Expert Panel: Review of California Department of Developmental Services Conservatorship Program Report

Convened by: California Department of Developmental Services & National Association of State Directors of Developmental Disabilities Services

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Expert Panel Review and Recommendations:

Executive Summary

In August 2022, the Department of Developmental Services (DDS) in conjunction with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) convened an expert panel (panel) to undertake a thorough review of DDS' conservatorship program. The nine-person panel met five times and conducted four focus groups with stakeholders, in addition to conducting preparatory and follow-up work during the interim between meetings.

As of September 2022, DDS was conservator for 416 individuals. The number of DDS conservatees has decreased over the past seven years by 100 individuals. Approximately 75 percent of DDS conservatorships were established prior to 2012. Requests for DDS to accept a conservatorship nomination are reviewed by DDS staff and the Director and are only accepted when there is credible evidence that there is immediate harm, danger or risk to the conservatee's well-being. DDS considers alternatives to conservatorship and accepts nominations for limited conservatorships only for those powers necessary to protect the individual's health, safety and well-being with the aim of maintaining the maximum independence and autonomy for conserved individuals.

By comparison, the number of regional center consumers conserved by someone other than DDS has increased by 46 percent during the past seven years from 39,252 to 57,365. The demographic data shows that 75 percent of regional center consumers conserved by DDS are 45 years of age or older while 75 percent of those not conserved by DDS are between the ages of 18 and 34. The increase of conservatorships for transition-aged youth is consistent with national trends and as noted by the National Council on Disability reflects a School-to-Guardianship Pipeline for Youth with ID/DD.[1]

This panel was asked to conduct a comprehensive review of DDS' conservatorship program and make recommendations to improve the DDS conservatorship process, strengthen DDS' oversight, and identify alternatives to conservatorship including supported decision-making[2]. The recommendations

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[1] Beyond Guardianship: Towards Alternatives That Promote Greater Self Determination, National Council on Disability March 22, 2018.
https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf

[2] Supported decision-making refers to the process set forth in California Welfare and Institution Code Section 21000 et seq., effective January 1, 2023.

are summarized below, with additional information provided in the body of the report.

DDS as the Conservator

DDS should continue its limited role in conservatorships with:

- Implementation of the recommendations included in this report to strengthen and improve its conservatorship processes and promote the use of alternatives to conservatorship; and
- A commitment to, in partnership and consultation with stakeholders, periodically evaluate the need for DDS to continue in its role as a conservator, the effectiveness of alternatives to conservatorship, and the consideration of others who could provide conservatorship services.

Information and Training on Conservatorships for People with Intellectual and Developmental Disabilities

To enhance and improve information and training it is recommended that DDS:

- Work with stakeholders and other state agencies, to develop a uniform and consistent state-wide approach to providing information and training about conservatorships and alternatives to conservatorship.
- Make training available to individuals with intellectual and developmental disabilities, self-advocates, family members and anyone who makes referrals or is involved in the conservatorship process. Training must be made available throughout an individual's life span and training for professionals must be available annually. The training should be developed in accordance with cultural and linguistic appropriate services (CLAS) standards and developed in plain language to ensure widespread understanding.
- Support efforts to provide information and training about supported decision-making and other alternatives to conservatorship that are consistent with the requirements of AB 1663 and aligned with the information and training provided by the State Council on Developmental Disabilities (SCDD).

Improvements to the Current DDS Conservatorship Program

To enhance oversight of the DDS conservatorship program it is recommended that DDS:

- Develop written guidelines for how it arrives at its initial conservatorship recommendations in a case. The guidelines should outline the review process and criteria for accepting a nomination, as well as steps that should be considered before a nomination. The guidelines should be developed in consultation with stakeholders, and once developed, shared with self-advocates, family members, regional centers and other stakeholders and be available to the public.

- Provide additional support to DDS conservatees by arranging for an independent advocate to meet with each DDS conservatee.
- Develop written standard guidelines and best practices for carrying out its responsibilities in delegated conservatorships. These should include procedures for a comprehensive annual review of each DDS conservatorship. The review should determine if the conservatorship is still needed, or if DDS' conservatorship powers can be reduced. If a conservatorship is no longer needed or DDS' powers can be reduced, DDS should notify the court and schedule a hearing.
- Develop written standard DDS conservatorship guidelines for use by all 21 regional centers.
- Provide annual training to regional centers about DDS conservatorships and alternatives to conservatorships.
- Finalize arrangements with other state agencies for automatic notifications of complaints in a DDS conservatee's living arrangement, when an individual resides at a home licensed by the California Department of Public Health (CDPH).
- Continue and expand current monitoring of all DDS conservatees.
- Enhance data systems to monitor and analyze DDS conservatorship trends.

Conservatorship System Improvement for Individuals with Intellectual and Developmental Disabilities Who Are Not Conserved by DDS

The following are additional recommendations for system improvements for regional center consumers:

- DDS should work with the California Department of Education (CDE) and other state agencies to develop strategies to increase understanding that a conservatorship is not needed for a family to continue participating with their young adult in making school-related decisions.
- DDS should use its relationships with other state agencies to discuss a state-wide strategy to train other professionals about alternatives to conservatorships. Training topics could include information on supported decision-making, the ability of individuals with intellectual and developmental disabilities to make decisions with and without support, and the services available from regional centers.
- Regional centers, in consultation with DDS and other stakeholders should develop written best practice guidelines for including additional information in the required initial court conservatorship reports.
- Regional centers should establish ongoing communication with their local courts and court investigators and provide court reports for annual or biannual court conservatorship reviews and assisting self-advocates and families in obtaining navigation support during court processes.

Background

In August 2022, DDS announced steps it was taking towards system improvements for Californians with intellectual and developmental disabilities when DDS is the court appointed conservator. The steps included a joint effort by DDS and NASDDDS to convene a panel of national experts. The panel was responsible for undertaking a complete review of DDS' conservatorship program and making recommendations to DDS about ways to improve its conservatorship process to include strengthening DDS' oversight and identifying alternatives to conservatorship, including supported decision-making.

The nine-member panel included individuals with disabilities, family members of individuals with intellectual and developmental disabilities and expertise in the fields of abuse and neglect, healthcare, advocacy, law, equity and inclusion and California's and other state's guardianship systems. A list of the panel members is included in Attachment A.

The panel began meeting in early September 2022. During these meetings the panel reviewed and discussed DDS' current conservatorship processes, data about DDS conservatees, and recent changes to California's conservatorship laws including the new supported decision-making statute (AB 1663). Panel members also reviewed national data from the National Core Indicators and national reports, including the National Council on Disability's report about national guardianship practices and areas for reform. In October, the panel held Focus Group meetings with diverse stakeholders including individuals with intellectual and developmental disabilities, family members, advocates, and regional center directors and staff. Through these Focus Group meetings, the panel learned about stakeholders' experiences with the current conservatorship process, and their ideas for improvements to the conservatorship system including alternatives to conservatorship and ways to strengthen DDS' oversight. All of this information informed the panel's discussions and recommendations in the following broad areas: Information and Training; Improvements to the Current DDS Conservatorship Process; and Conservatorship System Improvements for Individuals Who Are Not Conserved by DDS.

Demographic Information About Current Conservatees

As of September 2022, DDS was conservator for 416 individuals. The number of DDS conservatees has decreased over the past seven years by 100 individuals. The demographic data shows that of the 416 individuals, almost 75 percent were 45 years of age or older and 60 percent were White. DDS had been the conservator for more than 20 years for 60 percent of the individuals and over 75 percent were conserved prior to 2012. Most DDS conservatees, 81 percent, lived in either a community care facility (CCF) or an intermediate care facility (ICF).

The panel also reviewed data for 57,365 individuals served by a regional center and conserved by someone other than DDS. The number of individuals who are not conserved by DDS has increased since 2015 when there were 39,252 individuals. The demographics of these conservatees differ significantly from those conserved by DDS. For example, approximately 80 percent of the individuals live with their family and 75 percent are between the ages of 18 and 34, with the largest group, 47 percent, between the ages of 18 and 24. The majority of the individuals who have a conservator other than DDS are Latino or White, each representing 37 percent, and overall, the ethnicity of these conservatees is comparable to the ethnicity of individuals served by regional centers.

Current Process for DDS Review of Conservatorship Nomination Request and Oversight

Information provided by DDS shows that it receives conservatorship nominations from a variety of third parties concerned about the health, safety, or well-being of a regional center client[3]. DDS also explained its process for reviewing its conservatorships. Upon receiving a nomination, DDS staff requests and reviews documents supporting the need for the conservatorship and speaks with relevant individuals to gather facts, including the individual's court-appointed attorney once appointed. As part of the current review process, DDS staff ask if alternative and less restrictive methods (e.g., alternative supports or additional regional center funded services) have been tried and exhausted and considers if there is credible evidence that there is immediate harm, danger or risk of well-being. DDS staff prepare a comprehensive summary of the information and make a recommendation to accept or deny the conservatorship nomination. The DDS Director undertakes a thorough review of the staff recommendation including the circumstances that may require DDS to become the conservator, and the exploration of alternatives to conservatorship and/or other individuals who can serve as the conservator. If no appropriate alternatives are identified, DDS indicated that it applies for limited conservatorship only for those powers that are necessary to protect the individual's health, safety and well-being; however, DDS does not currently have written guidelines for deciding when to accept a conservatorship nomination.

A review of data between January 2020 and early October 2022 indicates that of the 19 conservatorship nomination reviews DDS completed, 42 percent of the nominations were accepted. The courts were the most common referring entity, 42 percent, followed by regional centers at 37 percent, and APS/Public Guardian at 21 percent. Of the nominations accepted, 88 percent were due to DDS'

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[3] The nominations can come from regional centers, protective service entities including Adult Protective Services, or Public Guardians, law enforcement, courts, court-appointed attorneys, medical professionals, or family members.

conclusion that there were credible allegations of third-party abuse/neglect, sexual assault, or undue influence; and the other 12 percent were accepted because no successor conservator could be identified. Of the nominations declined, there was no credible allegation of abuse or neglect, the individuals reportedly were doing well in their living arrangement, or the referral request was solely based on the death of their conservator and the court ultimately terminated the conservatorship.

DDS conservatorship petitions are filed and reviewed by a California Superior Court. If a court appoints the DDS Director as limited conservator, the DDS Director delegates its conservatorship authority to the regional center where the conservatee receives services. The regional center conducts an annual review, including information about the ongoing need for the conservatorship. Further, as of August 2022, regional centers are required to report to DDS changes in needs or circumstances for each conservatee. DDS' conservatorship liaison monitors DDS conservatees to ensure that their health, safety and well-being continue to be protected. Monitoring activities include review of each report filed by the regional center and the court investigator, any special incident reports filed including those by a service provider, and reports from licensing agencies to ensure that proper care is provided and to identify and correct any deficiencies in a conservatee's care. In August 2022, DDS added a requirement to the regional center contracts to submit a monthly report for each DDS conservatee. The reports provide information regarding any concerns about the conservatee's health, safety or well-being. If there is information suggesting harm to a conservatee, the DDS conservatorship liaison may visit the conservatee to check on the person's well-being and/or follow up with the regional center to ensure that the conservatee's health, safety, and well-being is protected.

DDS does not have a standardized process to review the continued need for a conservatorship. To strengthen its oversight and ensure a more comprehensive review of each conservatee and the on-going need for conservatorship, DDS and regional centers recently agreed to a contract amendment requiring each regional center to complete a person-centered comprehensive review for each conservatee.

Regional Centers Delegated Conservatorship Responsibilities

The DDS Director delegates the day-to-day conservatorship responsibilities to the regional center that provides services to its conservatee. Regional centers use common ways to carry out some of their delegated conservatorship responsibilities. These common approaches largely mirror the service coordination practices for individuals who are not conserved by DDS and include quarterly face-to-face monitoring visits for conservatees living in residential facilities, general conservatorship training annually or biennially, similar approaches to the day-to-day service coordinator responsibilities, including person-centered planning, individual program plan (IPP) meetings and required annual reviews of the conservatorship with a report to DDS, and more recently a required monthly report to DDS.

There are differences among regional centers regarding who can make decisions for the conservatee. It may be the service coordinator, service coordinator's supervisor or manager, or the executive director or other senior director who makes decisions, with more significant decisions such as non-routine medical care made by medical staff. Generally, there is no specialized training or different experience required for service coordinators whose caseload includes DDS conservatees. Other regional center staff who have delegated conservatorship responsibilities generally do not meet with the conservatee or do so infrequently. Some regional centers develop a conservatorship transition plan which identifies specific needs and goals to assist the conservatees with decision-making and other skills needed to end the conservatorship.

DDS as the Conservator

1. DDS should continue its role in limited conservatorships with the:
    - Implementation of the recommendations included in this report to strengthen and improve its conservatorship processes and promote the use of alternatives to conservatorship; and
    - Commitment to, in partnership and consultation with stakeholders, periodic evaluation of the need for DDS to continue in its role as a conservator and the effectiveness of alternatives to conservatorship
    - DDS should also consider other entities who could provide conservatorship services who:
        - Are able to provide a uniform, state-wide approach to conservatorships, have specialized knowledge of the needs of individuals with intellectual and developmental disabilities and alternatives to conservatorship with a philosophy that values autonomy and views conservatorships as a last resort.
        - Have the necessary independence and capacity to avoid conflicts of interest including financial conflicts of interest.

Information and Training

Self-advocates and family members report that basic information about conservatorships and alternatives is available from a variety of sources. However, the information is hard to understand, and often is not available in plain language or the individual's preferred language. Regional center service coordinators often do not have enough in-depth information to help families make conservatorship decisions and it would be helpful to have a more person-centered approach to help families and individuals make informed decisions. Information about conservatorships and alternatives often are discussed at the time an individual is transitioning to adulthood rather than throughout the individual's life span.

Information and Training Recommendations

Overall Recommendations:

1. DDS should work with stakeholders and other state agencies, as needed, to develop a uniform and consistent state-wide approach to providing information and training about conservatorships and alternatives to conservatorship. Information and training should be available for individuals with intellectual and developmental disabilities, family members and anyone who makes referrals or is involved in the conservatorship process.
2. The training should be developed in accordance with cultural and linguistic appropriate services (CLAS) standards and developed in plain language to ensure widespread understanding.
3. DDS information and training about supported decision-making and other alternatives to conservatorship should be consistent with the requirements of AB 1663 and aligned with the information and training provided by SCDD.

Recommendations for Self-Advocate and Family Member Training

1. Information and training for self-advocates and family members must be clear, user-friendly, and culturally responsive to the diverse needs of individuals served by regional centers. This means, it must be provided through a variety of mediums, in an individual's preferred language, and be provided by individuals trusted by the community, including individuals with lived experience from diverse backgrounds.
2. The content of the Information and training for self-advocates and family members should be available throughout the individual's lifespan and reflect that individuals can live productive lives in their community with or without supports. DDS' information about conservatorships should reflect its philosophy that conservatorships be used in limited circumstances and only after

considering and/or trying alternatives to conservatorship. In addition, information and training should do the following:

  a. Explain what a conservatorship entails, including limitations on the individual's rights and freedoms.
  b. Explain that conservatorships for individuals with intellectual and developmental disabilities should be limited conservatorships and are time limited.
  c. Discuss specific alternatives to a limited conservatorship and how to arrange for each alternative. The alternatives should include supported decision-making and ways to increase self-advocates' decision-making skills.
  d. Discuss person-centered planning and future planning.
  e. Teach self-advocacy skills, including independent decision-making skills.
  f. Address family members' concerns and fears about their child's future, show ways that their child's needs can be met without a conservatorship, including alternative options for supporting decision-making.
  g. Collaborate with other state entities as needed.

Recommendations for Regional Center Staff Training

1. Annual training for regional center service coordinators and other regional center staff should:
    a. Be in-depth so the regional center staff can appropriately respond to questions about conservatorships and alternatives.
    b. Include specific topics important to self-advocates and families such as the array of services that are available from regional centers and other agencies, person-centered and futures planning, and ways that self-advocates' decision-making can be supported.
    c. Identify ways to support and help families explore conservatorships and alternatives to conservatorship; and navigate systems to obtain the outcome that is best for the individual and their family.
    d. Address biases about individuals with intellectual and developmental disabilities, including biases about individuals who communicate differently, and presumptions of incompetence. Foster the understanding that individuals can make decisions with or without support.
    e. Include culturally relevant options and linguistic accommodations for families who are exploring conservatorship or alternatives to conservatorship.

Expert Panel Review and Recommendations: Improvements to Current Conservatorship Process

DDS Review of Conservatorship Nominations

DDS informed the panel about its current philosophy and approach is to accept conservatorship nominations in rare circumstances and as a last resort when needed to protect the health, safety and/or well-being of a regional center consumer. DDS' informal guidelines also consider whether there are alternatives to conservatorship and the availability of another individual who can serve as a conservator. Decisions are made only after a thorough review by DDS staff and the DDS Director. DDS' current processes would be enhanced with the implementation of the following recommendations.

Recommendations for DDS Review of Initial Conservatorship Nominations

1. DDS should develop written guidelines for its initial conservatorship recommendations. The guidelines should include the review process and criteria for accepting a nomination. The guidelines should be developed in consultation with stakeholders, and once developed, shared with self-advocates, family members, regional centers and other stakeholders and be made available to the public. The guidelines should include the following:
    a. DDS accepts a conservatorship nomination only as a last resort.
    b. The factors that DDS currently considers include protection of the individual's health, safety or well-being, alternatives to conservatorship, and the identification of others who may serve as a conservator should be continued. DDS should expand the factors to include consideration of the following:
        - Changing family dynamics (e.g., aging parents, family stressors), the adequacy of current services and any additional services, supports or training the family may need
        - The individual's disability related needs and new or additional services and supports to meet those needs
        - Protection of the individual's autonomy; and
        - The individual's ability to make decisions including information about the types of decisions the individual has made in the past, and the individual's ability to make decisions or gain decision making skills with additional supports with a lens toward less restrictive alternatives
    c. Criteria for filing a temporary conservatorship rather than an ongoing conservatorship. This criteria should include factors such as the time needed to identify new services or a different living arrangement, assess whether new or increased services and supports provided by regional centers or other agencies will eliminate the need for an ongoing conservatorship or reduce the conservator's powers, or explore

alternatives to conservatorship or other individuals familiar to the individual who are willing to serve as a conservator.

Support for DDS Conservatees

Individuals with intellectual and developmental disabilities often do not understand conservatorship proceedings, the powers the conservator has and how that limits the conservatee's ability to make some decisions and what decisions they can independently continue to make. Currently there is not a standardized process by which DDS obtains information from the conservatee about their expressed wishes including their preferences for where they live, the kinds of services and supports they want and their ideas about how they can increase their independence and decision-making skills so that a conservatorship may not be needed, or DDS' conservatorship powers could be reduced.

<u>Recommendations to Support for DDS Conservatees</u>

1. DDS should arrange for an independent advocate to meet with each DDS conservatee. The advocate should assist the conservatee in the following ways:
    a. Within 30 days following the court's approval of the conservatorship, meet with the conservatee to assist the conservatee in understanding the conservatorship, the powers DDS has, and the powers that the conservatee retains.
    b. Meet with the conservatee *at least* two times during the year, including as part of DDS' annual review of the conservatorship, and more frequently if the independent advocate determines it is needed. During these meetings the advocate shall learn about the conservatee's expressed interests, assist the self-advocate in identifying any additional services and supports including those that will assist the individual to increase their independence and decision-making and help the individual develop a transition plan with the goal of ending the conservatorship, limiting the conservators' powers and/or identifying alternatives to conservatorship.
    c. Assist the conservatee, as needed, at IPP meetings and/or interdisciplinary team meetings and take appropriate next steps if the conservatee's concerns are not addressed.

Regional Centers Delegated Conservatorship Responsibilities

Regional centers use common ways to carry-out some of their delegated conservatorship responsibilities. These common approaches largely mirror the service coordination practices for individuals who are not conserved by DDS. There are, however, differences among regional centers about who can make decisions for the conservatee, staff training requirements, and the development of a plan with specific goals to assist the conservatee with decision-making and other skills needed to end the conservatorship.

Recommendations Regarding Regional Center Delegated Conservatorship Responsibilities

1. DDS in consultation with regional centers and other stakeholders should develop written standard guidelines and best practices for carrying out delegated conservatorship responsibilities. These should include the following:
    a. A standardized list of delegated conservatorship responsibilities including the requirement that the individual with primary responsibility for carrying out the delegated conservatorship responsibilities meet periodically, in person, with the conservatee.
    b. Requirements, consistent with AB 1663, to avoid a conflict of interest including that neither the individual's service coordinator nor the service coordinator's supervisor or manager should carry out the delegated conservatorship responsibilities.
    c. The DDS conservatee's IPP should identify services and natural supports designed to assist them in becoming more independent, increase their decision-making ability, and allow for the exploration of alternatives to conservatorship, reduce the need for a conservatorship, and support a decrease in DDS conservator's powers.
    d. The required regional center annual review of the conservatorship should be made by an interdisciplinary team which includes the conservatee, the service coordinator, the regional staff member who carries out the delegated conservatorship responsibilities, a regional center peer advocate, and others as appropriate or requested by the conservatee.

Review of DDS Conservatorships

DDS does not currently have a formal process for reviewing all of its conservatorships, considering the conservatee's expressed wishes about the conservatorship, deciding if the conservatorship should continue, or whether its conservatorship powers should be reduced.

Recommendations for Review of DDS Conservatorship

1. DDS should develop written guidelines and procedures for an annual comprehensive review of each conservatorship. The review should determine if the conservatorship continues to be needed and if DDS' current conservatorship powers can be reduced. The guidelines should be developed in consultation with stakeholders, and once developed, shared with self-advocates, family members, regional centers and other stakeholders. In making these decisions DDS should consider:

    a. The individual's expressed wishes about the end for the conservatorship, the conservator's powers, and preferences for who should be the conservator.
    b. Changes in the conservatee's independence and decision-making skills.
    c. Whether the situation which resulted in DDS becoming the conservator has changed or may change with the provision of additional services from the regional center or another agency.
    d. Alternatives to conservatorship that are appropriate to address the individual's needs.
    e. Other individuals who are willing to be the conservator.
2. If following the review, DDS determines a conservatorship is no longer needed or that changes to the conservatorship are appropriate, it should proactively notify the court and request a hearing.
3. If DDS determines that a conservatorship continues to be needed, the independent advocate should meet with the conservatee to discuss DDS' decision. The advocate and conservatee should determine if any changes are needed to their current services and supports or living arrangement, including those which will help the conservatee become more independent and increase their decision-making skills. The advocate and conservatee may request an IPP meeting to discuss any needed changes.

DDS Oversight

DDS oversight is necessary to ensure a consistent state-wide philosophy and approach to conservatorships. Currently there are not consistent state-wide standards for all 21 regional centers.

<u>Recommendations for DDS Oversight</u>

1. DDS in consultation with regional centers and other stakeholders should develop written standard conservatorship guidelines which will be used by all 21 regional centers. The guidelines should be clear that conservatorship is an option of last resort and that if a DDS or regional center-initiated conservatorship is needed, a limited conservatorship should be used. The guidelines should require the exploration and use of decision-making supports and alternatives to conservatorships and the use of a comprehensive and individualized process for deciding if a conservatorship is needed and for the review of current conservatorships.
2. DDS should provide annual training to regional centers about conservatorships and alternatives to conservatorship.
3. DDS should continue its current oversight of conservatees including review of monthly and annual reports from regional centers, its review of special incident reports and court investigator reports and take action to follow-up on any concerns. This oversight should be expanded to include review of information provided by the conservatee and independent advocate.

4. Work with CDPH to finalize DDS' ability to receive automatic notification of any complaints at a CDPH licensed facility where a conservatee resides. DDS should also explore the feasibility of receiving notifications from other state agencies who license facilities.
5. Improve DDS and regional center data systems so that DDS and regional centers have access to additional information that allows it to track the number of years of the conservatorships, the powers granted to the conservatorship, the reason the petition was granted or denied, and other information needed to allow DDS and regional centers to analyze and respond to conservatorship trends. Other information could include the individual's living arrangement before and after the conservatorship, and conservatorship alternatives in place or considered such as support decision making and powers of attorney. Current and new conservatorship data fields in SANDIS should be required fields.

Other Conservatorship System Improvements

While the primary focus of the panel was a review of the DDS conservatorship process, input from Focus Group participants and a review of the DDS data identified areas in which the conservatorship process could be improved for individuals who are not conserved by DDS, particularly given the significant number of young adults who are conserved by someone other than DDS. The panel also heard from Focus Group participants about concerns that self-advocates and family members experience with current court conservatorship processes. The panel realizes these challenges cannot be solved by DDS or regional centers alone. However, the panel believes DDS can help raise these concerns with other state agencies and potentially work collaboratively to address these larger systemic issues.

Transition Aged Youth

A significant concern raised by all Focus Group participants was the large number of transition-aged youth who are conserved. A primary reason for this is reported to be school districts' practices of encouraging family members to obtain a conservatorship as their child turns 18. For example, it was reported that one district included on its Transition Planning Checklist "Get a Conservatorship". Family members report they are told they will not be able to participate in their child's individualized education program (IEP) if the family does not have a conservatorship. This is particularly impactful for families of color who may consider teachers or doctors as authority figures who should not be questioned. They also report that there is very little to no information provided about alternatives to conservatorship including supported decision-making. Self-advocates report that in special education transition classes, there is very little discussion about decision-making, self-advocacy skills or alternatives to conservatorship.

Recommendations for Concerns About Transition Aged Youth

1. DDS should work with CDE and other state agencies to develop strategies to reduce the perception that a conservatorship is the only way a family can continue to participate with their young adult in making school-related decisions. This could include:
    a. Joint DDS and CDE guidance to regional centers and school districts about the requirements of AB 1663, which allows family members to attend IEP meetings when the individual with a disability indicates that they want the individual's support and for the individual to develop a supported decision-making agreement.

   b. Support SCDD's training and technical assistance responsibilities to develop training and materials about supported decision-making for family members of transition-aged youth and self-advocates.

Training for Other Professionals

Focus Group members also provided information about barriers families and self-advocates experience when they interact with medical professionals, judges, attorneys, and court personnel. Concerns include biases that others have about individuals' with intellectual and developmental disabilities ability to make their own decisions with or without supports, the lack of knowledge about the services that are available from regional centers to support individuals and their families, and the difficulty of navigating court processes.

Recommendations for Training Other Professionals

1. DDS is encouraged to use its relationships with other state agencies, the Judicial Council and California's three University Centers for Excellence in Developmental Disabilities to discuss a state-wide strategy to train other professionals about alternatives to conservatorships including supported decision-making, the ability of individuals with intellectual disabilities to make decisions with and without support and the services from regional centers. State entities may be able to use the trainings and materials developed by SCDD for the training.

Making Court Processes Easier for Self-Advocates and Families

Family members indicate that it is difficult to understand the court conservatorship procedures and to navigate those processes without support. They are concerned that court forms are hard to understand and not always available in the language they speak.

Recommendations to Make Court Process Easier for Self-Advocates and Families

1. As a best practice, regional centers should establish ongoing relationships with the local county probate judges, court investigators and attorneys handling probate matters. They could offer, for example, to provide information and training about services available from regional centers to support individuals and their families, the ability of individuals with intellectual and developmental disabilities to make decisions, and ways to support individuals' decision-making abilities with each of the seven limited conservatorship powers.

2. Regional centers in consultation with DDS and other stakeholders should r develop best practice guidelines for additional information that could be included in the required court reports. For example, information about the array of services the individual receives to help them maximize their independence, the proposed conservatee's capacity to make their own

decisions under each of the limited powers including the supports and services that are available through the regional center to assist the individual, and alternatives to conservatorship that may work for the individual and their family.

3. Regional centers should provide court reports for the annual or biennial reviews of conservatorship in addition to any information the regional center shares with the court investigator. These reports could provide information about the progress the individual has made in their decision-making skills and independence and how this may reduce or eliminate the need for a conservatorship or reduce the conservator's powers.
4. Regional centers should tell families and self-advocates about the assistance that is available from service coordinators, navigators or peer advocates and others when they are navigating the court processes or accessing alternatives to conservatorship.

National Expert Panel to Review DDS Conservatorship Process

Mary P. Sowers, Executive Director, NASDDDS
Before joining NASDDDS in 2014, Mary provided consultation and technical assistance to state governments on a wide array of Medicaid-related issues, with a focus on integrated care, home and community-based services, and managed long-term services and supports. Mary has held senior positions with the federal Centers for Medicare & Medicaid Services (CMS), Disabled and Elderly Health Programs Group within the Center for Medicaid, and CHIP Services. During her tenure at CMS, Mary specialized in Medicaid home and community-based services, managed long-term services and supports (including strategies for reducing institutional reliance), self-direction, and strategies to design person-centered systems of care.

Caroline Brown, Brown & Peisch PLLC
Caroline has been practicing law in the area of government-sponsored health care and other public benefit programs for more than 25 years. Caroline has counseled dozens of state agencies on compliance with the federal public assistance statutes and implementing regulations involving a range of complex issues, including Medicaid managed care, payment for home and community-based services, dual eligibles, and Section 1115 demonstration projects. Caroline has supported clients through transformational change and brings unparalleled expertise with regulatory and statutory frameworks and system interactions.

Kecia Weller, Self-Advocacy & Community Liaison at the UCLA Tarjan Center
A disability rights advocate for the past 30 years at the local, state and national levels, Kecia is a self-advocate advisor to the National Center on Criminal Justice and Disabilities. Her recommendations for system change were published in the March 2019 online Ms. Magazine. Kecia is also a founding member of the California Silence = Violence Statewide Coalition and currently hosts the plain language podcast, *In Other Words*, which provides information from the Tarjan Center's Distinguished Lecture series in language that everyone can understand. Most recently, Kecia has been an advisor to, and featured in, the new national *Talk About Sexual Violence* training videos and guides for health care professionals and she's one of the national founding Co-Chairs of the Peer Support Network for sexual assault survivors with intellectual/developmental disabilities.

Mark A. Thomas, Director Guidehouse Consulting Services
Mark's professional areas of focus are Long Term Supports and Services for Individuals with Developmental Disabilities and Aging populations, Medicaid, Public Health, and Behavioral Health. Mark is a former Deputy Secretary/Chief Operating Officer for the Louisiana Department of Health and was Assistant Secretary for the Office for Citizens with Developmental Disabilities prior to filling the role of Deputy Secretary. Mark is the immediate past president of the National Association of State Directors of Developmental Disabilities Services. He is also a sibling of a person with developmental disabilities. He brings more than 29 years of experience in public and private sector disability supports and healthcare including work in successful statewide transformational activities.

Mary Faithfull, former Executive Director, Disability Rights Texas (DRTx)
As a person living with a disability, Mary knows firsthand the importance of the services provided by federally mandated Protection and Advocacy (P&A) agencies. Recently retired from 37-years at DRTx, Mary was Executive Director for the last 21-years. Before DRTx, Mary worked for The Institute of Rehabilitation and Research and was faculty at Baylor College of Medicine in Houston. During her tenure with DRTx, she provided direct services, advocated at the Texas legislature, coordinated special projects to transition students from special education to community living, and managed the Houston office before being named Executive Director. Mary believes that the right supports and services, combined with advocacy and enforcement of disability rights laws, levels the playing field so people with disabilities can be fully engaged, integrated and contributing members of their communities.

Mary Anne Harvey, former Executive Director, Disability Law Colorado
Mary Anne served as the Executive Director of Disability Law Colorado, the state's Protection and Advocacy agency, from 1980-2021. Beginning in 1988, Disability Law Colorado became the host agency for the Colorado State Long-Term Care Ombudsman Program and the Colorado Legal Assistance Developer for older adults. Mary Anne was active in the National Disability Rights Network (NDRN) as a former board member, past president and trainer. In addition, she participated in the development of national standards and outcome measurements for Protection and Advocacy Systems and she was a co-founder of the Executive Leadership Institute which supports the development of a group of peers from non-competing organizations and serves as a forum for creative problem-solving.

Sam Crane, Legal Director, Quality Trust
Quality Trust is an independent, non-profit advocacy organization focused on improving the lives of people with developmental disabilities in DC and beyond. Quality Trust partners with people and their families so they can succeed, thrive, and experience full membership in the communities they choose. Sam oversees the organization's legal advocacy activities, including the Jenny Hatch Justice Project and National Resource Center for Supported Decision-Making. Prior to joining Quality Trust, Sam was the Legal Director at the Autistic Self Advocacy Network. She has

advocated on a range of issues including increased access to supported decision-making, community-based services, and healthcare, as well as freedom from seclusion and restraint.

Shannon Cogan, Director of the Office of Clients' Rights Advocacy at Disability Rights California
Shannon leads the team of advocates who protect and advocate for the rights of people served by regional centers. She also has the unique experience of representing a Public Guardian in conservatorship cases and litigating financial elder abuse cases. These experiences provided Shannon with insight into the overwhelming need for alternatives to conservatorship and stronger court oversight to protect the individual rights of people with disabilities. Shannon became a disability rights lawyer due to her experiences advocating for her own child in disability-related systems. In 2021, Shannon served as a delegate to the Fourth National Guardianship Summit, a convening of conservatorship experts who approved 22 recommendations for reforming conservatorship systems nationwide.

Regina Rodriguez Sisneros, Director of Equity Initiatives & System Innovations, NASDDDS
Regina is the Director of Equity Initiatives and System Innovations at NASDDDS. Prior to joining NASDDDS, Regina spent 14 years with the Colorado Department of Human Services as the Contract Manager and Equity, Diversity, & Inclusion Manager for MINDSOURCE Brain Injury Network. Her experience related to disability started personally because of individuals with disabilities in her family, and professionally when she became a Certified Brain Injury Specialist in 2008. She is a graduate of Georgetown University's Leadership Institute for Cultural Diversity & Cultural and Linguistic Competence and an alum of the Colorado JFK LEND Program and was selected as the 2021 Emerging Leader for the Association of University Centers on Disabilities.

Catherine Blakemore, Facilitator
Catherine brings more than 40 years of expertise in advocating for Californians with disabilities to the table--the depth and breadth of which is unique and will contribute to facilitating the work of this panel. She is the former Executive Director of Disability Rights California (DRC), the federally mandated protection and advocacy agency in California and the nation's largest disability rights organization. Catherine previously represented individuals with disabilities and low-income Californians as an attorney with the Disability Rights Legal Center, the Legal Aid Foundation of Los Angeles and DRC. She currently is a consultant for DDS and consults for other protection and advocacy agencies, in addition to being the Chair of California's Alzheimer's Advisory Committee and Vice-Chair of the California Commission on Access to Justice, which works to identify innovations to increase access to courts and legal resources for individuals of modest or low means.

About DDS:

Under the Lanterman Developmental Disabilities Services Act, DDS is responsible for overseeing the coordination & delivery of services and supports to approximately 400,000 Californians with, or at risk for, developmental disabilities including cerebral palsy, intellectual disability, autism, epilepsy and related conditions. The state's service system is designed to meet the needs and choices of individuals at each stage of their lives, and, to the extent possible, support them in their home communities, providing choices that are reflective of lifestyle, cultural and linguistic preferences.

About NASDDDS:

NASDDDS represents the nation's agencies in 50 states, Puerto Rico, and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families.