2nd Civil No.
B290805

IN THE COURT OF APPEAL
OF THE STATE OF CALIFORNIA
SECOND APPELLATE DISTRICT, DIVISION 6

The Conservatorship of Olivia B.
Olivia B., Appellant

v.

Teri and Cleo B.
Respondents

ON APPEAL FROM
SUPERIOR COURT, COUNTY OF SANTA BARBARA
Case No. 17PR00325
The Honorable James F. Rigali

BRIEF *AMICUS CURIAE* OF THE AUTISTIC SELF ADVOCACY NETWORK IN SUPPORT OF PETITIONER

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INTRODUCTION AND SUMMARY OF ARGUMENT

The Autistic Self Advocacy Network ("ASAN") submits this brief *amicus curiae* in the hopes of providing relevant background on guardianship and alternatives to guardianship for autistic individuals.

ASAN has a longstanding interest in promoting less restrictive alternatives to conservatorship. Our advocacy efforts, however, have revealed pervasive misunderstanding of these alternatives among probate courts and improper evaluation of less restrictive alternatives. Notably, probate courts may inappropriately reject less restrictive alternatives for the sole reason that they are less restrictive; they may fail to identify concrete, compelling, and non-speculative reasons why a less restrictive alternative should be rejected; and they may assume without justification that less restrictive alternatives are unworkable or difficult for families to use. Where probate courts' decisions regarding less restrictive alternatives are based on improper considerations or lack sufficient evidentiary basis, they should be subject to careful review.

ASAN additionally has observed that probate courts may base determinations of incapacity on functional abilities that should, in general, not be considered relevant to conservatorship proceedings. They may paradoxically hold people with significant disabilities to a higher standard for adaptive functioning than other same-age peers; may impose conservatorship based on needs that can adequately be met non-coercively through supports and skill development; and may assume that conservatorship is necessary in order to meet needs that can easily be met through other formal or informal support arrangements.

This matter presents many of the same concerns that ASAN has noted in conservatorship proceedings. As a result, this appeal presents a unique opportunity to give guidance to probate courts on how to appropriately evaluate less restrictive alternatives and incapacity decisions. ASAN urges this court to carefully review the probate court's decision and to clarify the appropriate considerations that should be taken into account in adult guardianship proceedings.

ASAN'S HISTORY OF ADVOCACY REGARDING CONSERVATORSHIP AND LESS RESTRICTIVE ALTERNATIVES

The Autistic Self Advocacy Network (ASAN) is a 501(c)(3) nonprofit organization run by and for autistic people. Nearly the entirety of ASAN's board and the entirety of ASAN's staff are, like Appellant, autistic adults - including the author of this brief. ASAN represents autistic adults across the entire autism spectrum and its leadership includes people who need significant supports in order to live independently and autonomously.

ASAN's members and supporters include autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators, and friends. Notably, our constituency includes numerous individuals who, like Appellant, were placed under guardianship or conservatorship as young adults.

ASAN was created to serve as a national grassroots disability rights organization for the autistic community, advocating for systems change and ensuring that the voices of autistic people are heard in policy debates and the halls of power. Our staff work to advance civil

rights, support self-advocacy in all its forms, and improve public perceptions of autism.

ASAN has a longstanding interest in promoting less restrictive alternatives to guardianship, in particular supported decision-making. Supported decision-making is a well-established, flexible, customizable support arrangement in which a person with a disability chooses one or more supporters to assist in decision-making concerning financial, healthcare, education, housing, social, and other matters. Because supported decision-making arrangements are directed by the person with a disability, they enable the person with a disability to receive support while maintaining autonomy and gaining decision-making skills and life experiences that may lead to even greater independence. We will discuss supported decision-making in further detail in Section II.B. below.

In 2014, ASAN issued a toolkit on health care and the transition to adulthood, which proposed supported decision-making as an alternative to guardianship for autistic young adults who were unable

or unprepared to make independent medical decisions.[1] Although supported decision-making arrangements are typically effective even without specially enabling legislation, this toolkit included the first model legislation to promote supported decision-making agreements in the United States.[2]

In 2016, ASAN published *The Right to Make Choices: International Laws and Decision-Making by People with Disabilities*.[3] This toolkit, aimed at individuals with disabilities, discussed international efforts to promote less restrictive alternatives to guardianship, including supported decision-making. That same year, ASAN published *Roadmap to Transition: A Handbook for Autistic*

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[1] Autistic Self Advocacy Network, *Transition to Adulthood: A Health Care Guide for Youth and Families* (July 14, 2014), https://autisticadvocacy.org/2014/07/asan-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood/.

[2] Autistic Self Advocacy Network, *Model Legislation: An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults with Disabilities* (2014), *available at:* https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf.

[3] Autistic Self Advocacy Network, *The Right to Make Choices: International Laws and Decision-Making by People with Disabilities* (2016), https://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-For-Families-v3.pdf.

Youth Transitioning to Adulthood.[4] This resource, also aimed at autistic self-advocates, extensively discusses use of supported decision-making as an alternative to guardianship or conservatorship.

In 2016, ASAN held an invitational international summit titled, "*Supported Decision-Making and the Transition into the Community,"* in which over 40 stakeholders discussed how supported decision-making could be used to facilitate community integration. We published a policy brief on that summit with recommendations in 2018.[5]

ASAN's Legal Director, Samantha Crane, has additionally written two published academic articles on supported decision-making, including "*Is Guardianship Reform Enough? Next Steps in Policy Reforms to Promote Self-Determination Among People with*

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[4] Autistic Self Advocacy Network, Roadmap to Transition: A Handbook for Autistic Youth Transitioning to Adulthood (2016), *available at:* https://autisticadvocacy.org/wp-content/uploads/2016/11/Roadmap-to-Transition-A-Handbook-for-Autistic-Youth-Transitioning-to-Adulthood.pdf.

[5] Autistic Self Advocacy Network, *ASAN's Invitational Summit on Supported Decision-Making and Transition to the Community: Conclusions and Recommendations* (2018), https://autisticadvocacy.org/wp-content/uploads/2018/06/SDM-Summit-Conclusions-and-Recommendations.pdf.

Disabilities"[6] (hereinafter "Crane 2015") and *"Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship."*[7]

ARGUMENT

I. WHERE THE EXPRESS WISHES OF A PERSON WITH A DISABILITY ARE UNKNOWN OR IN DISPUTE, THE COURT SHOULD TAKE SPECIAL CARE TO ENSURE THAT THEY ARE NOT MISREPRESENTED BY OTHER PARTIES.

As an introductory matter, ASAN urges the court to exercise caution when evaluating competing representations regarding the express wishes of an individual with a disability who is a party to litigation. Upon review of the Appellant's and Respondents' briefs in this matter, it appears that Respondents are relying on second-hand statements by others - including themselves - regarding the Appellant's express wishes about appearing in court and filing an

[6] Samantha Alexandra Crane, *Is Guardianship Reform Enough? Next Steps in Policy Reforms to Promote Self Determination Among People With Disabilities?* 8 J. Int'l Aging L. & Pol'y 177 (2015).
[7] Margaret "Jenny" Hatch, Samantha Alexandra Crane, and Jonathan G. Martinis, *Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship.* 3 Inclusion 65, 65-74 (2015).

appeal. Respondents admit that they control access to Appellant and have admitted to restricting her use of technology - her one means of communicating independently with outsiders - in order to control her behavior. Respondents also themselves claim that Appellant is easily manipulable and can run "hot and cold" on matters of importance to her life. Resps.' Br. at 8; Appellant's Br. at 16.

As a self-advocacy organization, ASAN is extremely concerned about the possibility that Respondents' self-serving statements regarding Appellant's interests may result in deprivation of Appellant's right to adequate due process and appeal of a matter that may have lifelong consequences for Appellant. ASAN urges the court to remember that, regardless of their familial relationship, Respondents and Appellant are adverse parties in this litigation and must be treated as such in order to give full effect to Appellant's due process rights. As discussed in further detail below, conservatorship represents a dramatic and, most likely, lifelong curtailment of an individual's ability to act independently in nearly any area of life. Maintaining robust due process protections, including recognition of

the potentially conflicting interests of Appellant and Respondents, is critical. Due to their status as adverse parties and their attempts to restrict Appellant's ability to communicate with others who may independently verify Appellant's statements, representations by Respondents regarding what Appellant does or does not want should be given little to no weight.

In addition, we recognize that in some situations, an individual with a disability may in fact make apparently conflicting statements to different individuals at different times regarding their wishes. In such situations, an independent inquiry should be made to determine the individual's actual wishes. This inquiry should incorporate the principles of supported decision-making, as discussed in further detail below. The inquiry should include an investigation of the individual's understanding of the matter in question, including the long-term consequences of each potential outcome, and thorough discussion of those long-term consequences with the individual.

In some circumstances, as with all individuals whose interests are affected by litigation, it may be necessary for an attorney to obtain

information on the *results* or *outcomes* that the individual wishes to achieve, and then connect those results to the course of action most likely to achieve those results. For example, if an individual states that they wish to continue living with the conservator but also that they wish to achieve greater independence and make choices for themselves, this may indicate that the individual's goals are best met by challenging the conservatorship - despite the fact that the individual is not currently disagreeing with the choices the conservator has made so far on their behalf. The individual should have the opportunity to discuss how various courses of action may meet their goals with a qualified expert who is not personally interested in the outcome of the matter.

II. THE COURT SHOULD CAREFULLY EVALUATE WHETHER LESS RESTRICTIVE ALTERNATIVES WERE PROPERLY CONSIDERED.

California's statute governing conservatorship, like many others, requires consideration of less restrictive alternatives. Cal. Probate Code Section 1821(a)(3). Nevertheless, ASAN has found that probate courts often fail to *meaningfully* consider such alternatives.

Indeed, many courts - including, apparently, the probate court in this case - improperly reject less restrictive alternatives *because* they are less restrictive. *See* Crane 2015 at 189-91; Appellant's Br. 54 (noting that one respondent rejected the idea of a power of attorney as a less restrictive alternative "because it was revocable"). This approach to less restrictive alternatives undermines the very purpose of the requirement that less restrictive alternatives be considered.

A. Overview of less restrictive alternatives to conservatorship

Less restrictive alternatives to conservatorship can include both formal and informal support arrangements. Formal support arrangements may include powers of attorney, health care proxies or advance directives, representative payee arrangements, and other instruments by which a person with a disability appoints someone to assist with a particular task. Informal supports include periodically consulting with others on major life decisions and arranging for someone to help with activities of daily living, without the use of a legal document. These types of supports may be used in combination with each other. For example, a person with a disability may authorize

someone to manage finances through a power of attorney, but may informally rely on housemates to assist with activities of daily living.

The use of formal and informal supports to make decisions and manage daily life, while maintaining autonomy, is known as supported decision-making. In a supported decision-making arrangement, a person with a disability chooses one or more supporters to assist in decision-making concerning financial, healthcare, education, housing, social, and other matters. Because supported decision-making arrangements are directed by the person with a disability, they enable the person with a disability to receive support while maintaining autonomy and gaining decision-making skills and life experiences that may lead to even greater independence.

Supported decision-making arrangements may incorporate use of formal or informal supports. For example, an individual using supported decision-making may execute a limited power of attorney and/or health care proxy, authorizing a supporter to act on his or her behalf. These instruments may include agreements by the supporter not to act without express authorization by the person receiving

support. Supported decision-making arrangements are by definition self-directed and flexible. Supporters must be chosen by the individual and may be changed or replaced as needed.

Courts, policymakers and advocates are increasingly embracing supported decision-making as an alternative to guardianship or conservatorship. For example, in 2012, a probate court in New York issued a decision regarding the guardianship of a woman with an intellectual disability, finding that supported decision-making was a less restrictive alternative to guardianship in her case. *In Re Guardianship of Dameris L.*, 956 N.Y.S.2d 848 (NY Co., 2012). In 2013, a probate court in Virginia restored the rights of Jenny Hatch, a young woman with Down Syndrome who had been placed under guardianship, finding that her needs could adequately be met through supported decision-making. *Ross v. Hatch*, No. CWF120000426P-03(Va. Cir. Ct. Newport News, Aug. 2, 2013).[8] After her rights were

[8] Opinion *available at* http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf. The final 2013 court order in Jenny Hatch's case created a temporary guardianship with her chosen friends as guardians, with the goal of terminating the guardianship in one year

restored, Hatch was able to transition successfully back from the group home where she had been placed to life in the community with friends who could support her with financial decisions and provided some independent living supports. Her restoration also enabled her to regain employment in the community, at her church's thrift store.[9] In 2016, after protracted litigation, a D.C. probate court restored the rights of Ryan King, also finding that King could effectively meet his needs through supported decision-making. *In re Ryan Herbert King*, No. 2003 INT 249 (D.C. Superior Court Oct. 6, 2016).[10]

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and transitioning it to a supported decision-making arrangement instead.

[9] Jenny Hatch Justice Project, "Jenny Hatch," http://jennyhatchjusticeproject.org/jenny. *See also* Autistic Self Advocacy Network, "Disability Community Celebrates Guardianship Decision For Adult Woman With Down Syndrome" (Aug. 2, 2013), https://autisticadvocacy.org/2013/08/disability-community-celebrates-guardianship-decision-for-adult-woman-with-down-syndrome/; Margaret "Jenny" Hatch, Samantha Alexandra Crane, and Jonathan G. Martinis. *Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship,* 3 Inclusion 65, 65-74 (2015), *available at*: http://aaiddjournals.org/doi/abs/10.1352/2326-6988-3.2.65.

[10] Opinion is *available at* http://supporteddecisionmaking.org/sites/default/files/ryan-king-order.pdf. *See also* National Resource Center for Supported Decision-Making, "Freedom for Ryan King" (Dec. 12, 2016),

Following the *Ross v. Hatch* decision, Quality Trust, the legal organization that represented Hatch, founded the Jenny Hatch Justice Project, which promotes supported decision-making as an alternative to guardianship.[11] Quality Trust later was awarded a federal grant to administer the National Resource Center for Supported Decision-Making,[12] which provides information on supported decision-making to people with disabilities, families, advocates, attorneys, and courts.

Other organizations that have advocated for supported decision-making include not only ASAN but also the Arc of the United States,[13] American Civil Liberties Union,[14] the federal Administration

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http://www.supporteddecisionmaking.org/impact-stories/freedom-ryan-king.

[11] *See* http://jennyhatchjusticeproject.org/.

[12] *See* http://www.supporteddecisionmaking.org/.

[13] The Arc of the United States, Position Statement: Autonomy, Decision-Making Supports, and Guardianship, https://www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship.

[14] Am. Civil Liberties Union, *Supported Decision Making & the Problems of Guardianship*, https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making.

on Community Living,[15] the Center for Disability Rights,[16] and the Center for Public Representation,[17] among many others. Numerous legal scholars have also voiced support for supported decision-making.[18]

B. The principles of due process favor less restrictive alternatives to guardianship.

The Fifth and Fourteenth Amendments apply no less to people with disabilities affecting decision-making than they do to people

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[15] Administration on Community Living, *Supported Decision Making Program*, https://acl.gov/programs/consumer-control/supported-decision-making-program (discussing the administration's funding of a national technical assistance center on supported decision-making).
[16] Center for Disability Rights, Inc. of New York States, *CDR Policy Position: Adult Guardianship*, *available at* http://cdrnys.org/wp-content/uploads/2018/11/guardianship.pdf.
[17] Center for Public Representation, *Supported Decision-Making*, https://centerforpublicrep.org/initiative/supported-decision-making/.
[18] *See, e.g.*, Kristen Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 Colum. Hum. Rts. L. Rev. 93, 96-100 (2012); Leslie Salzman, *Guardianship for Persons with Mental Illness -- A Legal and Appropriate Alternative?*, 4 St. Louis U. J. Health L. & Pol'y 279, 289-293 (2011); Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157, 161 (2010).

without such disabilities. The Supreme Court has recognized that "the liberty to make the decisions and choices constitutive of private life" is "fundamental to our concept of ordered liberty." *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 340-42 (1990) (internal quotations omitted). Any curtailment of such rights is subject to strict scrutiny and must be narrowly tailored to achieve a compelling government interest. *See Reno v. Flores*, 507 U.S. 292, 301-02 (1993); *Dunn v. Blumstein*, 405 U.S. 330, 343 (1972) ("if there are other, reasonable ways to achieve [government interests] with a lesser burden on constitutionally protected activity, a State may not choose the way of greater interference."). When courts reject less restrictive alternatives to conservatorship *because* they are less restrictive, they fail to give effect to well-established constitutional principles.

When evaluating less restrictive alternatives to conservatorship, courts must therefore apply a presumption that the attributes associated with a lower level of restriction - such as revocability or the potential that an individual may act against the wishes of a supporter -

are positive features and not flaws. Any decision that rejects less restrictive alternatives in favor of conservatorship must identify a compelling interest that cannot be served without additional restrictions on the individual's liberty. Mere speculation that an individual may revoke a power of attorney or make a poor decision in the future is insufficient to meet strict scrutiny.

C. Less restrictive alternatives to conservatorship lead to better life outcomes.

People who need support in order to make decisions, but recognize the need for such support, are best served when they retain the option of choosing supporters and modifying support arrangements voluntarily when they believe that another supporter would do a better job or if they have gained skills such that that the supports are no longer necessary. Numerous legal and disability-focused groups have therefore expressed strong support for alternatives to conservatorship, including supported decision-making.

In its thorough evaluation of guardianship and conservatorship in the United States, the National Council on Disability (NCD) - an

independent federal agency charged with advising policymakers on issues concerning individuals with disabilities - found that:

> People with intellectual and developmental disabilities who exercise greater self-determination—who are "causal agents" with more control over their lives—have better life outcomes and quality of life, including being more independent, more integrated into their communities, better problem-solvers, better employed, healthier, and better able to recognize and resist abuse. People with intellectual and developmental disabilities learn through the process of making decisions, and self-determination, if taught, can also be learned."

National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities* (hereinafter "*Beyond Guardianship*") at 131 (2018).[19] Additionally, NCD noted that "professionally evaluated pilot programs" on supported decision-making practices have found that these less restrictive alternatives "led to positive outcomes for participants, including greater community inclusion, improved decision-making skills, increased social and support networks, and

[19] Available online at https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf.

increased self-confidence, happiness, and willingness to try new experiences." *Id*.

By contrast, NCD found that conservatorship can have significant negative effects on life outcomes, including "a negative impact on the person's functional abilities, physical and mental health, and general wellbeing." *Id.* at 102. People subject to conservatorship may additionally "feel helpless, hopeless, and self-critical," experience "low self-esteem, passivity, and feelings of inadequacy and incompetency" and lower "subjective well-being." *Id.* at 103 (internal quotations and citations omitted). These findings contradict Respondents' paradoxical argument that less restrictive alternatives to conservatorship would not help Appellant "gain the independence she needs to survive." Resps.' Br. at 41.

Conservatorship also undermines the goal of long-term independence, as compared to alternatives, because conservatorships are notoriously difficult to terminate. NCD has found that, once conservatorship is awarded, "restoration of rights is an alarmingly rare occurrence." *Beyond Guardianship* at 37. Case studies have shown

that even when people have been successfully making their own decisions with support, and where the guardians support restoration of rights, it may be extremely difficult to actually achieve restoration of rights. *Id.* at 91-92.

As a result, numerous legal and disability advocacy groups have voiced support for less restrictive alternatives to guardianship, including powers of attorney, health care proxy arrangements, and supported decision-making. The American Bar Association has published toolkits for lawyers considering conservatorship that begins with the instruction to "Presume guardianship is unnecessary" and "assume at the outset that there may be less restrictive alternatives that can address the individual's need." Am. Bar Ass'n, *PRACTICAL Tool for Lawyers: Steps In Supported Decision Making* (2016);[20] *see also Beyond Guardianship* at 121-122 (discussing PRACTICAL tool).

[20] Available online at http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html.

D. Less restrictive alternatives to conservatorship result in lower burden on the court system and family unit.

Less restrictive alternatives, such as supported decision-making and powers of attorney, also reduce load on probate courts and decrease the emotional and financial costs of conservatorship-related litigation. For example, in the event that a conservator becomes incapacitated, dies, develops a contentious relationship with the disabled individual, or otherwise stops performing his or her role effectively, the disabled individual and/or other concerned family members must return to court and engage in a potentially protracted court battle in order to release the individual from conservatorship or appoint another conservator. The probate court is then required to do the difficult work of fact-finding and predicting which alternative conservator, if any, would be better positioned to serve.

In contrast, if the individual were unconserved and instead used a power of attorney, the individual could easily revoke the power of attorney and execute a new power of attorney naming an individual who is better positioned to provide support. Likewise, an unconserved

individual using supported decision-making may simply turn to other supporters for assistance if one supporter becomes ineffective or is unable to provide support. If the individual disagrees fundamentally with the supporter's recommendation, the individual is free to pursue an alternative course of action without the need to petition a court to override the supporter's decision.

This arrangement benefits families as well as probate courts by enabling families to work out disagreements over an individual's supports without the need for costly and emotionally damaging litigation. ASAN and other disability-focused groups have found that the costs of litigation, and the inevitably adversarial proceedings in which one party must necessarily "win" over others, tend to make intra-family cooperation more difficult and may in fact permanently poison family relationships.

More importantly, because these proceedings are often inaccessible or difficult for people with disabilities to follow, the voice of the individual with a disability often becomes lost during the course of litigation. Instead, the interests of a person with a disability

are supposedly represented by a plethora of competing testimony by experts, family members, independent investigators, and guardians ad litem. The controversy over Appellant's express wishes - let alone her best interests - in this matter is illustrative of this phenomenon.

III. THE COURT SHOULD CAREFULLY EVALUATE THE PROBATE COURT'S BASIS FOR DETERMINATION OF INCAPACITY

In addition to considering less restrictive alternatives to guardianship, it is imperative that probate courts avoid basing determinations of incapacity on skill deficits that are discriminatory not directly related to the supposed need for conservatorship. For example, where a court considers an individual's inability to perform a task that numerous nondisabled people of the same age are also unable to perform, the court is effectively holding people with disabilities to a higher standard than similarly situated individuals without disabilities. Likewise, a court should not base determinations of incapacity on functional skill deficits that can easily be addressed

without the need for conservatorship through appropriate training, supports, or education.

A. Probate courts often inappropriately hold adults with disabilities to a heightened standard for adaptive functioning

One common concern that ASAN has encountered in the context of conservatorships is inappropriate focus on functional abilities that are not relevant to decision-making and/or are not commensurate with the level of functional abilities of same-age peers. For example, the probate court appears to have considered testimony regarding Appellant's inability to "clean or cook for herself" or "balance a checkbook," as well as her need for assistance in paying bills. Appellant's Br. at 15, 25. Respondents also have referred to Appellant's inability to "shop" or "do laundry," among other activities. Resps.' Br. at 38.

It is undisputed that Appellant is nineteen years old and has, at all times in her life, resided with her parents or parental figures. It is not uncommon for non-disabled teenagers, including teenagers over the age of eighteen, to rely on assistance in performing these types of

activities of daily living - especially if their family members have always been primarily responsible for cooking and assisting with laundry. This phenomenon is so common that that there is a massive market for guides aimed at adults entering college who never learned these skills prior to leaving the family home.[21] Likewise, staggeringly few people Appellant's age have ever had any need to write a check, let alone balance a checkbook. The inability to balance checkbooks in particular is so common among young people without disabilities that companies have begun offering tutorials in these kinds of skills.[22]

Fortunately, most young adults can expect help and support with learning adult independent living skills without having to fear a court proceeding that will potentially permanently deprive them of the ability to make independent decisions. Like others her age, nineteen-

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[21] *See, e.g.*, Betty Rae Frandsen and Linda Soderquist, Where's Mom Now That I Need Her?: Surviving Away from Home (30th anniversary spec. ed. (2018)); Tina Pestalozzi, Life Skills 101: A Practical Guide to Leaving Home and Living on Your Own (6th ed.2016).

[22] Terri Akman, "Don't know how to balance a checkbook or change a tire? Companies want to teach millennials how," Philly.com (Nov. 28, 2017), http://www2.philly.com/philly/home/how-to-balance-checkbook-laundry-millennials-marketing-20171128.html.

year-old who has been diagnosed with autism should receive the supports that she needs to learn these skills without suffering the loss of her basic right to autonomy.

Finally, the fact that a person has not received appropriate educational supports in the past or an individual's "behavioral problems" such as anger management concerns are not appropriate bases for appointment of a conservator. Again, numerous people without disabilities have received substandard educations and may experience anger management problems, yet remain entitled to basic self-direction and autonomy. Educational deficits and behavioral concerns may easily be addressed through provision of appropriate services, without the need for a conservator. It should also be noted that many examples that Respondents cite concerning Appellant's supposed emotional and behavioral difficulties took place immediately after Appellant's forcible relocation to their home and may not be meaningfully different from the expected reaction of any young adult in a comparable situation.

B. Conservatorship is not an appropriate response to difficulty with independent living skills.

Even where an autistic adult lacks independent skills that a nondisabled, same-age peer would normally have, these skills should not necessarily be considered in the context of a conservatorship proceeding. As noted above, conservatorship is not appropriate when it is not narrowly tailored to address concerns about decision-making and is not the least restrictive alternative.

It is relatively common for autistic adults to need assistance with some or many activities of daily living, including cooking, laundry, cleaning, and paying bills. Many autistic adults who need such assistance live completely autonomous, self-directed lives, relying on support to perform these tasks when necessary. Ability to do laundry independently has no direct connection to ability to make important life choices. People who need assistance with independent living may receive such assistance through natural supports, educational programs such as those available through California's Regional Centers, and Medicaid-funded home and community-based services (HCBS).

C. Need for support with educational decisions should not be a basis for conservatorship.

Although few guardianship statutes authorize conservatorship or guardianship to address needs for support in educational contexts, a staggering number of young adults with disabilities are funneled into conservatorships as a result of disputes over education. NCD has found that parents of young adults frequently seek guardianship or conservatorship on the recommendation of school administrators, despite the fact that school administrators have limited awareness of the long-term consequences of conservatorship. *Beyond Guardianship* at 92; *see also* Resps.' Br. at 22 (discussing testimony of the director overseeing special education programs in Lompoc School District, stating that it was "very common" for his autistic students to be under conservatorship regardless of their adaptive functioning).

Often, as in the instant matter, parents seek conservatorship because the school has inaccurately advised the parent that a conservatorship is necessary in order to continue to participate in the Individualized Education Plan (IEP) planning process. Conservatorship is not, in fact, necessary in order to permit a parent to

participate in an adult student's IEP process. A young adult attending high school may "voluntarily elect to continue to include their parent in their IEP meetings." *Beyond Guardianship* at 93. Inclusion of a parent in IEP meetings may help to safeguard an adult student's educational rights while providing the student with age-appropriate opportunities to participate meaningfully in his or her own educational planning process - opportunities that are likely to lead to greater decision-making skills. Indeed, when undertaken carefully, an IEP meeting that includes the participation of both the adult student and a parent can be an excellent example of supported decision-making.

D. Difficulties that can be remedied through improved education or training are not an appropriate justification for conservatorship.

Respondents also cite "educational deficits," behavioral concerns, difficulty with handling finances, and difficulty making informed medical decisions as justification for conservatorship. Resps.' Br. at 8, 36, 38. Throughout their brief, however, Respondents acknowledge that Appellant is not *incapable* of learning these skills

but simply has not learned them yet, due to inappropriate educational services or lack of experience. As noted above, the best way to support an adult with a disability in learning how to make decisions is to *preserve*, not remove, that adult's ability to make decisions.

In ASAN's toolkit on healthcare and the transition to adulthood, for example, we noted that the vast majority of autistic young adults have little or no experience making informed medical decisions.[23] This inexperience often results from doctors' failure to meaningfully include autistic teenagers in discussions about medical decisions, instead speaking primarily to the parent or guardian. Although the resulting difficulties with medical decision-making are often cited by physicians and others as justification for

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[23] *See* Autistic Self Advocacy Network, *Transition to Adulthood: A Health Care Guide for Youth and Families* 1, 2, 3 (2014), https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf; Autistic Self Advocacy Network, *The transition to adulthood for youth with ID/DD: A review of research, policy and next steps* 3-4 (2013), available at https://autisticadvocacy.org/wp-content/uploads/2013/12/HealthCareTransition_ASAN_PolicyBrief_r2.pdf.

conservatorship, conservatorship in fact hinders young adults from learning medical decision-making skills.[24]

During the transition to adulthood, autistic adults may need support from a parent or other supportive adult in order to make medical decisions. This support can easily be provided without the need for a conservator or even a medical power of attorney. HIPAA regulations permit adults to include supporters in all in-person discussions with medical providers, without the need for a signed HIPAA authorization.[25] HIPAA authorizations may also enable supporters to communicate directly with healthcare providers.[26] Finally, if a healthcare provider does not believe that an individual has capacity to provide informed consent even with supports, states typically enable a person's next of kin to act as a surrogate decision-maker without the need for a conservator. *Beyond Guardianship* at 93.

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[24] *See Beyond Guardianship* at 102-03 (discussing negative functional impacts of guardianship).
[25] 45 C.F.R. § 164.510(b)(2).
[26] 45 C.F.R. § 164.508.

Likewise, an individual who has not yet learned to pay bills independently or perform similar tasks may easily rely on natural supports to assist them in doing so, until they gain this skill.

CONCLUSION

For the foregoing reasons, ASAN urges the court to carefully review the probate court's reasoning in awarding a conservatorship. Because it is impossible to determine the extent to which improper considerations formed the basis for the award of conservatorship in this matter, ASAN urges the court to reverse the probate court's decision and, if necessary, remand with detailed instructions regarding the probate court's responsibility to consider less restrictive alternatives and to avoid consideration of irrelevant factors in determining incapacity.

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CERTIFICATE OF WORD COUNT
(California Rules of Court, Rule 8.204(c)(1))

I am Legal Director for *amicus curiae*, Autistic Self Advocacy Network, and the preparer of this brief. I hereby certify that pursuant to Rule 8.204(c)(1) and Rule 8.486(6) of the California Rules of Court, the enclosed Petition to File Brief *Amicus Curiae* and Brief *Amicus Curiae* was produced using 14-point Roman type. I hereby certify that the brief *amicus curiae* contains approximately 6,152 words, including footnotes, as counted by the Microsoft Word Office "Word Count" feature of the program used to generate this brief.

Dated: December 19, 2018

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