

United States Senate
WASHINGTON, DC 20510

July 1, 2021

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

The Honorable Merrick Garland
Attorney General
U.S. Department of Justice
950 Pennsylvania Avenue, NW
Washington, DC 20530

Dear Secretary Becerra and Attorney General Garland:

Last week, Britney Spears testified in superior court, asking to end her 13-years-long conservatorship and revealing disturbing details about the exploitative legal arrangement through which her father has been able to control her finances and her entire life.¹ Ms. Spears' case has shined a light on longstanding concerns from advocates who have underscored the potential for financial and civil rights abuses of individuals placed under guardianship or conservatorship, typically older Americans and Americans with intellectual, developmental, and mental health disabilities. Despite these concerns, comprehensive data regarding guardianship (referred to as conservatorship in some states) in the United States are substantially lacking—hindering policymakers and advocates' efforts to understand gaps and abuses in the system and find ways to address them. Because of your agency's work with states related to guardianship, and the role your agency may play in providing benefits to those under guardianship, we are writing to request information about data collected by your agency on the prevalence of guardianship and conservatorship in the United States.

Guardianship is a legal proceeding or relationship “created when a state court grants one person or entity the authority and responsibility to make decisions in the best interest of an incapacitated individual [...] concerning his or her person or property.”² Depending on the terms of the guardianship appointment, adults with mental, intellectual or developmental disabilities that are judged to lack capacity “may no longer have the right to sign contracts, vote, marry or divorce, buy or sell real estate, decide where to live, or make decisions about their own health

¹ National Public Radio, “Read Britney Spears’ Statement To the Court In Her Conservatorship Hearing,” Updated June 24, 2021, <https://www.npr.org/2021/06/24/1009858617/britney-spears-transcript-court-hearing-conservatorship>.

² U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 1, <https://www.gao.gov/assets/gao-17-33.pdf>.

care.”³ While guardians and conservators often serve selflessly and in the best interest of the person under guardianship, a lack of resources for court oversight and insufficient due process in guardianship proceedings can create significant opportunities for neglect, exploitation, and abuse.⁴ Although guardianship decisions lie exclusively within the authority of state courts, they can also raise significant federal spending and policy interests, making imperative that federal officials work collaboratively with state courts to identify gaps in our understanding of problems with America’s guardianship system and develop solutions to address them.

The National Center for State Courts (NCSC) estimates that 1.3 million adults are currently living under guardianship or conservatorship, and their guardians control roughly \$50 billion in assets.⁵ There is wide variation, however, among states on the type of information collected about guardianship, and NCSC’s estimate is based on extrapolation from a handful of states.⁶ In many states, it is impossible to identify the number of active guardianship cases, in part because they do not have a centralized data collection system.⁷ According to a 2018 U.S. Senate Committee on Aging report on guardianship, “few states appear to be able to track the total number of individuals subject to guardianship, let alone record demographic information, the types of guardianship being utilized, or the extent of a guardian’s authority.”⁸ Because of the lack of data, it is also impossible to understand potential disparities or disproportionate impacts of guardianship policies related to the race and ethnicity, age, sex, gender identity, sexual orientation, and type of disability of those subject to a guardianship.

This lack of data hinders the federal government’s ability to make policy changes and inform resource allocations. For example, in 2016, the Government Accountability Office (GAO) found that “the extent of elder abuse by guardians nationally is unknown due to limited data on the number of guardians serving older adults, older adults in guardianships, and cases of elder abuse by a guardian.”⁹ As a result, states and federal actors are unable to use this information to determine the best policy response and resource allocation regarding screening, education, monitoring of guardians, etc.¹⁰ The National Council on Disability notes that “we also cannot say for sure whether guardianship is a growing trend or if its popularity is waning, making it difficult to urge policymakers to address the problems in guardianship, since it is

³ U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 4, <https://www.gao.gov/assets/gao-17-33.pdf>.

⁴ National Council on Disability, “Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination,” March 22, 2018, pp. 22, https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf.

⁵ National Council on Disability, “Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination,” March 22, 2018, pp. 65, https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf.

⁶ *Id.*

⁷ National Council on Disability, “Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities,” June 10, 2019, pp. 41, https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf.

⁸ U.S. Senate Special Committee on Aging, “Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Americans,” November 2018, pp. 25, https://www.aging.senate.gov/imo/media/doc/Guardianship_Report_2018_gloss_compress.pdf.

⁹ U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 6, <https://www.gao.gov/assets/gao-17-33.pdf>.

¹⁰ U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 12, <https://www.gao.gov/assets/gao-17-33.pdf>.

difficult to prove that the problems are, in fact, growing.”¹¹ A 2009 survey from the NCSC “suggests the number of guardianship cases are either staying the same or increasing,”¹² but this data is outdated and is based on a small sample size. The lack of data to understand the gaps and abuses in the system also creates substantial opportunities for fraud and misappropriation of federal program dollars. For example, a state court may remove a guardian for malfeasance, but federal program managers will continue to direct payments to the removed official rather than redirect payments to the new guardian.¹³

While state and local courts have primary responsibility over the guardianship process, federal agencies have made efforts to support coordination and information sharing across states administering guardianship programs.¹⁴ For example, the Department of Health and Human Services (HHS)’s Administration on Community Living (ACL) has funded pilot efforts for guardianship reform, including providing funding for states’ Working Interdisciplinary Network on Guardianship (WINGS) programs and for the use of supported decision-making as an alternative to guardianship.¹⁵ HHS has also provided funding to the National Center on Law and Elder Rights to provide technical assistance, policy guidance, training, and resources to states on guardianship and other elder rights issues, oversight and monitoring improvements, standards of practice for guardians, etc.¹⁶ The Consumer Financial Protection Bureau (CFPB) has developed materials that can be used by guardians, banks, and others to help better protect older adults with guardians from abuse.¹⁷

Your agencies have made some efforts to increase data collection, but these efforts have primarily focused on elder abuse, rather than a more comprehensive scope of guardianship information. In 2013, HHS’s Administration on Aging began developing a national reporting system for state adult protective services agencies to submit data on the exploitation and abuse of older adults and adults with disabilities, called the National Adult Maltreatment Reporting System (NAMRS).¹⁸ During the development phase of NAMRS, HHS indicated that, once developed, the system would be able to collect information regarding abuse involving a

¹¹ National Council on Disability, “Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination,” March 22, 2018, pp. 66,

https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf.

¹² U.S. Senate Special Committee on Aging, “Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Americans,” November 2018, pp. 25,

https://www.aging.senate.gov/imo/media/doc/Guardianship_Report_2018_gloss_compress.pdf.

¹³ U.S. Government Accountability Office, “Elder Justice: National Strategy Needed to Effectively Combat Elder Financial Exploitation,” November 15, 2012, <https://www.gao.gov/products/gao-13-110>; U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, <https://www.gao.gov/assets/gao-17-33.pdf>.

¹⁴ U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 15-16, <https://www.gao.gov/assets/gao-17-33.pdf>.

¹⁵ National Center on Law and Elder Rights, “Guardianship,” <https://ncler.acl.gov/Legal-Training/Guardianship.aspx>.

¹⁶ *Id.*

¹⁷ U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 17, <https://www.gao.gov/assets/gao-17-33.pdf>.

¹⁸ U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 12, <https://www.gao.gov/assets/gao-17-33.pdf>.

guardian.¹⁹ Subsequently, in 2017, Congress passed the *Elder Abuse Prevention and Prosecution Act*, which directed the Department of Justice (DOJ) to establish best practices for data collection related to elder abuse for states, and directed DOJ and HHS to establish interagency coordination for federal data collection related to elder abuse.²⁰

Finally, the Social Security Administration (SSA), the Department of Veterans Affairs (VA), and the Office of Personnel Management (OPM), may also have information on the prevalence of guardianships based on their administration of programs that appoint representative payees to manage federal benefits received for individuals who may be in a guardianship.²¹ Subagencies at HHS, including the Centers for Medicare and Medicaid Services (CMS) and the Substance Abuse and Mental Health Services Administration (SAMHSA), could also be able to provide insights into guardianship if the agencies collected relevant information about the beneficiaries of programs they administered, such as Medicare and Medicaid. The National Council on Disability (NCD) has recommended that Congress and the Administration develop initiatives to produce effective and comprehensive data on guardianship—including the SSA, CMS, VA, and SAMHSA—to determine whether or not the individuals they serve are subject to guardianship.²² NCD has also studied the “the existence of a ‘school-to-guardianship pipeline’” and finds “schools are the number one referral source for guardianship,” suggesting data collection efforts through the Department of Education could provide a mechanism for federal data collection.²³

In order to help us better understand existing federal agency infrastructure for data collection, and inform future efforts to develop a more consistent national data collection effort, we ask that you please provide the following information by no later than July 14, 2021:

1. What data systems are in place for officials at your agency to access information regarding the following:
 - a. Number of adults under guardianship in the United States, broken down by demographic information (race and ethnicity, age, sex, gender identity, sexual orientation), geography, reason for alleged incapacity, and type of guardianship (limited vs. full/plenary);
 - b. Number of guardians in the United States, broken down by demographic information (race and ethnicity, age, sex, gender identity, sexual orientation), geography, whether the guardian is over the person, property, or both, whether the guardian serves as a representative payee and type of guardian (professional vs. family);

¹⁹ *Id.*

²⁰ P.L. 115-70, “S.178 Elder Abuse Prevention and Prosecution Act,” November 18, 2017, <https://www.congress.gov/bill/115th-congress/senate-bill/178/text>.

²¹ U.S. Government Accountability Office, “Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults,” November 2016, pp. 26, <https://www.gao.gov/assets/gao-17-33.pdf>.


²² National Council on Disability, “Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination,” March 22, 2018, pp.18, https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf.

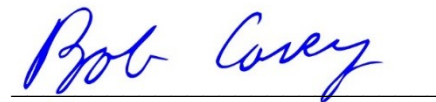
²³ National Council on Disability, “New federal research examines guardianships of people with intellectual, developmental disabilities, finds school-to-guardianship pipeline,” June 10, 2019, <https://ncd.gov/newsroom/2019/new-federal-research-examines-guardianships>.

- c. Value of assets controlled by the guardian;
 - d. Complaint and grievance information about guardians (number of cases opened, closed, investigated, and in need of investigation);
 - e. Sanctions placed on guardians;
 - f. Appeals of guardianship;
 - g. Any data collected on implementation of alternatives to guardianship including, but not limited to, supported decision making; and
 - h. Data about restoration of rights, including, where appropriate, whether the individual had received information about restoration and whether the continued needs for guardianship is periodically reviewed, and if so, at what intervals.
2. Does your agency, or its subagencies, collect data on whether or not the individuals to which it provides benefits are subject to guardianship? Please specify the extent of the information collected and how that information is collected.
 3. Please provide an update of your agency's efforts to prevent guardianships, or to support individuals under guardianship and their guardians, including any new initiatives that are planned to address concerns related to guardianship.
 4. Please provide an update on your agency's implementation of the *Elder Abuse Prevention and Prosecution Act*.
 5. What resources do you need from Congress or what recommendations do you have for Congress to improve federal efforts to design, test, and improve data collection systems related to guardianship and alternatives to guardianship?

Thank you for your attention to this matter.

Sincerely,


Elizabeth Warren
United States Senator


Robert P. Casey, Jr.
United States Senator