sit there indefinitely. Nowhere else to go.*

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For more serious cases, attorneys reported that state mental health hospitals are commonly relied on to assess capacity to stand trial and to restore capacity. Since defendants with dementia who lacked capacity to stand trial are normally not restorable, they viewed state facilities for mental health restoration to be an inappropriate option for dementia. Depending on the state, three different scenarios post-arrest for people with dementia were described, none of which addressed the underlying needs or condition of the defendant.

In the first, the defendant is released back into the community from the state mental hospital where resources such as halfway houses or other residential facilities are usually inadequate for their care. If the case involves a sexual offense or violence, placement may be difficult, since nursing homes and other residential placements tend to resist accepting such cases. The judge may also determine that community safety or potential community backlash may outweigh the defendant's needs. This leads to the other two scenarios: remaining in the mental hospital for restoration indefinitely (sometimes longer than their prison sentence would have been), or being deemed capable of standing trial and convicted, in which case they enter prison highly vulnerable to deterioration and abuse. If found NGRI, one attorney described a promising program. (See below).

In some more research-rich jurisdictions, there may be assessment resources other than state mental hospitals available locally. Defendants with money can also access more resources for assessment in the private sector, but the attorneys all converged on the opinion that the psychologists and the psychiatrists that are called upon to do these evaluations usually lack sufficient knowledge, experience, and proper tools for evaluating dementia. Even neuroimaging, while helpful, is often seen as inconclusive and controversial, especially if collateral evidence is weak. Public defenders and those in rural areas tend to have even fewer resources, although one attorney praised the availability of assessment resources at a local university.

Most of the attorneys were emphatic that the best assessment starts with a thorough social case history by a qualified social worker, because it helps identify and fill-in a more holistic and longitudinal progression of the individual's condition. Building collateral evidence in addition to medical evidence is important in these cases. Some of the private attorneys interviewed employed social workers on their staff.

## **Not Guilty by Reason of Insanity (NGRI)**

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### ***The Philosophical Chasm***

*"There is a wide gap in mission and philosophy between the criminal courts and civil mental health systems: The criminal courts are focused on control and supervision. The civil commitment and mental health systems are focused on autonomy, necessity of the least restrictive alternative, and respecting individual choice, including the right to refuse medications. The result: those with dementias that will only decline have repeating cycles in and out of both systems." A Chief Public Defender*

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One attorney pointed to the development in their state of a progressive program for people found not guilty by reason of insanity (NGRI) that the attorney viewed as very successful. They are sent to the state hospital where they get treatment and often go back into the community in a supervised setting. They are overseen by a special NGRI Outreach Clinic which provides very good monitoring and coordination of treatment and services for at least their entire sentence, even for those with life sentences. The shortcoming, however, is that others who enter the criminal legal system and never go to trial; they are determined to lack the capacity to stand trial do not get those community services. It is assumed that the civil mental health and probate court will address their problems, which has not been the case.

### ***Incarceration and Reentry***

One interviewee whose work is in a correctional setting described several environmental conditions detrimental to people with dementia as well as older people in general, including:

- The lack of disability accessible spaces (for wheelchairs, beds, etc.)
- Lack of variation in painting, poor signage, adverse lighting conditions
- Uncomfortably noisy and malodorous environments
- Multiple levels of stairs and use of bunk beds
- Lack of hand bars or rails or door openers

Added to this is the culture of the environment, which was described as viewing all failures to follow orders or directions as misbehavior requiring punishment (which can include solitary confinement). All these factors speed up the deterioration of anyone experiencing dementia. To quote: "It just destroys people."

### ***Recommendations***

Resources:

- ▶ Facilities and community support services with care coordination need to be developed to meet the long-term care needs of people with dementia (as well as people with mental health issues) in order to enable meaningful diversion from entering the criminal

legal system. To implement this goal, one interviewee recommended legislation to authorize criminal courts to treat those found incapacitated to stand trial (and not amendable to restoration) for as long as their sentence could be if convicted, with the aim of reintegrating them into the community or a residential facility under intensive supervision by a clinical team. The geographic disparities in resources were noted as an especially difficult challenge. The lack of community resources needs to be addressed at both the front end and the back end (parole, compassionate release) of the continuum.

- ▶ Public defenders in particular need greater support in investigative resources, medical assessment, and analysis of evidence with dementia and mental health issues. They lack time because of large caseloads and their clients lack the ability to pay to access such resources.

#### Diversion:

- ▶ All recommended prioritizing diversion up front and acknowledge the multiple resources needed to make that happen in terms of training and resources for evaluation, care and treatment.

#### Corrections issues:

- ▶ Two of the attorneys who had experience with parole, commutation, or early release issues reiterated the theme of inadequate geriatric expertise in the system and noted especially the need for changes in compassionate release criteria to include not only terminal illness, but also disability, including dementia, in which the person is not a danger to the community.
- ▶ While prisons must in theory comply with the Americans with Disabilities Act, compliance is marginal or poor in an undetermined number of prisons, and even when basic accommodations exist for physical disabilities, the environmental conditions remain averse to people with dementia as well as intellectual disabilities. Stronger efforts are needed to raise the baseline of environmental quality for these groups.

#### More and better training, specifically:

- ▶ Training for early identification and screening of mental health issues, including dementia, by lawyers and police. The assumption is the earlier treatment and care management is provided, the better the chances of good outcomes.
- ▶ More training in defense attorney practice skills, specifically in how to build a case (for either incapacity to stand trial or NGRI) not only through medical evidence but with in-depth records investigation of one's family, social, educational, and work history.
- ▶ One aspect of attorney skills that was highlighted for lawyer training is how to work with clinicians to assess capacity to stand trial. Clinicians may read a legal definition but don't really understand all the elements and abilities needed to assist counsel in defending the case. And lawyers don't know how to use the elements of clinical

evaluations at every step of the case from bail hearing to sentencing, and beyond that to parole and commutation.

### ***Jurisprudence cultural, policy, and practice changes needed***

The science on dementia needs to penetrate the thinking about sentencing schemes in the way that the neurological development of juveniles' brains has affected the courts handling of juvenile criminal cases. It requires a combination of recognition by legislatures and courts of dementia and its impact on human development and criminal behavior. This includes rethinking standards for incapacity to stand trial and NGRI.

Practice guidelines for the criminal courts that address dementia are needed. In forensic mental health, there are practice guidelines that have been developed by the American Academy of Psychiatry and the American Psychological Association. The American Bar Association has Criminal Justice Standards on Mental Health, but in the opinion of one respondent who participated in their development, these existing standards do not sufficiently address or provide guidance on dementia.

### ***Judges' Perspective***

The judges focused primarily on the need for a strong diversion program and high-quality assessment at the first stage of contact with arrestees. A diversion court such as one created in Miami-Dade County, Florida, was a suggested model. The following information about the programs is derived from the interviews and web-based program information.

### ***A Promising Model that Could Encompass Dementia***

Florida's Eleventh Judicial Circuit in Miami-Dade County established the Criminal Mental Health Project (CMHP) in 2000 to divert individuals with serious mental illnesses (SMI) or co-occurring SMI and substance use disorders away from the criminal legal system and into comprehensive community-based treatment and support services. SMI includes conditions such as major depression, schizophrenia, bipolar disorders, and trauma), but the screening resources of the program are also able to screen for dementias and other brain disorders. The front-end component of the program includes a Crisis Intervention Team that focuses on prebooking jail diversion. It consists of Crisis Intervention Teams that works with law enforcement officers that have also undergone diversion training. The second component of the program focuses on post-booking screening and diversion serving individuals booked into the county jail and awaiting adjudication.

The court identifies itself as a diversion court, not a mental health court, because it takes virtually all misdemeanors and non-violent felonies. With 13 full-time psychiatrists, assessments are available without delay. The court does not assess for capacity to stand trial, but rather for diversion. In the case of a serious felony where a judge or a party raises the issue of capacity to stand trial, assessment resources assess for that too, but the person will not be institutionalized for restoration. More likely, there will be an evaluation to determine if the insanity defense is

applicable.

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Judge: “The Criminal system is a repository for failed public policy.” ... We need to get people treated, not restored.”

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Wrapping around these two components are an array of resources and services for further assessment, case management integrated with community-based treatment and support services, and other resources such as help in accessing federal and state benefits. The planning and support services have been especially targeted at those who might otherwise be noncompliant with treatment or likely to fall back into behaviors that trigger law enforcement contact again.

The impact of the CMPH has been a significant drop in recidivism rates, so much so that one of the county’s three main jails was closed, at a savings of \$12 million per year. The savings have enabled new investment in a new mental health justice/treatment facility that co-locates the courtroom with the services described above, along with providing primary health care to address multiple co-morbidities, short-term residential, transitional housing, and employment and vocational services.

A key requisite for the success of the program has been training at all levels from the judges down to law enforcement officers. So far, over 7600 police officers have completed a 40-hour training program on crisis intervention police training. While mental health issues have been a primary focus, mental health has not been the only focus, and with the inclusion of training, assessment, and community-resources targeted to providing long-term care to people with dementia, the program serves as a powerful model for the nation.

### ***Conclusion***

Several facts appear across the spectrum of this research coming up in published professional literature, case law, interviews, surveys and the South Carolina database analysis: the number of people living with dementia involved in the criminal legal system is growing, and the correctional system and correctional health care are by and large unable to provide appropriate care, and often create a danger to the life of the person. The dramatic increase in the percentage and number of people with dementia will increase this crisis unless steps are taken. The current system of referring defendants found unable to assist counsel to stand trial for mental health restoration is a total failure for people with dementia, and often results in harm. There is a near total lack of placement and care options for people living with dementia who have a history of violence. Nationally there is a lack of data on how many people living with dementia are involved in the criminal legal system.

### ***Next Steps and Dissemination***

This research is drawing interest, even before the report is published. The findings and recommendations contain action steps for moving forward.

A journal article has been submitted to the *“International Journal of Prisoner Health”* titled *“Dementia in the Incarcerated Population: A retrospective study using the South Carolina Alzheimer’s Disease Registry, USA.”* It is anticipated that article will be published before the end of 2022.

Lucy Guarnera, PhD, a member of the research team will present at the National Academy of Neuropsychology (NAN) annual conference, which will take place on October 12-15 of 2022 in Denver, Colorado. Title of presentation, *“Persons Living with Dementia and the Criminal Legal System: What Neuropsychology Can Offer.”*

The May Issue of BIFOCAL, the e-journal of the ABA Commission on Law and Aging included an article *“The Experience of Persons with Dementia in the Criminal Legal System”* written by David Godfrey, JD, Director of the ABA Commission on Law and Aging and a member of the research team.

Abstract to speak has been submitted to the American Public Health Association for a presentation at their annual meeting by Jennifer Bronson.

If you are interested in being a speaker on the subject of this research please email [David.Godfrey@Americanbar.org](mailto:David.Godfrey@Americanbar.org).

# Appendices

## A. Full Review of Case Law

### Dementia in Criminal Appeals: A Review of the Case Law\*

\* Paper written by Kevin Bui, Class of 2023, University of Virginia School of Law

#### I. COMPETENCE TO STAND TRIAL

Most case law regarding dementia centers on the adjudication of competence to stand trial. Competence refers to the “ability to consult with [one’s] lawyer with a reasonable degree of rational understanding and whether [one] has a rational as well as factual understanding of [the] proceeding[s],” without which one cannot stand trial or be convicted or sentenced without violating due process.<sup>1</sup> Case law reveals several recurrent issues regarding the competence of persons with dementia who have been charged with a crime.

#### A. Procedural Protections for Ensuring Competence

The first important issue is whether there were adequate procedures to “protect a defendant’s right not to be tried or convicted while incompetent to stand trial.”<sup>2</sup> Specifically, defendants have alleged that a court deprived them of due process by refusing to authorize a competence assessment or hold a competency hearing upon the defendant’s explicit request -- or to order an evaluation *sua sponte* (on its own motion) even if the defendant did not raise a request. The alleged error in these cases is not that the court has incorrectly adjudicated the defendant as competent, but that the court erred in failing to order a hearing to determine competency in the first place, given the defendant’s apparent impairments. Relevant factors in evaluating such a claim may involve the defendant’s medical history or behavior in and out of court.<sup>3</sup> Non-dementia case law suggests that the bar for raising a successful due process challenge on appeal may be high.<sup>4</sup> But dementia-related case law suggests that the bar may be particularly difficult to meet for those afflicted with dementia. Specifically, the subtle presentation of symptoms and variability in behavior found in dementia-related diseases may make appellate courts reluctant to second-guess trial court failures to order an assessment after the trial has already occurred.

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<sup>1</sup> Dusky v. U.S. 362 U.S. 402 (1960).

<sup>2</sup> Drope v. Missouri, 420 U.S. 162, 172 (1975).

<sup>3</sup> *Id.* at 180.

<sup>4</sup> See U.S. v. Garza, 751 F.3d 1130, 1135 (9th Cir. 2014). See, e.g., Woolfolk v. Kentucky, 339 S.W.3d 411, 421-23 (Ky. 2011) (holding that trial court did not abuse its discretion in not granting defendant’s motion to hold a competency hearing when defendant’s doctor told him he was suffering from early symptoms of disease, when he had a history of dementia in his family, when he experienced sudden memory loss regarding a “significant admission [the defendant] had made to trial counsel only moments before”, and when the court explained defendant’s memory-loss as being due to an emotional reaction to the victim’s testimony).

*U.S. v. Garza* is illustrative, where the appellate court rejected the defendant's claim that the judge deprived him of due process when the judge failed to order a competency hearing based on his alleged dementia. The court noted that, to prevail on a due process claim, there "must be substantial evidence that, due to a mental disease or defect, the defendant is unable to understand the nature and consequences of the proceedings against him or to assist properly in his defense."<sup>5</sup> Relevant factors were "medical history, the defendant's behavior in and out of court, and defense counsel's statements about the defendant's competency."<sup>6</sup> The court noted that caselaw revealed that medical history was usually very important.<sup>7</sup> The court summarized the overall legal standard in two requirements: 1) "strong evidence of a serious mental disease or defect" and a 2) "clear connection between that disease or defect and some failure by the defendant to understand the proceedings or assist in his own defense."<sup>8</sup> The court then reasoned that since there was a lack of medical history and experts disagreed about the diagnosis, the defendant's behavior had to be abnormal to prove that there was a serious mental disease.<sup>9</sup> But the defendant had exhibited "appropriate behavior in interactions with other prisoners and staff," "sat through trial and testified without incident," and was able to describe various actors in the criminal justice system.<sup>10</sup> The defendant also appeared to anticipate some of the prosecutor's questions.<sup>11</sup> The behavior was not sufficiently abnormal to raise serious doubt about competency.<sup>12</sup> Furthermore, there was "no clear connection between [the] disease and some failure . . . to understand the proceedings or assist in [the] defense" since the defendant "testified and allocated unremarkably with no complaints from counsel."<sup>13</sup> Finally, the fact that the defendant's lawyer in a previous competency hearing dropped the issue of competency suggested that the defendant was competent.<sup>14</sup>

Although there may be nothing flawed about the outcome in *Garza*, the legal standard may be too high for defendants afflicted with dementia to meet. First, there may be a lack of the continuous, sustained observation necessary for a dementia where behavior may fluctuate, and a defendant could appear normal on particular isolated incidents. It is also unclear how apathy and natural fluctuations in behavior are considered in the analysis of behavior. There was no such discussion in *Garza*, for example. Second, counsel's lack of familiarity with the symptoms of dementia or how behavior may fluctuate may cause counsel to drop the motion or not raise any concerns about the defendant's competence, and counsel's action or inaction may subsequently be used as evidence that the defendant is competent. Third, a defendant

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<sup>5</sup> *Garza*, 751 F.3d at 1134.

<sup>6</sup> *Id.*

<sup>7</sup> *Id.* at 1135 ("an appellant who has absolutely no medical history evidence indicating incompetency will almost certainly fail to upset his conviction").

<sup>8</sup> *Id.*

<sup>9</sup> *Id.* at 1137.

<sup>10</sup> *Id.*

<sup>11</sup> *Id.* at 1133.

<sup>12</sup> *Id.* at 1137.

<sup>13</sup> *Id.*

<sup>14</sup> *Id.*

may have had undiagnosed dementia prior to the hearing since the symptoms may have been hard for the defendant to notice, thus making formal medical history sparse. A successful due process challenge based on the trial judge's failure to order a pre-trial competence appears to be an uphill battle. The implication is that defense attorneys should seek a competence exam whenever they have a good faith doubt about the cognitive capacities of the client, especially if the client is older than 50.<sup>15</sup>

### B. Adjudication of Competence

Logically, one would imagine that that the adjudication of whether a defendant with dementia has the capacity to understand the proceedings and the charges against him and to assist counsel would be pretty straightforward. However, a diagnosis of Alzheimer's disease or other form of dementia does not automatically render one incompetent, rather, whether an individual with dementia is competent largely depends on the progression and severity of the disease.<sup>16</sup> So, even when the diagnosis is contested, the prosecution may take the position that the disease has not progressed to the point where it precludes competence to stand trial.<sup>17</sup> In such contested cases, the assessment and the testimony may turn on some fine questions about the defendant's cognitive abilities. For instance, the court in *U.S. v. Brown* held that Alzheimer's disease made the defendant "severely impaired in her ability to plan a legal strategy" as a result of "substantial deficits in recalling names and dates."<sup>18</sup> Another court held that the trial court erred in failing to hold a competency hearing, finding that the defendant's frontotemporal dementia could have impaired the defendant's impulse control such that he could not allocate in sentencing without potentially hurting his own case.<sup>19</sup>

A recurrent issue in competence adjudication involving defendants with dementia is whether variability in behavior and abnormal test scores in a competence assessment is attributable to dementia symptomology or to malingering. Specifically, Alzheimer's disease, frontotemporal dementia, or atypical Alzheimer's disease affecting the frontal lobes can cause apathy, lack of motivation, and sensitivity to changes in extraneous environmental factors.<sup>20</sup>

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<sup>15</sup> See, e.g., *Dreyer*, 705 F.3d at 957, 963-65 (holding that trial court erred in failing to order a competency hearing even though the defendant did not request a hearing at the time of trial, after multiple experts-including the government's witness- testified that defendant had frontotemporal dementia, when the defendant had no criminal history prior to the crime and had a drastic change in behavior after a medical emergency, and the defense counsel told the court that the defendant would not allocate because counsel [did not] know what he [was] going to say" and "could speak inappropriately").

<sup>16</sup> See *U.S. v. Gigante*, 996 F.Supp. 194, 219 (E.D.N.Y. 1998). Cf. *Trevino v. Arellano*, No. 09-1048.330, 2009 WL 1492559, at \*1 (10th Cir. May 29, 2009) (noting that amnesia about a crime does not make one per se incompetent); *U.S. v. Bradley*, No. CR405-59, 2006 WL 8429613, at \*6 (S.D. Ga. Jan. 24, 2006) (noting that "forgetting his keys, forgetting to shave," and other "minor memory lapses "do not foreclose his ability to interact with his attorney and plan his defense").

<sup>17</sup> *James v. Boles*, 339 F.2d 431, 433 (4th Cir. 1964).

<sup>18</sup> *U.S. v. Brown*, 147 F.Supp.3d 312, 325-26 (E.D. Pa. 2015).

<sup>19</sup> *U.S. v. Dreyer*, 705 F.3d 951, 962 (9th Cir. 2013). See also *U.S. v. Rothman*, No. 08-20895-CR, 2010 WL 3259927, at \*33 (S.D. Fla. Aug. 18, 2010) (Frontotemporal dementia impairing language function such that defendant could not "comprehend what statements [in the pre-sentencing report] really allude to").

<sup>20</sup> See *Rothman*, 2010 WL 3259927, at \*12.

These symptoms can lead to variability in behavior and test scores. However, courts often conclude that the variability in behavior and test scores is attributable to malingering rather than dementia, either because the defendant did not suffer from dementia or the malingering explained most of the symptoms, even if genuine dementia could have existed. Courts have considered two factors when evaluating dementia-based explanations for variability in behavior and test scores: 1) the degree to which behaviors are consistent with physiological indicators, test scores, and genuine dementia symptomology, or 2) the amount of physical evidence supporting a dementia-based explanation of variability.

The complexity of the diagnosis, as well as a considerable degree of judicial skepticism about dementia-based claims of incompetence are illustrated in the following cases. Highlighting the importance of physical evidence supporting a dementia-based explanation of the defendant's behavior, the court in *U.S. v. Patel* ignored expert testimony supporting the dementia diagnosis, opining that the defendant's evidence of dementia was based on self-report instead of physical evidence.<sup>21</sup> Even if there is substantial physical evidence indicating genuine organic pathology, courts may be persuaded instead by behavioral evidence indicating malingering. For example, in *U.S. v. Gigante*, the court rejected the defendant's explanation of variability in test scores as being due to apathy and held that malingering caused most of the defendant's symptoms despite physical evidence of early Alzheimer's disease.<sup>22</sup> Here, the degree to which behaviors were inconsistent with physiological indicators, test scores, and clinical symptomology was dispositive. While the defendant's brain scans were consistent with Alzheimer's disease since they showed hypometabolism in the temporal and parietal areas, he acted in ways highly inconsistent with neuropsychological test results and physiological indicators. For example, the defendant's poor performance on multiple neuropsychological tests belied his ability to hold multiple interview questions in his short-term memory.<sup>23</sup> The defendant also allegedly had auditory and visual hallucinations and exhibited an unusual catatonic state in the court room.<sup>24</sup> This severely impaired behavior was simply inconsistent with typical clinical presentations and with brain scans showing only mild hypometabolism and no lesions consistent with vascular dementia.<sup>25</sup> The court also appeared to ignore one expert witness's argument that that there could have been malingering in the beginning that evolved into genuine, severe dementia.<sup>26</sup>

In contrast, the court in *U.S. v. Rothman* held that the defendant was incompetent after finding that the defendant's frontotemporal dementia and concomitant frontal lobe degradation caused variability in test scores and behavior.<sup>27</sup> The court accepted expert

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<sup>21</sup> *Id.* at 125-27.

<sup>22</sup> *Gigante*, 996 F.Supp. at 222.

<sup>23</sup> *E.g., Id.* at 226. ("That he could remember for 20 minutes a topic of conversation is an example of the integrity of implicit memory that [is] not consistent with the profound impairment he shows on formal tests of memory").

<sup>24</sup> *Id.* at 205, 219.

<sup>25</sup> *Id.* at 220-22.

<sup>26</sup> *Id.* at 217.

<sup>27</sup> *Rothman*, 2010 WL 3259927, at \*36.

testimony arguing that people with frontotemporal dementia were particularly vulnerable to motivational deficits and to anxiety-inducing situations, and therefore that one needed to evaluate malingering tests in that context.<sup>28</sup> In contrast to *Patel* and *Gigante*, there was extensive physical evidence supporting a diagnosis of a variant of dementia that is particularly vulnerable to apathy/variability in behavior (e.g. diffuse slowing in EEG tests over three years, development of peripheral neuropathy, development of hypometabolism in left frontal lobe and bilateral medial temporal regions as compared to previous scans).<sup>29</sup> The ruling in *Rothman* suggests that physical evidence of specifically frontal lobe dysfunction may increase the likelihood that a court will adopt the dementia-symptomology explanation of variability in behavior. The court also noted that the government’s witness, being a psychologist with no formal training in forensic psychology who also used psychology interns to implement the tests, likely did not sufficiently consider the effects of frontal lobe degradation while evaluating the Test of Memory Malingering (TOMM) and other psychological tests.<sup>30</sup> It is unclear how many cases, like *Rothman*, have properly considered explanations relating to apathy and natural fluctuations in behavior. For example, the court in *U.S. v. Loman* did not appear to consider organic explanations of the defendant’s variability in malingering test scores and only mentioned the government’s argument that “individuals often malingering only when they believe they need to do so” and that it was therefore “not a static behavior.”<sup>31</sup> The government witness here, as in *Rothman*, was also a psychologist without training in brain imaging interpretation who relied on the TOMM and may not have adequately considered organic explanations.<sup>32</sup> The court discounted evidence that the defendant once performed above the malingering cut-off for the TOMM, that he performed poorly on several cognitive tests, that his house was in “disrepair,” and that he was “unable to recall basic details of his personal history.”<sup>33</sup>

Case law also shows that observable behavior in the courtroom or behavior outside of formal evaluation in general can be important when there is conflicting expert testimony or ambiguous physical evidence.<sup>34</sup> For example, the court in *U.S. v. Knox* held that the defendant was competent when physical evidence was inconclusive, but his behavior was indicative of

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<sup>28</sup> *Id.* at 13, 15.

<sup>29</sup> *See Id.* at 13-25.

<sup>30</sup> *Id.* at 35-36.

<sup>31</sup> *U.S. v. Loman*, 597 Fed.Appx. 518, 521 (10th Cir. 2015).

<sup>32</sup> *Id.* at 520-21.

<sup>33</sup> *Id.* at 521.

<sup>34</sup> *See, e.g.*, *U.S. v. Bumagin*, 114 F.Supp.3d 52, 56 (E.D.N.Y. 2015) (noting that although the question of competency was a close call, the court’s “personal observations of defendant” and his “interactions with counsel on numerous occasions” implied that the defendant was competent); *U.S. v. Fuenmayor-Arevalo*, 490 Fed.Appx. 217, 225-26 (11th Cir. 2012) (holding that the trial court did not abuse its discretion in holding defendant competent to plead guilty when there was “irreconcilable” expert testimony, when the government witness had a longer period of observation, the defendant appeared competent in the court and “intelligent and capable of learning” to his relative codefendants, and displayed “adaptive functioning in the detention-center environment” and “informed medical personnel about recently diagnosed medical conditions.”); *Sanders v. Forniss*, 2018 WL 3421600, 9 (M.D. Ala. 2018) (holding that trial court did not abuse discretion in holding defendant competent when there was conflicting expert testimony and when trial court emphasized the fact that the government experts observed the defendant for a more continuous, longer period of time).

normal functioning.<sup>35</sup> The defendant's MRI was consistent with Alzheimer's but was not conclusive,<sup>36</sup> neuropsychological test results were inconsistent,<sup>37</sup> and the defendant had multiple coherent telephone conversations with his wife where he was able to "recall events, calculate money and dates, and carry on normal conversation."<sup>38</sup> The defendant also "learned and retained new information about his medical care" and "correct[ed] the physician assistant about the accuracy of information" while he was staying at a federal medical center.<sup>39</sup> Again, one potential problem may be that in cases where there is conflicting expert testimony and ambiguous physical evidence, normal behavior is not being analyzed in the context of a disease which may cause variability in behavior. None of the aforementioned cases incorporated this kind of contextual analysis.

Finally, another relevant factor may be the consistency between the defendant's current symptoms and the alleged onset of the disease, and the rate at which symptoms progressively worsen for a given individual. For example, in *U.S. v. Liberatore*, the defendant failed to argue for a new trial based on evidence of incompetence at the time of trial after the court considered the difficulties of estimating the rate of disease progression.<sup>40</sup> Though the trial had already ended, the defendant argued that the court could infer that the defendant was incompetent at the time of trial based on his current symptoms.<sup>41</sup> Relying on expert testimony, the court concluded that this kind of retrospective computation was "outside the appropriate use of existing data according to the standards and norms of the mental health profession" since individuals deteriorated at indeterminate unique rates.<sup>42</sup> The court noted that the defendant's symptoms may have worsened near the end of trial due to depression, thus making the "starting point" for extrapolating competence at time of trial particularly indeterminate.<sup>43</sup> The court also noted that the defendant's rapid rate of decline in less than two months was inconsistent with the progression of regular Alzheimer's disease, but consistent with another expert's opinion that the disease's effects may have been transiently exacerbated with a depressive episode.<sup>44</sup> The court ultimately held that the defendant's symptoms simply reflected an "unimpaired reaction to trial."<sup>45</sup>

In contrast, other courts could potentially disregard the fact that individuals deteriorate at indeterminate unique rates and conclude that one's symptoms at a certain time period are inconsistent with the average rate of a disease's progression and the purported onset of disease. For example, the court in *U.S. v. Patel* held that the defendant was likely malingering

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<sup>35</sup> *U.S. v. Knox*, No. 05-00270-CB, 2010 WL 2643566, at \*9-10 (S.D. Ala. June 29, 2010).

<sup>36</sup> *Id.* at \*7.

<sup>37</sup> *Id.*

<sup>38</sup> *Id.* at \*10.

<sup>39</sup> *Id.*

<sup>40</sup> *U.S. v. Liberatore*, 846 F.Supp. 569 (N.D. Ohio 1994).

<sup>41</sup> *Id.* at 363.

<sup>42</sup> *Id.* at 363-64.

<sup>43</sup> *Id.*

<sup>44</sup> *Id.* at 365.

<sup>45</sup> *Id.*

since the defendant's pretrial behavior was inconsistent with the purported onset of disease.<sup>46</sup> The defendant had engaged in complex business ventures at a time where he should not have been able to do so.<sup>47</sup>

In sum, recurrent issues in the adjudication of competence include" (i) whether behaviors exhibited in the assessment are consistent with test results and physiological indicators; (ii) the continuity and length of observation of the defendant; (iii) whether symptoms at any given time are consistent with the rate of a disease's projected progression and purported onset of disease; and (iv) whether retroactive extrapolation of the defendant's mental state at time of trial is feasible in a particular case given individualized rates of disease progression and other pertinent variables, such as presence of other co-occurring mental conditions (e.g. depression, anxiety). Based on a review of the reported cases, one wonders whether courts have sufficiently considered apathy and natural fluctuations in behavior in explaining seemingly normal behavior in a person with *bona fide* dementia. Current case law suggests that these explanations may not easily be accepted and are considered only if there is significant physiological evidence supporting such an explanation and if behavior is sufficiently consistent with neuropsychological tests, typical clinical presentations, and physiological indicators.

### C. Restoration of Competence

The second important issue about competence to stand trial concerns restoration of competence for defendants who have been found incompetent to proceed. Not surprisingly, it is unlikely that a person with dementia found incompetent to stand trial would be found to have "recovered" the necessary capacities in light of the irreversible decline associated with dementia-related diseases. But, if the defendants are unlikely to be restored to competence, what should be done with them and their criminal cases? Most state statutes automatically commit incompetent defendants for purposes of competency restoration, even in cases involving dementia.

Many defendants, afflicted with conditions that appear to be irreversible in their effects, have understandably alleged due process violations when faced with statutes that automatically commit defendants without any individualized determination of whether competency can realistically be restored.<sup>48</sup> However, nearly all of these claims have failed. Adjudication of these cases depends on application of the holding in *Jackson v. Indiana*, where the U.S. Supreme Court struck down an Indiana statute that allowed for indefinite commitment of an incompetent defendant without requiring periodic evaluation or an assessment of

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<sup>46</sup> *Patel*, 524 F.Supp.2d at 118.

<sup>47</sup> *See Id.* at 118-21.

<sup>48</sup> *See* U.S. v. Reese, No. 18-39, 2018 WL 4854660 (E.D. Pa. Oct. 5, 2018) (afflicted with dementia); U.S. v. Musto, No. 3:10-CR-338, 2014 WL 47351 (M.D. Pa. Jan. 7, 2014) (mild cognitive impairment); U.S. v. Filippi, 211 F.3d 649 (1st Cir. 2000) (vascular dementia); U.S. v. Dalasta, 856 F.3d 549 (8th Cir. 2017) (deficits associated with temporal lobectomy); Carr v. State, 303 Ga. 863 (Ga. 2018) (low intellectual functioning and cerebral palsy).

dangerousness.<sup>49</sup> The case stands for the proposition that “due process requires that the nature and duration of commitment bear some reasonable relation to the purpose for which the individual is committed.”<sup>50</sup> However, federal courts across multiple circuits have consistently distinguished cases involving irreversible conditions from *Jackson*, a case involving mental illness; they have routinely upheld the automatic confinement provision of the federal statute for a variety of reasons. Some courts have held that the commitment facilitates more accurate diagnoses and determinations of future competency.<sup>51</sup> The attorney general also commits the defendant only “as is necessary” and thus may afford individualized lengths of confinement.<sup>52</sup> Finally, commitment could facilitate evaluation of a defendant’s dangerousness.<sup>53</sup>

The sole outlier is the case of *Carr v. State*, where the Georgia Supreme Court held unconstitutional a state statute that automatically committed incompetent defendants charged with violent crimes to inpatient treatment but gave courts discretion on whether to place incompetent defendants charged with nonviolent crimes in outpatient programs.<sup>54</sup> Rebutting various federal holdings, the court reasoned that evaluating dangerousness was not one of the purposes of the competency restoration statutes, that none of the federal courts “[had] explained why inpatient commitment is reasonable in every case to achieve [a] more ‘careful and accurate diagnosis’” as opposed to mandatory outpatient treatment, and that only the defendant’s mental state rather than the charged crime is relevant to the purpose of determining future competence.<sup>55</sup> The court also emphasized legislative intent, noting that the statutory availability of outpatient treatment for those charged with nonviolent offenses reflected the Georgia legislature’s judgment that “inpatient evaluation is not always necessary to accurately determine whether competency can be restored.”<sup>56</sup> And unlike Congress, the Georgia legislature did not commit the issue of competency to a particular medical professional/individual.<sup>57</sup> The Georgia Supreme Court concluded that automatic confinement of those charged with violent offenses “[did] not bear a reasonable relation to the State’s purpose of accurately determining the restorability of individual defendants’ competence to stand trial.”<sup>58</sup> The case suggests that successful due process challenges may depend on legislative intent and the peculiarities of a particular statute rather than broad abstractions about the inherent unfairness in automatic commitment.<sup>59</sup>

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<sup>49</sup> *Jackson v. Indiana*, 406 U.S. 715 (1972).

<sup>50</sup> *Id.* at 738.

<sup>51</sup> See *Reese*, 2018 WL 4854660, at \*8; *U.S. v. Strong*, 489 F.3d 1055, 1062 (9th Cir. 2007); *U.S. v. McKown*, 930 F.3d 721, 728-30 (5th Cir. 2019).

<sup>52</sup> *Filippi*, 211 F.3d. at 652 (1st Cir. 2000); *McKown*, 930 F.3d at 727.

<sup>53</sup> *Dalasta*, 856 F.3d at 554.

<sup>54</sup> *Carr v. State*, 303 Ga. 863 (Ga. 2018).

<sup>55</sup> *Carr*, 303 Ga. at 866-67.

<sup>56</sup> *Id.* at 865.

<sup>57</sup> *Id.* at 867.

<sup>58</sup> *Id.* at 869.

<sup>59</sup> See also *McKown*, 930 F.3d at 730 (upholding the federal statute after distinguishing the case from *Carr v. Georgia* and holding that the federal statute did not reflect the legislative judgment that inpatient evaluation is not always necessary).

While courts may be reluctant to strike down automatic inpatient commitment statutes, legislatures may be motivated to revise them because of a different kind of due process challenge. Specifically, defendants may successfully allege a due process violation if they are forced to wait too long in a jail cell before entering inpatient treatment.<sup>60</sup> Limited availability of inpatient beds and resources along with a high number of incompetent defendants have made such due process violations a very real and common possibility. Indeed, “[s]tates are currently under assault from lawsuits alleging that these defendants’ constitutional rights are being violated by their lengthy stays in jails while awaiting transfer to inpatient facilities . . . and they are losing,” with Washington state failing to comply with a court order to reduce the delay and subsequently being fined \$12 million.<sup>61</sup> This problem will likely be exacerbated with the increasing elderly population.

## II. CRIMINAL RESPONSIBILITY

As with the adjudication of competence, dementia is clearly relevant to the adjudication of criminal responsibility. Specifically, a diagnosis of dementia could potentially result in a successful affirmative “insanity defense,” where the defendant may receive no conviction if the disease makes one unable to “appreciate the nature/wrongfulness of the crime” (the so-called “cognitive” test) or “conform one’s conduct to the law”<sup>62</sup> (the “volitional” test). The precise test depends on the governing law in the state. In the federal courts, the sole test is the cognitive test. Dementia at the time of crime could also bear on whether or not the defendant had the particular mental state required to satisfy the elements of a given crime (e.g. the requisite mental state of “malice” or “recklessness”).<sup>63</sup>

Dementia-related case law on criminal responsibility is generally sparse compared to dementia-related case law on competence, but a few cases illustrate that adjudication of criminal responsibility raises issues similar to those explored above relating to competence adjudication. First, many insanity defense cases rely on lay behavioral observations around the time of the crime, and yet do not appear to consider whether seemingly normal behavior may coincide with severe dementia. Courts may not be adequately considering the possibility that seemingly “rational” or “purposeful” behavior at times is consistent with dementia-symptomology and is explained by natural fluctuations in behavior and vulnerability to

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<sup>60</sup> *E.g.*, *J.K. v. Alaska*, 469 P.3d 434 (Alaska 2020).

<sup>61</sup> Susan McMahon, *Reforming Competence Restoration Statutes: An Outpatient Model*, 107 GEO. L.J. 601, 643 (2019).

<sup>62</sup> *See generally* Allen P. Wilkinson & Arthur C. Roberts, Annotation, *Insanity Defense*, American Jurisprudence Proof of Facts 2d [§ 3, 5](#) (discussing cases regarding different kinds of insanity defenses).

<sup>63</sup> *See, e.g.*, *Field v. State*, 507 S.W.3d 333 (Tex. Crim. App. 2016) (holding that trial court did not err by excluding ex-wife’s testimony opining that defendant had Alzheimer’s since the testimony was “insufficient to negate mens rea”); *People v. Cruz*, F065388, 2014 WL 2212478 (Cal. Ct. App. May 28, 2014) (holding as harmless error the trial court’s failure to give jury instructions to find defendant guilty of involuntary manslaughter if it found that dementia precluded him from possessing necessary malice for second degree murder); *State v. Hreniuk*, 2010 WL 2195716 (N.J. Super. Ct. App. Div. May 28, 2010) (holding that counsel’s decision to not present a diminished capacity defense based on Alzheimer’s was not ineffective assistance of counsel, since it was a strategy designed to avoid the state’s damaging cross-examination).

situational variables. For example, although the court in *People v. Reed* relied on the defendant’s “goal-oriented” and “rational” behavior around the time of committing a crime to conclude that the defendant was not legally insane, it did not consider the possibility that such behavior could be consistent with dementia-symptomology.<sup>64</sup> The court discounted expert testimony that the defendant suffered from dementia and displayed symptoms such as memory loss, periods of confusion, and delusions.<sup>65</sup> The court potentially put too much weight on several behavioral observations. The defendant had apparently followed police instructions and was courteous during his interactions with investigators.<sup>66</sup> He had answered questions in a “normal” fashion.<sup>67</sup> He did not appear to act “totally confused and demented” during psychological examination.<sup>68</sup> The victim also testified that the defendant “seemed like he was in complete control of what he was doing to [the victim] because he was just a person with a temper.”<sup>69</sup> An expert testified that the defendant showed a “degree of impulse control [since] he tried to kick [the victim] before using the gun.”<sup>70</sup> The court also considered the defendant’s behavior prior to the crime. The defendant apparently appeared “calm” before the shooting, and managed an apartment building, snack shop, and decorating business.<sup>71</sup> And yet nowhere in the opinion did the court analyze any of the seemingly normal behaviors through a contextualized lens taking account of the effects of dementia.

The lack of analysis contextualized by the defendant’s dementia diagnosis and symptoms is problematic since the jury is generally free to rely on lay testimony regarding the apparent normalcy of behavior over expert testimony.<sup>72</sup> Such lay testimony can be dispositive in cases where there is conflicting expert testimony or even when there is clearly some kind of mental illness at play. For instance, the court in *Watts v. State* upheld the jury’s verdict of sanity when all experts testified that defendant was legally insane due to dementia and temporal lobe epilepsy, when the defendant shot at a gas station attendant without any apparent motive, and when he said someone was “trying to poison him” at a hospital after a high-speed chase incident.<sup>73</sup> The court emphasized the fact that those who testified for the defendant interviewed him “several months after the incidents [of the crime],” and that the police officers, a local farmer, and the defendant’s family physician who all testified that the defendant was sane observed the defendant on the day of crime.<sup>74</sup> The lay testimony was somewhat conclusory, with the witnesses simply stating that the defendant seemed sane or

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<sup>64</sup> *People v. Reed*, 209 Ill.App.3d 575, 582-83 (Ill. App. Ct. 1991).

<sup>65</sup> *Id.* at 579.

<sup>66</sup> *Id.* at 578-59.

<sup>67</sup> *Id.*

<sup>68</sup> *Id.* at 580.

<sup>69</sup> *Id.* at 578.

<sup>70</sup> *Id.* at 580.

<sup>71</sup> *Id.*

<sup>72</sup> See generally W.E. Shipley, Annotation, *Modern Status of Rules as to Burden and Sufficiency of Proof of Mental Irresponsibility in Criminal Case*, 17 A.L.R.3d §7[a], 14 (discussing various cases where jury put more weight on lay testimony rather than expert testimony).

<sup>73</sup> *Watts v. State*, 680 S.W.2d 667, 669, 673 (Tex. Crim. App. 1984).

<sup>74</sup> *Id.* at 673.

that the defendant could recognize and call witnesses by their names.<sup>75</sup> Again, the court relied on behavioral observations but there was no contextualized analysis.

Similarly, the court in *State v. Summers* upheld a jury verdict of sanity when the government witness testified that defendant “cooperated fully with evaluation” and was “alert/responsive and . . . displayed full range of affect in interview,” a detective testified that defendant appeared “very logical” in responses to questions, the defendant told an officer he was not insane, and there was conflicting expert testimony.<sup>76</sup> The jury may have improperly discounted the fact that the defendant continually underwent treatment for various mental illnesses between 1990-2000 (bipolar disorder, schizoaffective disorder with psychotic features, paranoid psychosis disorder, and dementia) and that the crime was notably committed in 2000.<sup>77</sup> He was also good friends with the victim, and yet killed the victim after the victim told him he was being too loud in his room only two times.<sup>78</sup> The defendant had also stabbed the victim for an excessively long amount of time (lasting between eight and thirty minutes).<sup>79</sup>

Courts may also grapple with the feasibility of retrospective determination of mental state at the time of a crime when there were no diagnostic evaluations prior to when the crime or indictment occurred. Caselaw is limited but suggests that courts are likely to be highly skeptical of retrospective inquiries.<sup>80</sup> Skepticism towards retrospective inquiries may be especially problematic if a disease alters cognition such that one commits crimes but does not notice the symptoms so as to seek medical attention. In such circumstances, there will be no formal medical history or diagnostic imaging or evaluation available to build an argument that the defendant had dementia when the crime occurred, so a defendant may have to rely on retrospective arguments instead.

However, one case suggests that retrospective determinations of mental state at the time of crime can sometimes be strengthened with lay behavioral observations. In *U.S. v. Orlansky*, the court upheld exclusion of expert testimony diagnosing the defendant with dementia after noting that the expert witnesses admitted that they could not precisely

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<sup>75</sup> *Id.*

<sup>76</sup> *State v. Summers*, No. E2002-01996-CCA-R3-CD, 2003 WL 22432413, at \*3,5.

<sup>77</sup> *Id.* at \*2.

<sup>78</sup> *Id.* at \*1.

<sup>79</sup> *Id.* at \*2. *See also* *State v. Ford*, Nos. 88946, 88947, 2007 WL 3105267, at \*3 (Ohio Ct. App. Oct. 25, 2007) (rejecting the irresistible impulse defense and holding that defendant’s frontotemporal dementia did not affect the capacity to appreciate wrongfulness of the crime when “defendant engaged in a variety of behavior which manifested his intention to perform planned offenses at secretive locations, and [when] he engaged in extensive efforts to conceal his identity and escape detection.”).

<sup>80</sup> *See, e.g., U.S. v. Mezvinsky*, 206 F.Supp.2d 661, 675 (E.D. Pa. 2002) (holding post-indictment PET scan showing Alzheimer’s disease to be inadmissible evidence since experts could not infer precise mental/brain state during period of crime); *Miller v. State*, 161 So.3d 354, 373 (Fla. 2015) (holding that counsel was not ineffective for failing to produce a pre-trial PET scan which could have revealed frontotemporal dementia, since one could not infer the brain state at the time of crime based on the current PET scan conducted over five years later). *But see U.S. v. Rainone*, 32 F.3d 1203, 1208 (7th Cir. 1994) (engaging in retrospective analysis and concluding competence at trial implied that defendant was competent to commit crimes).

determine the defendant's mental state during 1994-2003 (the period of crime) based on brain scans conducted in 2004.<sup>81</sup> The experts opined that a progressive cyst led to dementia and extensive frontal, temporal, and parietal lobe damage.<sup>82</sup> The expert witnesses, in an attempt to compensate for lack of pre-indictment brain scans, argued that a pre-indictment diagnoses could be legitimately supported by the defendant's wife's testimony that the defendant engaged in bizarre "ritualistic" behavior and cognitively declined prior to the crime, and that clinical observations "compris[ed] 95 percent of medical diagnosis."<sup>83</sup> Though the court did not appear to reject this methodology, it noted that the experts did not say that they could conclude the defendant was legally insane even after considering the wife's testimony.<sup>84</sup> The case suggests that retrospective determinations are difficult but not impossible and could successfully incorporate lay behavioral observations. However, this again leads to the problem of not analyzing behavior in the context of dementia. Courts could give improper weight to observations suggesting that a defendant was "rational" or "goal-oriented." The skepticism towards retrospective inquiries thus represents a potential barrier to many insanity defense or diminished capacity claims.

### III. NGRI COMMITMENT

Even if defendants with dementia are found not guilty by reason of insanity (NGRI), the prospects of liberty and release may be particularly low because of how the disease gradually worsens and is irreversible. To elaborate, all defendants found NGRI may be automatically and involuntarily committed to an institution for purposes of ameliorating the mental condition that led to the crime.<sup>85</sup> NGRI Commitment statutes generally provide periodic release hearings that mandate the NGRI patient to be released if the patient is no longer dangerous or mentally ill.<sup>86</sup> There appears to be no caselaw directly addressing dementia in the context of NGRI commitment, but relevant caselaw suggests that the irreversibility and gradual worsening of the condition may lead to courts finding that patients are too dangerous to be released.

The vulnerability of patients afflicted with dementia can only be understood in the context of the general lack of procedural protections in NGRI commitment hearings. The U.S. Supreme Court in *Jones v. United States* set the stage for prolonged periods of institutionalization after it found that the differences between a civil commitment verdict and an NGRI verdict warranted fewer procedural protections for those found NGRI.<sup>87</sup> The defendant there was automatically institutionalized after a jury found that he committed a

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<sup>81</sup> U.S. v. Orlansky, No. 03-20951-CR-JORDAN, 2006 WL 8434739, at \*12-15 (S.D. Fla. Feb. 27, 2006).

<sup>82</sup> *Id.* at 6.

<sup>83</sup> *Id.* at 9, 12-13.

<sup>84</sup> *Id.* at 12-13.

<sup>85</sup> See generally MICHAEL L. PERLIN & HEATHER ELLIS CUCOLO, MENTAL DISABILITY LAW: CIVIL AND CRIMINAL (Matthew Bender & Company, Inc., 2021).

<sup>86</sup> See *Foucha v. Louisiana*, 504 U.S. 71 (1992) (holding that insanity acquittees can only be committed if they are both mentally ill and dangerous, and that dangerousness alone cannot justify confinement).

<sup>87</sup> *Jones v. United States*, 463 U.S. 354 (1983).

non-violent property crime beyond a reasonable doubt and additionally found that he was NGRI based on a preponderance of the evidence.<sup>88</sup> He alleged that a finding of insanity based on a preponderance of the evidence was insufficient to justify automatic commitment, since those involuntarily committed under civil statutes could only be institutionalized under a higher burden of proof- that is, under “clear and convincing evidence” that one was dangerous due to mental illness.<sup>89</sup> The court held that automatic commitment based on an NGRI verdict for a non-violent property crime did not violate the due process clause, since the fact of crime was sufficient to prove dangerousness, the insanity acquittal “support[ed] an inference of continuing mental illness,” and the distinction between “violent” and “non-violent” crimes was constitutionally irrelevant for purposes of involuntary commitment.<sup>90</sup>

The court also noted that the reasons that justified a higher standard of proof for civil commitment proceedings did not apply to NGRI acquittees.<sup>91</sup> Civil commitment proceedings involved a risk that one could be committed “on the basis of some abnormal behavior which might be perceived by some as symptomatic of a mental or emotional disorder, but which is in fact within a range of conduct that is generally acceptable.”<sup>92</sup> Crime, however, is not within the range of generally acceptable conduct, and the interest in reducing error is also lessened since the defendant is the one who raises an insanity defense claim in criminal hearings.<sup>93</sup> The defendant also claimed that his due process rights were violated after he was institutionalized for a time period exceeding the maximum possible jail sentence that he could have received if he were found guilty instead of NGRI.<sup>94</sup> However, the court held that prolonged institutionalization was justified since incarceration based on a guilty verdict had the purpose of deterrence/retribution, while commitment based on a NGRI verdict had the purpose of restoring one’s sanity or rectifying dangerousness.<sup>95</sup> There was “no necessary correlation between severity of the offense and length of time necessary for recovery to repair dangerousness,” and thus the length of the maximum criminal sentence was irrelevant.<sup>96</sup>

The total effect of *Jones* was to cause the indeterminate institutionalization of even those that committed non-violent crimes, with the institutionalization potentially extending beyond the maximum prison sentence for that crime. And though *Jones* did not necessarily reach the burden of proof required to re-commit patients in release hearings, courts have interpreted *Jones* to justify harsh evidentiary standards in release hearings (clear and convincing evidence) or shifting the burden of proof to patients to prove that they are no

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<sup>88</sup> *Id.* at 362, 365.

<sup>89</sup> *Id.* at 362.

<sup>90</sup> *Id.* at 363-66.

<sup>91</sup> *Id.* at 366-68.

<sup>92</sup> *Id.* at 367.

<sup>93</sup> *Id.*

<sup>94</sup> *Id.* at 362-63.

<sup>95</sup> *Id.* at 368-70.

<sup>96</sup> *Id.* at 369.

longer mentally ill nor dangerous.<sup>97</sup> The irreversibility and gradual deterioration characteristic of progressive dementias only exacerbates the effects of a harsher burden of proof. Since the amenability to treatment is an important factor in determining release,<sup>98</sup> the irreversibility of dementia may interact with the difficult burden of proof and cause courts to conclude that patients are irreparably dangerous. It is also possible that the gradual deterioration found in dementia may lead to earlier release, since a patient could decline to the point where they may no longer be dangerous. There are no NGRI cases addressing this possibility, but cases involving statutes that involuntarily commit sex offenders based on their mental illnesses indicate that the disabling effects of dementia may warrant release.<sup>99</sup>

Release hearings may become complex if expert witnesses disagree about whether the dementia has progressed to the point of incapacitation as opposed to making the patient more dangerous. Again, there is no dementia-related NGRI commitment caselaw, but caselaw about sex offender-commitment statutes is relevant. In *People v. Linkogle*, the court grappled with this exact issue when the defendant was civilly committed as a sexually violent predator.<sup>100</sup> The defendant had committed multiple sexual offenses over the course of thirty-five years, and was diagnosed with pedophilia, either bipolar or schizoaffective thought disorder, and dementia.<sup>101</sup> One expert witness argued that, while dementia could incapacitate patients and prevent sexually offensive behavior, the patient's dementia had not progressed to the point of incapacitation.<sup>102</sup> Another witness argued that the dementia likely made the patient *more* dangerous, since it reduced his impulse-control.<sup>103</sup> In contrast, a third expert witness testified that the dementia made the patient harmless since the patient had displayed all the signs of severe deterioration: gait, uncontrollable drooling, poor bladder control, non-responsiveness, poor recall, a severely impaired score under the Mini Mental State Exam, and the intellectual functioning of a three/four-year old.<sup>104</sup> The defendant also did not recently behave in a sexually aggressive manner in the past year, and he would have likely been confined in a facility that children could not access.<sup>105</sup> In addition, the other witnesses opining was that the patient was still dangerous and had evaluated him several months before the third witness's evaluation,

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<sup>97</sup> See, e.g., *Green v. Commissioner*, 750 A.2d 1265, 1271-72 (Me. 2000) (holding that *Jones v. United States* implied that requiring the NGRI acquittee to prove, by clear and convincing evidence, that they were no longer mentally ill or dangerous did not violate due process); *Hearne v. United States*, 631 A.2d 52 (D.C. 1993) (holding that *Jones v. United States* implied that it was constitutionally permissible to place burden of proof on NGRI acquittee). See generally PERLIN & CUCOLO, *supra* note 85, at 13-17 (discussing impact of *Jones*).

<sup>98</sup> See, e.g., *People v. Bolden*, 217 Cal.App. 3d 1591, 1600 (Cal Ct. App. 1990) (holding that trial court committed error by failing to instruct the jury to consider if medication could control the patient's dangerousness and if the patient would efficiently self-medicate).

<sup>99</sup> See, e.g., *In re Pers. Restraint of Meirhofer*, 182 Wn.2d 632, 639 (Wash. 2014) (noting that one of the statutory factors justifying a new release hearing is a dementia that "renders the committed person unable to commit a sexually violent act"); *People v. Linkogle*, 2012 WL 6100525 at \*3, 5-8 (Cal. Ct. App. 2012).

<sup>100</sup> *Linkogle*, 2012 WL 6100525, at \*1-8.

<sup>101</sup> *Id.* at \*1-2.

<sup>102</sup> *Id.* at \*3.

<sup>103</sup> *Id.* at \*5.

<sup>104</sup> *Id.* at \*5-7.

<sup>105</sup> *Id.* at \*7-8.

and thus the dementia may have subsequently worsened and made the prior evaluations invalid.<sup>106</sup> The trial court may have improperly put too much weight on past behavior and not enough weight on the inevitable incapacitation caused by dementia when it expressed doubt that “the dementia has just taken over and all of [the] sexually deviant behaviors that he had for 35, 40 years [were] now gone.”<sup>107</sup> The appellate court upheld the trial court’s decision to institutionalize the defendant after noting that the trial court was free to place more weight on certain expert testimony.<sup>108</sup>

Whether or not the trial court was justified, the decision suggests that there is a substantial risk of patients being institutionalized until they are rendered severely disabled. It is unclear how future courts will accurately determine when dementia either justifies or prohibits release. But ultimately, we are left with a system that potentially allows patients, charged with any kind of offense, to be perpetually committed to the point of total mental incapacitation.

### III. CRIMINAL SENTENCING AND PUNISHMENT

In recent years, most litigation relating to persons with dementia in the criminal process has related to severity of punishment. The cases are of two types: (1) mitigation claims pertaining to sentencing based on the argument that severe punishment is disproportionate to the defendant’s *culpability at the time of the offense* (diminished responsibility); and (2) claims arising after imprisonment arguing the prisoner’s *current mental condition* (relating to onset and symptoms of dementia) warrant mitigation of the previously prescribed punishment. Both of these claims are anchored in arguments about proportionality.

#### A. Mitigation Claims at Sentencing

At the time of sentencing, the judge may decide to reduce an otherwise applicable prison sentence. Dementia may potentially establish the criteria of what is often called “diminished responsibility” -- mitigating factors that echo the exculpatory criteria of the insanity defense (diminished capacity to “appreciate the wrongfulness of the conduct or to ‘conform one’s conduct to the law’”). For example, the court in *State v. Stuard* held that the defendant’s dementia established the mitigating factor of being unable to conform one’s conduct to the law, such that it outweighed the aggravating factors of previous convictions and the cruelty of the crimes and warranted a life sentence rather than a death sentence.<sup>109</sup> Here, the defendant had assaulted four elderly women in the course of several burglaries within a few days of each other, with three of the victims dying from their injuries.<sup>110</sup> Though the crime was carried out in an “especially heinous” manner and the defendant was “previously convicted of another offense for which life imprisonment or death could be imposed (the other murder

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<sup>106</sup> *Id.* at \*11-12.

<sup>107</sup> *Id.* at \*8-9.

<sup>108</sup> *Id.* at \*11-12.

<sup>109</sup> *State v. Stuard*, 176 Ariz. 589, 608-10 (Ariz. 1993).

<sup>110</sup> *Id.* at 593-96.

counts and a previous robbery),”<sup>111</sup> the defendant’s boxing career likely led to brain damage to the point of causing a dementia that significantly reduced his impulse-control and culpability.<sup>112</sup> One expert had also suggested that the dementia did not affect him in his decision to do the burglaries in the first place but may have caused him to kill the victims during the burglaries.<sup>113</sup> The court also noted that the “lack of motive or any other discernable reason or explanation for these killings reinforc[ed] [its] conclusions.”<sup>114</sup> Interestingly, the court further held that the defendant’s mental illness warranted making his multiple life sentences to be served consecutively as opposed to concurrently, since his mental illness made him “obviously” dangerous and he would “continue to be very dangerous to others.”<sup>115</sup> In effect, dementia was used to mitigate the punishment by precluding the death penalty, while aggravating the punishment by prolonging the period of imprisonment for incapacitation purposes.

In contrast, the court in *Simmons v. State* held that the trial court did not abuse its discretion when it sentenced the defendant to death after finding that the cruelty of the crime outweighed the non-statutory mitigating factor of neurocognitive deficits associated with alcohol-induced dementia.<sup>116</sup> Specifically, the defendant had disemboweled the victim, had spread various organs throughout the bathroom floor, and likely caused the victim pain.<sup>117</sup> The court did not specify exactly how the dementia could have been a mitigating factor, or why the cruelty of the crimes outweighed the dementia. The court further held that the trial court did not abuse its discretion in holding that the dementia did not establish the statutory mitigating factor of being unable to appreciate the criminality of one’s conduct or conforming one’s conduct to the law, since there was conflicting expert testimony, and the trial court was free to place more weight on one opinion over the other.<sup>118</sup> Again, the court did not specify exactly how the dementia failed to establish the mitigating factor.

In general, case law on dementia-related mitigation is extremely limited, and thus the degree to which courts will consider dementia as a mitigating factor in the most severe crimes is unknown. However, the same issues involving insanity defense and diminished capacity claims will likely apply, as mitigation cases similarly require the determination of a defendant’s mental state at the time of crime. Courts may again be skeptical of retrospective determinations of mental states and could potentially fail to consider the possibility that seemingly “rational” and “goal-oriented” behavior is consistent with dementia-symptomology. For instance, the court in *Grissom v. Duckworth* held that the counsel’s failure to produce a PET scan proving dementia did not amount to ineffective assistance of counsel since the PET scan would not have made a difference in the sentence, and the PET scan would not have made a

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<sup>111</sup> *Id.* at 605.

<sup>112</sup> *Id.* at 606-10.

<sup>113</sup> *Id.* at 608.

<sup>114</sup> *Id.* at 610.

<sup>115</sup> *Id.*

<sup>116</sup> *Simmons v. State*, 797 So.2d 1134, 1185-86 (Ala. Crim. App. 1999).

<sup>117</sup> *Id.* at 1185.

<sup>118</sup> *Id.* at 1181-83.

difference since the “planned” and “rational” nature of the attacks belied any alleged cognitive difficulties associated with dementia.<sup>119</sup> The defendant had apparently “planned” to commit robbery with a homeless hitchhiker he had met one day before the robbery and ended up committing murder and attempted murder during the course of the robbery.<sup>120</sup> Though the opinion does not appear particularly flawed, the court did not consider the possibility that such “planned” or seemingly “rational” behavior could have been consistent with dementia symptomology anyway and could have coincided with real cognitive deficits in reasoning and judgment.<sup>121</sup>

Finally, case law regarding the appropriateness of alternate sentencing for individuals with dementia is also limited. Two cases suggest that the irreversibility of progressive dementia and the lack of amenability to treatment often displayed by individuals with dementia are relevant factors in determining the appropriateness of alternate sentences. In *State v. Clinton*, the defendant’s sentence of twenty years in prison for “lewd contact with a minor child under [sixteen]” was upheld because it was “unclear whether treatment [for his dementia] would be successful” and because the defendant’s dementia reduced his impulse-control.<sup>122</sup> The court rejected the defendant’s argument that he ought to receive probation because of his adequate social support and employment history since the defendant had already received sexual offender treatment and had previously abused fifty other children.<sup>123</sup> The defendant was also eligible for release to an assisted living facility without access to children after three years of serving his prison sentence if things “loo[ked] less bleak.”<sup>124</sup> Similarly, in *State v. Wheeler*, the court reversed the trial court’s decision to give a lenient sentence of probation based on vascular dementia after holding that the statute only allowed for reduced sentences for mental illnesses if there was a “reasonable possibility” that treatment for the illness would be successful.<sup>125</sup> With there being only two cases on alternate sentencing, it is unclear precisely how the irreversibility of progressive dementia may affect adjudication of alternate sentencing. However, when considering both the non-alternate sentencing case law and alternate sentencing case law, it appears that dementia could mitigate sentences by reducing culpability but could simultaneously aggravate sentences by suggesting that defendants are not amenable to rehabilitation.

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<sup>119</sup> Grissom v. Duckworth, No. CIV-11-1456-R, 2016 WL 4146157, at \*9 (W.D. Okla. Aug. 3, 2016).

<sup>120</sup> *Id.* at \*1-3.

<sup>121</sup> See discussion *supra* Section II.

<sup>122</sup> *State v. Clinton*, No. 38755, 2012 WL 3569687, at \*1, 14 (Idaho Ct. App. 2012).

<sup>123</sup> *Id.* at 14.

<sup>124</sup> *Id.*

<sup>125</sup> *State v. Wheeler*, 891 So.2d 614, 616 (Fla. Dist. Ct. App. 2005).

## B. Amelioration of Punishment after Sentencing

### 1. Incompetent to be Executed?

Persons under sentences of death may develop severe dementia in prison. The argument then arises that execution violates the eighth amendment prohibition against “cruel and unusual punishment,” even though they may have possessed the requisite mental states for satisfying the elements of a crime at the time of the offense and even though the death sentence penalty was otherwise constitutional. In *Ford v. Wainwright*, the U.S. Supreme Court ruled that execution of a mentally incompetent person violated the eighth amendment since it “simply offends humanity,” “it provides no example to others,” “madness is its own punishment,” and “executing a [mentally incompetent] person serves no retributive purpose.”<sup>126</sup> In *Panetti v. Quarterman*, the court clarified that the required mental state to preclude execution was a lack of rational understanding of the State’s rationale for execution.<sup>127</sup> One did not necessarily possess this “rational understanding” simply because one could verbally recite the State’s explicit purpose for punishment.<sup>128</sup> The court held that the “potential for a prisoner’s recognition of the severity of the offense and the objective of community vindication [were] called in question . . . if the prisoner’s mental state [was] so distorted by a mental illness that his awareness of the crime and punishment ha[d] little or no relation to the understanding of those concepts shared by the community as a whole.”<sup>129</sup>

Most recently, in *Madison v. Alabama*, the Supreme Court further clarified that *Ford* did not require a particular mental disorder diagnosis. The court held that all that is required to preclude execution is that the defendant does not have a rational understanding of the purposes of execution, which could conceivably be caused by any given mental disorder and not just those disorders mainly involving psychosis.<sup>130</sup> It follows that dementia may or may not preclude execution, since there may be “milder forms” of dementia which may not affect a rational understanding.<sup>131</sup> The court did not elaborate on what this “milder form” entails. The court did note, however, that simply forgetting the crime was not an excuse, and that executing one who did not remember the crime did not “offend humanity” to an unconstitutional extent.<sup>132</sup> The court also held that memory loss could still be relevant if it “combin[ed] and interact[ed] with other mental shortfalls” to eliminate a rational understanding.<sup>133</sup> The court speculated that one could have “difficulty preserving any memories, so that even newly gained knowledge (about crime and punishment) will be quickly forgotten” or that “cognitive deficits [may] prevent acquisition of such knowledge at all, so that memory gaps go forever

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<sup>126</sup> *Ford v. Wainwright*, 477 U.S. 399 (1986).

<sup>127</sup> *Panetti v. Quarterman*, 551 U.S. 930, 958-59 (2007).

<sup>128</sup> *Id.* at 958.

<sup>129</sup> *Id.* at 958-959.

<sup>130</sup> *Madison v. Alabama*, 139 S.Ct. 718, 728 (2019).

<sup>131</sup> *Id.* at 729.

<sup>132</sup> *Id.* at 727-29.

<sup>133</sup> *Id.* at 727-28.

uncompensated.”<sup>134</sup> There is no post-*Madison* case law clarifying what exactly this memory-impaired mental state looks like in those afflicted with dementia. But delusional beliefs regarding the state’s “true motives” behind execution remain relevant to adjudicating whether persons with dementia are competent to be executed.<sup>135</sup>

## 2. Eighth Amendment Argument for Ameliorating Lengthy Sentences?

Madison has no direct implications for sentencing -- persons with dementia can potentially be *sentenced* to death or *sentenced* to life without parole (LWOP) without offending the constitution, since again, *Madison* holds that it is not automatically unconstitutional to *carry out* a death sentence with respect to prisoners afflicted with dementia.<sup>136</sup> However, the holding that execution may serve no penological purpose with cases of advanced dementia may be relevant to other kinds of punishments. One scholar has argued that the holding ought to extend to LWOP, noting that LWOP has been historically viewed as extreme and has rarely been used, that “like death sentences, LWOP represent[s] an irrevocable determination that the condemned lack all ability to redeem themselves,” and that LWOP of severely incapacitated prisoners would similarly serve no deterrent or retributive purpose.<sup>137</sup> The “confluence of [various] factors and the unique vulnerability of incarcerated elderly population [may also] make their endless incarceration out of proportion with that of others serving life sentences.”<sup>138</sup> Specifically, the population is vulnerable to abuse and victimization by other prisoners. Prisons are also generally ill-equipped to provide adequate healthcare, such that only 4% of state institutions provide geriatric healthcare and many prisoners are forced to “take it upon themselves to care for this ailing population.” Prisoners may also be unable to conform to prison rules such that they are further punished (e.g., through solitary confinement), and may be unable to conform to life-saving protocols in medical emergencies/pandemics (e.g., the COVID-19 pandemic).<sup>139</sup>

## 3. Compassionate Release

In theory, at least, prisoners afflicted with severe dementia might successfully allege eighth amendment violations for non-LWOP sentences if they lack a rational understanding of the purposes for punishment. A more realistic possibility is that *Madison* may be used to

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<sup>134</sup> *Id.* at 728.

<sup>135</sup> *See, e.g.,* Mays v. State, No. AP-77,055, 2019 WL 2361999, at \*17 (Tex. Crim. App. June 5, 2019) (holding defendant potentially afflicted with dementia competent when there was insufficient evidence “that he believed that the State planned to execute him in order to stifle his renewable energy invention”).

<sup>136</sup> *See also* State v. Moen, 4 Wash.App.2d 589, 601-03 (Wash Ct. App. 2018) (holding that mandatory LWOP for those afflicted with dementia was not cruel and unusual punishment since there was “no national consensus against sentencing those with dementia to life imprisonment, several jurisdictions have held it is not cruel and unusual to sentence an elderly defendant with infirmities to either death or life imprisonment,” those with dementia may not have diminished culpability compared to juveniles since they may not be easily rehabilitated, and numerous jurisdictions have held LWOP for brain damaged or intellectually disabled defendants constitutional).

<sup>137</sup> Rachel Lopez, *The Unusual Cruelty of Nursing Homes Behind Bars*, 32 FED. SENT’G REP 5, 265-67 (2020).

<sup>138</sup> *Id.* at 268.

<sup>139</sup> *Id.*

support compassionate release motions.<sup>140</sup> Compassionate release motions are statutory motions which allow for a prisoner’s early release from prison, and are typically based on whether there are “extraordinary” or “compelling reasons” warranting release.<sup>141</sup> These reasons can include “terminal illness, debilitating physical illness that prevents self-care, and death or incapacitation of the only family member to care for a child.”<sup>142</sup> However, compassionate or early release statutes have rarely been used.<sup>143</sup> Prior to reform in 2018, the Federal Compassionate Release Statute was problematic for several reasons. It forced prisoners to write and submit their own requests, which may have been a particularly difficult task for those suffering from advanced dementia.<sup>144</sup> The request also must have passed through several stages of approval, thus making the review process last too long (extending for months to years) with many prisoners not surviving the process. The request needed to be approved by the warden, the regional director of the Bureau of Prisons (BOP), General counsel of the BOP, and then finally the Director of the BOP—with only the Director being empowered to petition the court.<sup>145</sup> The BOP had also historically interpreted the statute such that the BOP was obligated to petition the court only if a prisoner had a projected life span of less than twelve months, the result being that many prisoners could potentially die in prison even before they reached the predicted time at which they had less than twelve months to live.<sup>146</sup> This interpretation had remained constant even though it had never been judicially enforced nor explicitly statutorily required.

Compared to the federal statute, many state statutes are also harsher in terms of the requirements to be released.<sup>147</sup> For example, California allows for compassionate release based on medical conditions only if the prisoner is “permanently incapacitated and unable to perform activities of daily living.”<sup>148</sup> In Arizona, statutes are unclear as to when a prisoner can be released for having a terminal illness, with prisoners being released only if they are projected to die within either three, four, or six months.<sup>149</sup> In Kansas, the prisoner must be projected to die

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<sup>140</sup> See Jennifer Leto, *Extraordinary and Compelling: Madison v. Alabama and The Issue of Prison Reform for Elderly Prisoners*, 10 U. MIAMI RACE & SOC. JUST. L. REV. 41, 50 (2019). *E.g.*, U.S. v. Lochmiller, 473 F.Supp.3d 1245, 1249 (D. Colo. 2020) (holding advanced Alzheimer’s was an “extraordinary and compelling” reason for sentence reduction after noting that “the most important factor . . . is the need for a sentence that provides ‘just [deserts]’ and citing Madison for the proposition that punishment serves no retributive purpose if the prisoner does not understand the reasons for punishment); U.S. v. Miller, 690 F.Supp. 1578, 1579 (E.D. Mich. 1988) (“where a defendant suffers dementia to such a degree that he is unable to appreciate the reasons for his incarceration, imprisonment fails to serve any useful purpose”).

<sup>141</sup> *Id.* at 48.

<sup>142</sup> *Id.* at 49.

<sup>143</sup> See generally Casey N. Ferri, *A Stuck Safety Valve: The Inadequacy of Compassionate Release for Elderly Inmates*, 43 STETSON L. REV. 197 (2013) for discussion on why these statutes are rarely used.

<sup>144</sup> *Id.* at 222.

<sup>145</sup> *Id.* at 221.

<sup>146</sup> *Id.* at 223-25.

<sup>147</sup> *Id.* at 222.

<sup>148</sup> Mary Price, *Everywhere and Nowhere: Compassionate Release in the States*, FAMM, 13 (June 2018), <https://famm.org/wp-content/uploads/Exec-Summary-Report.pdf>.

<sup>149</sup> *Id.* at 14.

within 30 days.<sup>150</sup> States also may categorically prevent certain defendants from compassionate release (e.g. Louisiana excluding prisoners with contagious diseases, Maine allowing only those in minimum security to be released).<sup>151</sup> These procedural difficulties have resulted in very few prisoners being released early on both the state and national level. For example, only nine prisoners were released early from Pennsylvania prisons between 2009 and 2015 and seven prisoners were released from Kansas prisons between 2009 and 2016.<sup>152</sup> Only about .01% of all federal prisoners were released early between 1990 and 2000.<sup>153</sup>

Recently, however, Congress amended the federal statute with the First Step Act in 2018.<sup>154</sup> The new act gives a prisoner the right to petition the court if the Director fails “to bring a motion on the prisoner’s behalf” and considers whether “extraordinary and compelling reasons warrant [a sentence] reduction” and whether “such a reduction is consistent with applicable policy statements issued by the Sentencing Commission.”<sup>155</sup> However, the act “does not define ‘extraordinary and compelling reasons,’” and “the policy statement pertains to the old law rather than the new law and thus is of questionable applicability.”<sup>156</sup> The likelihood of successful future post-*Madison* compassionate release motions is thus unclear. With virtually no dementia-related case law on post-*Madison* compassionate release motions and eighth amendment claims, it is unknown how *Madison* will affect the adjudication of cases where post-crime dementia is alleged to affect the justifiability of punishment. But such claims are almost certain to arise with the increasing size of the elderly population.

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<sup>150</sup> *Id.* at 16.

<sup>151</sup> *Id.* at 14.

<sup>152</sup> *Id.* at 12-13.

<sup>153</sup> Ferri, *supra* note 104, at 198.

<sup>154</sup> See U.S. v. Champagne No. 4:97-cr-089, 2020 WL 3472911 (D. N.D. 2020) and U.S. v. Elias, 984 F.3d 516 (6<sup>th</sup> Cir. 2021) for discussion and application of the new statute.

<sup>155</sup> *Champagne*, 2020 WL 3472911, at \*2.

<sup>156</sup> *Id.* at 3.

## B. Supplemental Literature Review

As the US population ages and rates of dementia increase, the prevalence of dementia among those involved in the criminal justice system can be expected to increase. However, a lack of data and information on justice-involved adults with dementia significantly impairs the field's ability to set a policy agenda that addresses the unique needs of this population across the justice intercept points. To help fill the gap, this mixed-methods, cross-collaborative research effort collected survey data and conducted interviews with a variety of correctional health and legal field stakeholders to learn about their experiences working or interacting with people with dementia in the criminal justice system.

### Introduction

The American population is “graying” as the Baby Boomer generation ages. The US Census projects that by 2035, there will be more older adults than children for the first time (Census, 2018). In 2020, there were 56 million Americans age 65 and older, or about 1 in 6 people, and this number is expected to increase to 73 million (FIFARS, 200). These demographic changes have led to corresponding increases in health conditions for which older age is a risk factor, such as dementia. Currently an estimated 6.2 million Americans age 65 and older have dementia, and in a parallel trend to aging Americans, the number with dementia is predicted to increase to 12.7 million by 2050 (Alzheimer's Association, 2022 see <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf> ).

Dementia is a general term used to describe a person's cognitive decline and impaired ability to remember, think, make decisions, or care for themselves in a way that interferes with everyday activities (CDC, 2019). Although aging is a known risk factor for dementia and the prevalence of dementia is higher among older adults, it is important to note that dementia is not a natural part of aging (CDC, 2019). People younger than 65 can also develop dementia although it is less common and the prevalence is unknown (Alzheimer's Association, 2020, <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>). The most common forms of dementia are Alzheimer's disease, frontotemporal dementia, vascular dementia, and Lewy body dementia (NIA, 2021). Dementia symptoms vary from person to person and by type of dementia, but typically include memory loss and confusion, poor judgment, difficulty with communicating and understanding others, wandering and getting lost in familiar places, mishandling of money and finances, impulsivity, aggression, hallucinating or experiencing paranoia or delusion, and repeating questions (NIA, 2021). As dementia progresses, an individual's ability to live independently and perform self-care tasks, such as feeding and dressing themselves, typically becomes impaired and they will require more medical and support services.

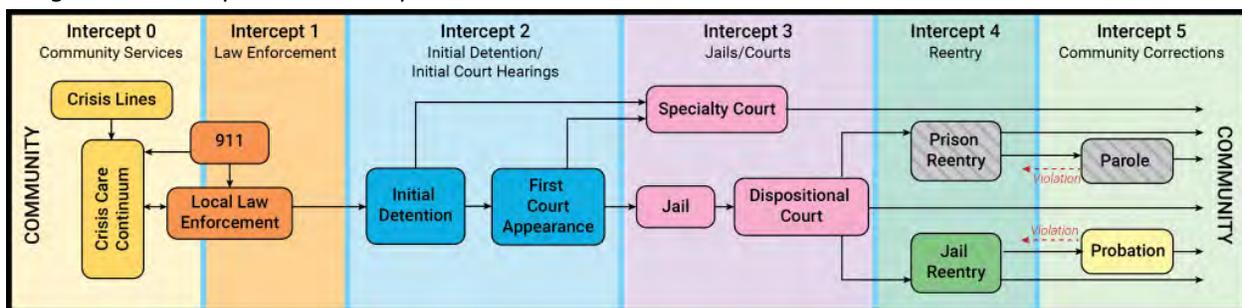
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An overlooked group of people with dementia are those who are involved in the

criminal justice system, and this is an important subgroup because the prison population is also aging. The number of state prisoners age 55 and older has increased by 400% from 1993 to 2013 and it is predicted that by 2030, this age group will account for one-third of the US prison population (Carson and Sabol, 2016; Osbourne Association, 2018). The incarceration of people with dementia poses a unique set of legal, ethical, and healthcare-related questions that impact multiple social systems and demand attention. Common challenges associated with dementia in the general population, such as timely and accurate assessment and access to appropriate care, are often magnified and more complex for individuals in the criminal justice system.

Criminal justice involvement among people with dementia can be conceptualized with the sequential intercept model (SIM). Initially designed for people with mental illness, the SIM offers a framework to understand the different points at which a person can be diverted out of the justice system, or a point where their involvement shifts and an opportunity for services can be established (see Figure 1 below) (Munetz and Griffin, 2006). Although dementia is not a mental illness, the SIM can guide the identification of intervention and solution points to better address justice-involved adults with dementia.

Figure 1. The Sequential Intercept Model



<https://www.prainc.com/uresact-sim/>

## People with Dementia in the Criminal Justice System

### Prevalence of dementia among justice-involved adults

The prevalence of dementia among people in prison and jail is largely unknown. In addition, there is virtually no data on the prevalence of dementia among people along other points in the justice system, from contact with law enforcement and arrests to probation and parole. These data gaps make it difficult to know the extent of the problem, including its scale, scope, and to identify points for intervention or diversion to a more appropriate placement. The lack of information is a barrier to providing recommendations and implementing programs and practices to improve the correctional care and treatment of

individuals with dementia.

Prevalence data on dementia among people in prison and jail is challenging to collect and currently there is no evidence of a national survey that captures it (Cipriani et al., 2017; Moll, 2013). While the Bureau of Justice Statistics (BJS) periodically collects correctional health data through its national-level inmate surveys, dementia is not included. However, BJS does ask about having a cognitive disability, defined as serious difficulty concentrating, remembering, or making decisions because of a physical, mental or emotional problem. An estimated 20% of people in prison and 33.5% of those in jail age 50 or older reported a cognitive disability (Bronson, Maruschak, and Berzofsky, 2015). Data also show that when compared to the general population, people in prison and jail have significantly worse health outcomes, which has led correctional health scholars to posit that inmates over 50 have health profiles similar to adults outside of prison who are over 65 (Maruschak, Berzofsky, & Unangst, 2015; Dulisse, Fitch, & Logan, 2020). For example, 38.4% of adults in prison versus 15.4% of adults in the general population report having a disability (Maruschak, Bronson, and Alper, 2021).

#### *Entry pathways for people with dementia in the criminal justice system*

There are two general pathways for which people with dementia become incarcerated. The first pathway is that a person develops dementia during the course of serving their sentence. The second pathway is an older adult with symptoms of neurocognitive decline becomes a first-time arrestee in their 70s or 80s. Cognitive impairments have been noted to be a significant cause of first-time criminal offenses by older adults (Miller, 2011). Individuals with dementia may exhibit behavioral problems that cause safety concerns and warrant police involvement, such as wandering, indecent exposure, shoplifting, traffic violations, or violence towards others (Sun et al., 2019). Cognitive and sensory impairment in dementia patients may escalate police involvement during crisis, and police are often not properly trained to identify and address these health-related issues (Moll, 2013). In both of these pathways, the timely identification of dementia is essential to understanding the person's behaviors as related to neurocognitive decline, provide treatment and services to delay the progression of dementia and address existing symptoms, and consider alternative placements that offer the appropriate level of care.

#### *Competency to stand trial and criminal responsibility*

Dementia researchers and criminal justice practitioners agree that the scope and articulation of criminal responsibility for those with dementia needs to be clearly defined. At a minimum, a diagnosis of dementia should call into question an individual's competency to stand trial and criminal liability, as dementia may impair one's ability to provide informed consent for their legal defense strategy and understand court proceedings (Padama, 2018). In

a study of those age 60 or older among the forensic population, defendants with Alzheimer's Disease were found to be incompetent to stand trial at a rate of 30 to 50% (Sfera et al., 2014). Determining competency is a critical psycholegal factor during the adjudication process, however, there is a lack of clarity regarding how neurocognitive impairments potentially affect functional abilities related to competency to stand trial (Miller, 2020). State definitions vary, but generally a defendant is deemed incompetent to stand trial, if as a result of mental disorder or disability, they are unable to understand the criminal proceedings and assist in their defense (Bartos et al., 2017). However, unlike many mental health disorders for which the appropriate treatment can mitigate symptoms and restoration is possible, dementia is both progressive and irreversible and this complicates restoration. One study found that while restoration is possible for some people with dementia, the likelihood of successful restoration decreased by 10% per five-year increase in age (Morris & Parker, 2009).

If competent and taken to trial, whether or not a diagnosis of dementia may be used to mount an insanity defense is dependent upon how a state defines insanity. Twenty-five states use the M'Naghten test to determine legal insanity, which requires an individual to be incapable of understanding the nature or wrongness of their criminal act to qualify as insane. This test excludes individuals with frontotemporal dementia from using the insanity defense, as early frontotemporal dementia does not affect cognitive capacity or cause impairment to rationality (Mendez, 2010; Sfera et al., 2014). Twenty-one states use the American Law Institute (A.L.I.) test to determine legal insanity. This test differs from the M'Naghten test in that in addition to evaluating a defendant's capacity to understand the wrongfulness of their act, it also considers whether mental "defect" may compromise ability to conform one's behavior to the requirements of the law (American Law Institute, 1962). Therefore, because symptoms of frontotemporal dementia may render an individual incapable of controlling their behavior even when they understand that an action is wrong, an individual with this dementia may qualify as legally insane in states that use the A.L.I. test but not the M'Naghten test (Berryessa, 2016).

People with dementia may constitute a special population requiring categorical protections, or systematic protections for a population to mitigate criminal culpability or restrict sentencing (Arias & Flicker, 2020). Though little research has focused specifically on dementia patients and categorical protections, parallels can be drawn between other analogous populations in which assignment of liability must be given special consideration, including juveniles and individuals with psychiatric illness. Categorical protections concede that a crime has occurred but allow for special treatment within the criminal justice system on grounds that the individual did not have the requisite mental status necessary to be criminally liable (Arias and Flicker, 2020). The progressive nature of dementia may limit applicability of categorical protections, however.

Individuals often display symptoms of dementia before they meet clinical criteria for diagnosis, raising questions about the diagnostic criteria threshold an individual must meet to qualify for categorical protections, and unlike juveniles and individuals with mental illness, individuals with dementia are unlikely to benefit from rehabilitative programs that could serve as alternatives to sentencing (Arias & Flicker, 2020).

### *Dementia and the correctional environment*

In most cases, incarceration is not the right placement for persons with dementia, particularly as the condition progresses. Individuals with dementia experience unique health risks, have high service needs, and may benefit from diversion from incarceration to treatment-based alternatives (Ahalt & Williams, 2016). They are also at significant risk for victimization from other inmates, injuries from falls, declining physical and emotional wellbeing, and placements in restrictive housing units particularly for those who are undiagnosed (Davies, 2011; Moll, 2013; Garavito, 2019). Early symptoms of dementia that appear before memory loss typically include disinhibition, emotional shifts, irritability, and violent outbursts. As such, the symptoms are overlooked, dismissed, or classified as bad behavior by correctional personnel who are not trained to recognize or respond to signs of dementia (Garavito, 2019; Miller, 2011). Furthermore, symptoms of dementia often go unnoticed by the individual themselves, meaning they are unable to advocate for themselves and unlikely to receive healthcare until the symptoms are noticed by staff or another inmate (Garavito, 2019).

However, even when there is a desire to remove the person from jail or prison, this population is difficult to place in alternative settings as there are few to no community placement options for adults with dementia and a criminal record. Furthermore, for those who commit violent crimes, even as a symptom of cognitive impairment and with no prior history, probation or intermediate sanctions are unlikely to be considered viable sentencing options (Yates & Gillespie, 2000). One option for diversion is the establishment of dementia courts that could be modeled after other established diversion courts which exist in every state (Strong, 2016).

Similar to existing diversion courts that are specific to people with behavioral health challenges, a dementia court would be comprised of defendants with dementia or degenerative neurocognitive impairment, a collaborative, non-adversarial team that links the defendant with a suitable local treatment provider, and sanctions for failure to comply with the court's requirements (Dubljevic, 2020). However, because dementia is progressive and incurable, treatment options the court may impose are limited, and how to finance alternative dispositions must be considered (Kapp, 2020).

### *Best practices, recommendations, and interventions in the literature*

There is very limited research in the literature regarding best practices or even recommendations for people with dementia in the justice system, particularly those in prison and for whom a community placement cannot be found or is not suitable. Recommendations include screening people in prison for dementia, developing specialized units inside prison facilities, utilizing volunteer inmates to aid the person with dementia, improving the physical environment, developing pathways for compassionate or medical release, and training justice actors about dementia.

Scholars and stakeholders in the field have identified early and regular screening for dementia as a priority need for all older prisoners, especially first time offenders, and annually for those who turn 55 during incarceration (Williams et al., 2012; Garavito, 2019; Dulisse, Fitch, & Logan, 2020; Sfera et al., 2014). Dementia screening results can be used for decisions related to classification and housing assignments, programming, treatment of chronic conditions, and discharge planning and parole supervision (Williams et al., 2012). However, currently available cognitive screening tools are designed for community populations and may not perform as well in prison settings; an improved comprehensive assessment that measures the unique challenges of this population should be created (Williams et al., 2012; Dulisse, Fitch, & Logan, 2020).

There are also recommendations for creating palliative, hospice, or specialized geriatric units within prisons that can house prisoners (Ahlat & Williams, 2015; Lyon, 2019) such as the Memory Disorder Unit located in the Federal Medical Center (Massachusetts) that is modeled after nursing home memory care units (Bollinger et al., 2019). The unit houses 36 inmates with middle stage dementia, and the staff is certified in dementia care (Bollinger et al., 2019). Specialized units, however, are expensive to operate and this likely contributes to their rarity (Maschi et al., 2011). Even in the absence of specialized programs, research suggests some relatively inexpensive and easy-to-implement structural changes, such as marking cell doors with different colors, installing handrails and non-slippery floors, placing older inmates in lower bunks, and allowing for more time to respond to stimuli such as drills, may be helpful in maintaining independence and dignity for those with dementia in prisons (Mistry & Muhammad, 2015). Inmate peer programs have also been used to positively support the person with dementia, such as California's Gold Coats program and California Men's Colony that utilizes a peer support program in which volunteer inmates provide protection and facilitate social integration for those with dementia in the correctional setting (Garavito, 2019; Maschi et al., 2011).

Compassionate release or medical parole are also discussed by scholars in the field as a means to provide individuals with dementia to more appropriate healthcare in the community (Garavito, 2019; Pro & Marzell, 2017). Whether released after completing their

sentence or through a compassionate or medical release program, there is a scarcity of geriatric-focused reentry programs, especially those specialized for individuals with dementia (Ahalt & Williams, 2016). Additionally, justice-involved individuals are often stigmatized and that may impact their ability to be placed in nursing homes or long-term care facilities, which are often hesitant to accept patients with a criminal record (Pro & Marzell, 2017). For those who were convicted of sexual offenses or who are perceived to pose a threat to care staff, it is nearly impossible to find community placements (Mistry & Muhammad, 2015). Connecticut developed a nursing home specifically to accept patients from the Department of Corrections, but the facility has faced many setbacks including ineligibility for Medicare and lawsuits from the community (Garavito, 2019).

Training on dementia is recommended for those in the justice system who could come into contact with people with dementia, but few dementia-related training programs currently exist for law enforcement and correctional officers (Moll, 2013). Evidence shows that individuals with dementia can become violent during crisis events, so proper training in addressing dementia symptoms and de-escalation techniques are crucial (Moll, 2013). Trainings for police officers should also include information about community resources that can be utilized to divert the person from further involvement in the criminal justice system (Sun et al., 2019).

Attorneys and prosecutors would also benefit from training as any cases involving people with dementia need not reach a point where affirmative defenses and sentencing options become relevant, as prosecutors are allowed to practice discretion regarding the bringing of criminal charges, as well as the deposition of any charges filed (Kapp, 2020). Efforts should be made to inform prosecutors about the nature and consequences of dementia, including resources available, so that they may use their discretion to handle incidents involving individuals with dementia outside of the criminal justice system (Kapp, 2020).

In light of the knowledge gaps and the need to identify interventions for people with dementia in the criminal justice system, this mixed-methods, cross-collaborative research effort collected survey data and conducted interviews with a variety of correctional health and legal field stakeholders. The purpose was to learn about their experiences working or interacting with people with dementia in the criminal justice system, in order to better understand how and why these individuals are behind bars and make recommendations to improve policy, data collection, and treatment.

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