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CASE NO. A147987

IN THE COURT OF APPEAL OF THE STATE OF CALIFORNIA
FIRST APPELLATE DISTRICT
DIVISION FOUR

CALIFORNIA ADVOCATES FOR
NURSING HOME REFORM, et al.
Plaintiffs and Appellants,
v.
KAREN SMITH, MD., MPH, as Director of the
California Department of Public Health,
Defendants and Appellants.

NOTICE OF ERRATA RE: [PROPOSED] *AMICUS CURIAE* BRIEF BY DISABILITY RIGHTS CALIFORNIA IN SUPPORT OF PLAINTIFFS AND APPELLANTS

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TO THE COURT, EACH PARTY, AMICI CURIAE, AND COUNSEL OF RECORD FOR THE PARTIES AND AMICI CURIAE:

Please take notice that Disability Rights California hereby respectfully submits this Notice of Errata in the *Amicus Curiae* Brief electronically filed with this Court on September 29, 2017.

Changes are made throughout the entire document and are all minor and unsubstantial, including: minor edits to citations to conform to California Style Manual; adding several authorities that were inadvertently omitted from the Table of Authorities; reformatting the numbering of one section heading in the Brief and in the Table of Contents; clarifying in the Table of Authorities that both statutes and regulations are listed; correcting minor typographical errors, and changing the word count to reflect the foregoing changes. There are no substantive changes to the Brief.

A corrected Brief is attached hereto as Exhibit A. Disability Rights California respectfully requests this Court to substitute Exhibit A for the Application and Brief electronically filed on September 29, 2017.

Dated: October 2, 2017

Respectfully submitted,

DISABILITY RIGHTS CALIFORNIA

By: /s/ Salma Enan
Attorneys on Behalf of Applican

EXHIBIT A

CASE NO. A147987

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Defendants and Appellants.

APPLICATION BY DISABILITY RIGHTS CALIFORNIA IN SUPPORT OF PLAINTIFFS AND APPELLANTS; [PROPOSED] *AMICUS CURIAE* BRIEF BY DISABILITY RIGHTS CALIFORNIA IN SUPPORT OF PLAINTIFFS AND APPELLANTS

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TABLE OF CONTENTS

TABLE OF AUTHORITIES

CASES

STATUTES AND REGULATIONS

OTHER AUTHORITIES

Mayerson, *History of the Americans with Disabilities Act, A Movement Perspective,* 1992. <https://dredf.org/news/publications/the-history-of-the-ada/> ---------- 12

Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act* (2010) 81 U. Colo. L. Rev. 157 ---------- passim

Salzman, Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative? (2011) 4 St. Louis U. J. Health L. & Pol'y 279 22

Schenkler, et. al. (2007) *The Impact of Language Barriers on Documentation of Informed Consent at a Hospital with On-Site Interpreter Services*, J. Gen. Intern. Med. 22 (Suppl 2): 294 18

The Deadly Failure of a Hospital to Follow a Patient's Decisions about his Medical Care (Lew and Morrison, Disability Rights California (2013) http://www.disabilityrightsca.org/pubs/702601.pdf ---------- 30

The Joint Commission, *What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety* (2007), https://www.jointcommission.org/assets/1/18/improving_health_literacy.pdf 17, 18, 19

U.S. Census Bureau, 2011 American Community Survey, *Language Use in the United States: 2011*, Table 4 ---------- 17

U.S. Dep't of Health & Hum. Svs., Administration for Community Living, Administration on Intellectual and Developmental Disabilities, *Supported Decision Making*, HHS-2014-ACL-AIDD-DM-0084 22

U.S. Dep't of Justice, *Protecting the Rights of Parents and Prospective Parents with Disabilities Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act,* https://www.ada.gov/doj_hhs_ta/child_welfare_ta.html ---------- 19

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APPLICATION FOR PERMISSION TO FILE AMICUS CURIAE BRIEF

Pursuant to Rule 8.200(c) of the California Rules of Court, Disability Rights California respectfully requests permission to file the following *amicus curiae* brief in support of Plaintiffs/Appellants California Advocates for Nursing Home Reform (CANHR) et al.

Disability Rights California is California's protection and advocacy agency and the nation's largest non-profit disability rights law firm, mandated under state and federal law to advocate for the rights of people with disabilities. This work includes challenging discriminatory actions under federal and state anti-discrimination laws, and investigating allegations of abuse and neglect of people with disabilities. 42 U.S.C. § 15001 *et seq*., 29 U.S.C. § 794e *et seq*.; 42 U.S.C. § 10801 *et seq*., Welf & Inst. Code §*4900 et seq.* Since its founding in 1978, Disability Rights California has represented people with disabilities in numerous individual and class action cases involving their right to be free from discrimination including segregation in facilities. Disability Rights California has investigated hundreds of cases involving the abuse and neglect of individuals with disabilities living in facilities. These investigations include cases of the involuntary administration of psychotropic medication and the withdrawal of life-sustaining treatment against the expressed wishes of the resident. These cases highlight the vulnerability of people with disabilities in nursing facilities and the importance of ensuring that people with disabilities have a meaningful opportunity to engage in decision making, as well as adequate notice and due process when medical decision making is delegated to care staff, particularly decisions involving a serious risk of physical harm and death. For these reasons, Disability Rights California has a substantial interest in this matter.

After reviewing all submitted briefs of the parties and *amici curiae* in this case, Disability Rights California's attorneys are very familiar with the issues presented but have determined additional briefing is still necessary. Disability Rights California supports and supplements the points and arguments made by *amicus curiae* American Civil Liberties Union Foundation and American Civil Liberties Union Foundation of Northern California regarding the need for and importance of supports for people with disabilities to enable them to meaningfully participate in medical decision making, the importance of meaningful notice, and to support the position that Section 1418.8 should not apply to end-of-life decision making. Disability Rights California further submits that as *amicus curiae*, it can assist the court in providing further briefing as to the following matters:

(1) The historical perspective, importance and requirements of federal and state anti-discrimination laws such as the Americans with Disabilities Act ("ADA"), 42 U.S.C. §§ 12101 *et seq*., Section 504 of the Rehabilitation Act. 29 U.S.C. §§ 701 *et seq*., and California Government Code section 11135 in ensuring that the rights of people with disabilities in facilities are protected with respect to meaningful participation in medical decision making;

(2) The importance of meaningful notice, which includes consideration of the fundamental right to self-determination and advancements in the law and practice for supporting people with disabilities to effectively participate in medical decision making; and

(3) To support the lower court's finding that Section 1418.8 should not apply to end-of-life decisions, and to encourage the Court to go further and extend the court's ruling to decisions concerning hospice and comfort care.

No party or counsel for any party authored any portion of this *amicus* brief. In addition, no party, person, or entity made a monetary contribution to fund the research, the preparation, or the drafting of this *amicus* brief.

For the reasons stated in this application and further expressed in the Introduction and Summary of Argument, Disability Rights California respectfully requests leave to file this *amicus curiae* brief attached to this application.

Dated: October 2, 2017 DISABILITY RIGHTS CALIFORNIA

By: /s/ Katherine Mathews
Katherine Mathews
Attorneys on Behalf of Applicant

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[PROPOSED] AMICUS CURIAE BRIEF BY DISABILITY RIGHTS CALIFORNIA IN SUPPORT OF PLAINTIFFS AND APPELLANTS

I. INTRODUCTION AND SUMMARY OF ARGUMENT

Disability Rights California is California's protection and advocacy agency and the nation's largest non-profit disability rights law firm, mandated under state and federal law to advocate for the rights of people with disabilities and investigate allegations of abuse and neglect. 42 U.S.C. § 15001 *et seq.*; 29 U.S.C. § 794e *et seq.*; 42 U.S.C. § 10801 *et seq.*; Welf. & Inst. Code, §*4900 et seq.* Since its founding in 1978, Disability Rights California has represented people with disabilities in numerous individual and class action cases involving their right to be free from discrimination including segregation in facilities, and has investigated hundreds of cases involving the abuse and neglect of individuals with disabilities living in facilities.

Disability Rights California concurs with and adopts the legal reasoning of the brief of *amicus curiae* American Civil Liberties Union. Disability Rights California submits this brief to supplement the points and arguments made by the ACLU regarding the need for supports for people with disabilities to enable them to participate in medical decision making, the importance of meaningful notice, and to support the lower court's ruling that Section 1418.8 should not apply to end-of-life decision making. Disability Rights California further submits that:

(1) Section 1418.8 runs afoul of federal and state anti-discrimination laws such as the Americans with Disabilities Act ("ADA"), 42 U.S.C. §§ 12101 et seq., Section 504 of the Rehabilitation Act. 29 U.S.C. §§ 701 et seq., and California Government Code section 11135, which require that the rights of people with disabilities in facilities are protected with respect to meaningful participation in medical decision making, including through reasonable modifications to policies and practices;

(2) Meaningful notice is required, which includes consideration of the fundamental right to self-determination and advancements in the law and practice

for supporting people with disabilities to effectively participate in medical decision making; and

(3) The lower court properly ruled that Section 1418.8 should not apply to end-of-life decisions, and that this Court should go further and extend the court's ruling to decisions concerning hospice and comfort care.

II. SECTION 1418.8 UNDERMINES PROTECTIONS IN THE AMERICANS WITH DISABILITIES ACT AND OTHER ANTI-DISCRIMINATION LAWS, WHICH REQUIRE EFFECTIVE COMMUNICATION AND REASONABLE ACCOMMODATIONS IN MEDICAL DECISION MAKING

A. **People With Disabilities Are Protected From Discrimination**

The Americans with Disabilities Act (ADA) of 1990, the most comprehensive federal legislation protecting the civil rights of people with disabilities, provides a national mandate for eliminating discrimination against individuals with disabilities such as residents of facilities subject to Section 1418.8. ("ADA"), 42 U.S.C. §§ 12101 *et seq*. These protections are echoed in Section 504 of the Rehabilitation Act. 29 U.S.C. §§ 701 *et seq*. ("Section 504") and in California Government Code section 11135.[1] The Findings and Purposes of the

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[1] Nursing facility residents and residents of Intermediate Care Facilities are qualified individuals with disabilities under the ADA and are entitled to its rights and protections. 42 U.S.C. § 12131(2). "The term qualified individual with a disability means an individual with a disability who, with or without reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity."

ADA Amendments Act of 2008 found that, "in enacting the ADA [in 1990], Congress recognized that physical and mental disabilities in no way diminish a person's right to fully participate in all aspects of society, but that people with physical and mental disabilities are frequently precluded from doing so because of prejudice, antiquated attitudes, or the failure to remove societal and institutional barriers." 42 U.S.C. § 12101(a)(2).

The passage of civil rights laws such as Section 504 of the Rehabilitation Act of 1973 and the ADA in 1990 reflected a shift in attitudes and treatment of people with disabilities under the law. Decades of discriminatory policies and legally sanctioned practices such as forced sterilization, institutionalization and segregation reflected societal prejudices and the perception that people with disabilities are inferior. *See*, Mayerson, *History of the Americans with Disabilities Act, A Movement Perspective*, 1992. https://dredf.org/news/publications/the-history-of-the-ada/; *see also* Cook, *The Americans With Disabilities Act: The Move to Integration* (1991) 64 Temp. L. Rev. 393, 399-407 (discussion of "'lengthy and tragic' history of segregation and discrimination that can only be called grotesque", quoting *City of Cleburne, Texas v. Cleburne Living Center, Inc.* (1985) 473 U.S. 432, 454) These laws not only brought tangible legal protections, but "also reflected a shift in the view of individuals with disabilities from a largely medical

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model to a social model of disability that recognizes the civil and human rights of individuals with disabilities." *Devaluing People with Disabilities, Medical Procedures that Violate Civil Rights* (May 2012) http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf at 16 (NDRN 2012).

Adhering to this shift in the rights of people with disabilities, courts have increasingly sought to determine a person's expressed interest, and not simply to follow the wishes of parents, guardians, and care providers. "Many courts began to describe ways to adequately consider the individual right of the person with a disability in cases where the treatment proposed by parents, guardians and care providers was thought to be in the best interest of the individual, but was not actually appropriate given the expressed interest of the individual or his or her rights as a person separate from those of a family." (NDRN 2012 at 14-15). For example, in *Matter of Guardianship of Hayes* (1980) 93 Wash.2d 228, the Washington State Supreme Court found that a sixteen-year-old girl with a developmental disability could not be sterilized unless (1) she is represented by a disinterested *guardian ad litem*; (2) the court has received independent advice based on a thorough evaluation of her; and (3) the court has elicited and taken into account her expressed wishes.93 Wash.2d at 238; *see also Conservatorship of Valerie N. (1985)* 40 Cal.3d 143end (California Supreme Court found that parent/conservators of developmentally disabled woman were not entitled to authorize her sterilization, that statute prohibiting sterilization of conservatees impermissibly deprives developmentally disabled persons of privacy and liberty interests protected by federal and State Constitution, and discussion of history of forced sterilization of people with disabilities). The substitute decision making power granted to physicians in Section 1418.8 flies in the face of these evolving laws and understanding of the rights and capabilities of people with disabilities.

B. The ADA Requires Equal Access and Reasonable Modifications So Patients Can Participate In Healthcare Decision-Making

Under the ADA, discrimination against people with disabilities includes "the discriminatory effects of…overprotective rules and policies." 42 U.S.C. § 12101(a)(5). By limiting individuals' right to make decisions, Section 1418.8 discriminates against people with disabilities in violation of the ADA, in that a person who is found to lack capacity under 1418.8 loses the right to make fundamental decisions affecting their life, including whether they receive medical care and what care they will receive. 28 C.F.R. § 35.130(b). Such a significant deprivation occurs without the benefit of due process and a meaningful opportunity to participate in the decision-making process. "By limiting an individual's right to make decisions, [a finding of incapacity] not only divests the individual of the important right to self-determination but also marginalizes that person and removes him or her from a host of interactions involved in decision-making." Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act* (2010) 81 U. Colo. L. Rev. 157, 160 ("Salzman 2010").[2]

Moreover, the ADA includes specific obligations to address discrimination, and affirmatively requires that state and local governments provide reasonable modifications to policies and practices and identify methods to communicate effectively with people who have communication disabilities whether due to physical or cognitive impairments. 42 U.S.C. §§ 12131-12134; 28 C.F.R. §§ 35.160 – 35.164.

1. The Failure To Provide Reasonable Modifications Has Adverse Health Implications For Individuals With Disabilities

Effective communication with people with disabilities in nursing facilities is essential to ensuring that patients can meaningfully participate in decision-making and to avoid adverse outcomes. *See* Dep't of Health and Hum. Svs., Office for

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[2] The ADA also requires that states "administer [their] services, programs, and activities in the most integrated setting appropriate to the needs of the qualified individuals with disabilities." 28 C.F.R. § 35.130(d). The United States Supreme Court ratified the ADA's "integration mandate" and held that unjustified institutional isolation is a form of disability discrimination. *Olmstead v. L.C. ex rel. Zimring* (1999) 527 U.S. 581, 600. People who are subject to Section 1418.8 suffer the same discrimination and harm as was found in *Olmstead*, as was the case with Plaintiff Gloria A., who was denied outings with family members because of a physician's determination of her incapacity without any notice or opportunity to challenge the decision.

Civil Rights, *Effective Communication Dear Colleague Letter*, at *1 (2016), https://www.hhs.gov/sites/default/files/ocr-hrsa-effective-communication-dear-colleague-letter.pdf ("HHS Letter"). "Failure to ensure effective communication in such settings may lead to a misunderstanding of a patient's symptoms and thus to an inappropriate diagnosis and delayed or improper medical treatment." *Id*.

For people with intellectual disabilities or cognitive impairments, failure to effectively communicate, in a manner the individual can understand, can also lead to adverse health outcomes. For example, the United Kingdom's Public Library of Science (PLoS ONE) published a study in August 2013 that found people with intellectual disabilities have more obstacles obtaining health care, and die 25 years earlier than the general population, possibly due to resulting disparities in the medical care that they receive. Ali, et al. (2013) *Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers*. PLoS ONE 8(8): e70855, at 1 (Ali 2013) https://doi.org/10.1371/journal.pone.0070855.

In Dr. Ali's study, the problem with communication was a barrier to health care access. Ali 2013, *supra*, at 4. Eighty-six percent of patients interviewed felt "ignored" by clinicians or were "talked over" when their caretaker was present. *Id.* The study found that "[s]taff failed to modify and adapt their communication to the needs of the patient, including asking too many questions, speaking too quickly, giving too much information, and not giving the person enough time to respond." *Id.* at 4-5. Also, the study found that doctors failed to communicate essential details, such as potential side effects to prescriptions, and inadequate information about the appropriate number of doses or how long the patient was supposed to take the medication. *Id.* at 5.

Issues with communication can intensify if the patient both has a disability and limited English proficiency (LEP) or limited literacy. California is an incredibly diverse state with many individuals who either do not speak fluent English or have low literacy. The United States Census Bureau reported that 43.8 percent of Californians speak a language other than English. U.S. Census Bureau, 2011 American Community Survey, *Language Use in the United States: 2011*, Table 4. For non-English speakers in California, the census indicates that 8.4 percent report that they speak English "not at all" and 16.6 percent speak English "not well." *Id.*

In addition, the Joint Commission, a nationwide, independent, non-profit health care accreditation organization, published a report in 2007 that found: (1) five percent of American adults are non-literate in English; (2) fourteen percent of the American adult population has below basic prose literacy skills; and (3) twenty-nine percent only have basic literacy skills. The Joint Commission, *What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety* (2007) https://www.jointcommission.org/assets/1/18/improving_health_literacy.pdf (Joint Commission 2007).

Language and literacy barriers directly affect the health of these populations. The University of California, San Francisco, found that English-speaking patients were significantly more likely than LEP patients to have successful and complete documentation of informed consent in their medical files. Schenkler, et. al. (2007) *The Impact of Language Barriers on Documentation of Informed Consent at a Hospital with On-Site Interpreter Services*, J. Gen. Intern. Med. 22 (Suppl 2): 294 (Schenkler 2007). Comparing informed consent documentation in a hospital with on-site translators for the patients studied, 53 percent of English speakers had full documentation while only twenty-eight percent of LEP patients had their full informed consent paperwork. *Id.* The New England Journal of Medicine found that "among patients with psychiatric conditions, those who encounter language barriers are more likely than others to receive a diagnosis of severe psychopathology." Flores, *Language Barriers to Health Care in the United States* (2006) N. Engl. J. Med. 355:230.

For the forty-seven percent of American adults with literacy obstacles, the Joint Commission similarly found problems with low-literacy patients giving consent (Joint Commission 2007, *supra,* at 4), effectively communicating with doctors (*id.* at 5), making errors in medication dosages (*id.* at 11), and entering into medical surgeries and trials without fully understanding what was going on. *Id.* at 33. For example, a patient named Toni Cordell "consented" to a hysterectomy by signing a consent form she could not read. *Id.* at 33. She did not realize until weeks after the surgery what had happened. *Id.*

Protections to ensure effective communication with patients who have cognitive, intellectual, or mental health disabilities are critically important, and especially so for such individuals who may have limited English proficiency and/or low literacy. Steps to ensure that all patients with disabilities can meaningfully participate in medical decision making are required by the ADA, as discussed below.

2. **Reasonable Modifications And Effective Communication As Required By The ADA Can Enhance Capacity**

Courts have acknowledged that people with disabilities have a wide range of communication needs that must be accommodated. According to the United States Department of Justice, such determinations must be made on an individual basis: "An individualized assessment is a fact-specific inquiry that evaluates the strengths, needs, and capabilities of a particular person with disabilities based on objective evidence, personal circumstances, demonstrated competencies, and other factors that are divorced from generalizations and stereotypes regarding people with disabilities." U.S. Dep't of Justice, *Protecting the Rights of Parents and*

Prospective Parents with Disabilities Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, https://www.ada.gov/doj_hhs_ta/child_welfare_ta.html; *see also* 28 C.F.R. pt. 35, App. B; *PGA Tour, Inc. v. Martin* (2001) 532 U.S. 661, 690 (explaining that an individualized inquiry is among the ADA's most "basic requirement[s].").

Although those who would be subject to Section 1418.8 generally will need accommodations due to cognitive, rather than physical, disabilities, the analysis and approach for ensuring effective communication for people with hearing or visual impairments are instructive. In the context of those who are deaf, many courts have found ADA violations where public entities failed to take measures to ensure effective communication, ordering a range of accommodations, from sign language interpreters to mental health counselors with knowledge of the deaf community and its differing needs. *See, e.g., Hernandez v. County of Monterey* (N.D. Cal. 2015) 110 F.Supp. 3d 929, 954-955 (court found the county violated the ADA by failing to provide services in accessible locations in the jail and failed to provide sign language interpreters); *Clarkson v. Coughlin* (S.D.N.Y. 1995) 898 F.Supp. 1019, 1052 (holding that medical treatment depends upon effective communication between patients and medical personnel, and therefore where proper accommodations are not provided to remedy barriers to communication, medical treatment was inadequate); *Tugg v. Towey* (S.D. Fla. 1994) 864 F.Supp. 1201, 1204 (court ordered the state to devise a means of providing equal access to mental health services to persons who are deaf through counselors who possess knowledge and understanding of the deaf community and the ability to use sign language).

In addition to ensuring effective communication, reasonable modifications to policies and practices can help people with disabilities fully and meaningfully participate in fundamental decisions impacting their lives by helping to enhance capacity. 42 C.F.R. §§ 84.4(b)(1), (4); 28 C.F.R. §§ 35.130(b)(3), (7). "In many cases, if not most, individuals with impairments affecting decision making abilities would be able to participate in the decision making process with appropriate assistance." Salzman 2010, *supra*, at 201. Reasonable modifications can include any support or accommodation considered necessary to assist people with disabilities in exercising control over their decisions. Such accommodations or modifications can include: setting the time and location to discuss medical issues that will optimize the individual's ability to understand, ease anxiety, and participate; if desired by the patient, encouraging a friend or relative to participate in discussions; allowing additional time for such discussions; using understandable language instead of technical words, etc.

One prominent example of a reasonable modification used to enhance capacity is supported decision making. Supported decision making, unlike substituted decision making as is the case in 1418.8, is required based on the current legal scheme and is supported by scholarly understandings of what capacity means. "Supported decision making is a process that provides individuals, including older adults and people with [Intellectual/Developmental Disabilities]; assistance to understand the situations and choices they face, so they can make life decisions for themselves." U.S. Dep't of Health & Hum. Svs., Administration for Community Living, Administration on Intellectual and Developmental Disabilities, *Supported Decision Making*, HHS-2014-ACL-AIDD-DM-0084. Through supported decision making, "an individual with limitations in decision making abilities can receive support to understand relevant information…." *Salzman, Guardianship for Persons with Mental Illness – A Legal and Appropriate Alternative?* (2011) 4 St. Louis U. J. Health L. & Pol'y 279, 306.

Underlying supported decision making is the principle that "persons with disabilities have the right to autonomy, presumption of capacity, and right to make decisions on an equal basis with others," and the recognition that "persons with disabilities may need assistance in decision making through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language." Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN*

Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making (2012) 19 Hum. Rts. Brief 8, 10-11 (Dinerstein 2012). Supported decision making also furthers the purpose of the Developmental Disabilities Assistance and Bill of Rights Act: to "assure that individuals with developmental disabilities…have access to needed…forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life." 42 U.S.C. § 15001(b).

Recent cases have recognized the need for finding less restrictive alternatives, like supported decision making, in assessing capacity to prevent the erosion of self-determination. *See, e.g.*, *In re D.D.* (N.Y. Sur. Oct. 28, 2015) No. 2014-2185, 2015 WL 6872634, 3 (court rejected application for guardianship finding that D.D. was able to make decisions "with assistance and supervision from his family and supportive programs"); *Ross v. Hatch*, No. (Va. Cir. Ct. Aug. 2, 2013) CWF120000426P-03, slip op. at 7 (petition for permanent guardianship denied in favor of Supported Decision-Making relationship the person had developed); *In re Dameris L.* (2012) 956 N.Y.S.2d 848, 856 (guardianship terminated because person was "able to engage in supported decision-making"); *In re Peery* (1999) 727 A.2d 539, 540 (guardianship terminated because the person had a "circle of support to assist her in making rational decisions").

Consistent with the constitutional touchstone of self-determination, discussed, *infra*, Section III.A., supported decision-making helps enhance capacity thereby empowering people to remain meaningful participants in decisions affecting their lives and, in step with the purpose of the ADA, fully integrated members of society. Kohn, *Supported Decision-Making: A Viable Alternative to Guardianship?* (2013) 117 Penn St. L. Rev. 1111,1154.

Simply stated, 1418.8 is discriminatory when it is used without reasonable modifications that allow individuals with disabilities to participate in the medical decision-making process. In addition to the legal requirement that people with disabilities be provided with such modifications, approaches such as supported decision making and other means of assisting people to meaningfully participate are available and effective.

III. MEANINGFUL NOTICE MUST RECOGNIZE THE LEGAL AND SOCIAL DEVELOPMENTS IN DEFINING CAPACITY THAT SUPPORT THE FUNDAMENTAL RIGHT TO SELF-DETERMINATION

A. <u>The Right To Self-Determination Is A Fundamental Right, Deprivation Of Which Requires Due Process</u>

Underlying the protections of the ADA and Section 504 is the principle of self-determination, a principle that due process seeks to protect. Under California law a "competent, informed adult has a fundamental right of self-determination to refuse or demand the withdrawal of medical treatment of any form irrespective of the personal consequences." *Thor v. Superior Court* (1993) 5 Cal.4th 725, 732. Before a determination of capacity is made, the person remains competent in the eyes of the law, and therefore retains all rights of a competent person, including the right to participate in decisions impacting their medical treatment. *Id.* A finding of incapacity decreases self-determination, which can negatively impact the individual's functional abilities and quality of life causing further isolation. Salzman 2010, *supra*, at 169.

Before deprivation of the fundamental right of self-determination, due process compels that adequate notice be given; this notice includes a meaningful opportunity to oppose the proposed deprivation. *Goldberg v. Kelly* (1970) 397 U.S. 254; *Mullane v. Central Hanover Bank & Trust Co.* (1950) 339 U.S. 306, 313 ("there can be no doubt that at a minimum [due process] require[s] that deprivation of life, liberty or property by adjudication be preceded by notice and opportunity for hearing appropriate to the nature of the case"). Adequate notice is an essential protection, and makes a meaningful difference when done appropriately and with methods to ensure effective communication.[3] An opportunity to oppose cannot be truly meaningful unless a person has all necessary supports to fully participate in

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[3] Relatedly, the Plain Writing Act is intended to achieve a similar purpose: "to improve the effectiveness and accountability of Federal agencies to the public by promoting clear Government communication that the public can understand and use" by using "plain writing" in written communication. Sec. 2. Plain Writing Act of 2010. 5 U.S.C. § 301, Pub. L. No. 111-274, 124 Stat. 2861.

the decision making process including reasonable modifications to ensure effective communication and enhanced capacity. HHS Letter, *supra*, at 1; Salzman 2010, *supra*, at 201; Dinerstein, *supra*, at 10-11; Kohn, *supra*, at 1154.

B. What It Means To Have Or Lack Capacity Has Been Redefined And Requires A Modern Approach Consistent With Current Knowledge

Developments in our understanding about capacity and people with disabilities has developed such that adequate notice must and can include notice that is appropriate to the cognitive, sensory and language needs of patients. "With changes in medical practice, psychology, and a burgeoning legal framework of civil rights and procedural due process, we have moved to a functional, cognitive understanding of incapacity. This current paradigm leads to…the least restrictive means of protection, the promotion of greater autonomy for the incapacitated person, and robust procedural protections in the determination of incapacity…." Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond* (2012) 44 Colum. Hm. Rts. L.Rev. 93, 98.

A determination of capacity is not straightforward, and must be individually tailored, particularly because of the fundamental rights it threatens to erode. "There is a wide divergence of opinion as to how much the cognitive and emotive abilities of an adult must be diminished before one can conclude that the adult is decisionally incapable. There are no agreed upon objective standards for measuring the degree of diminished cognitive and emotive abilities…At all levels, healthcare providers have received inadequate training and monitoring in the practice of determining decisional incapacity.” Ethics Committee Consortium, Center for Practical Bioethics, *Guidelines for the Determination of Decisional Incapacity*, p. 2 (2015) https://www.practicalbioethics.org/files/ethics-consortium-guidelines/Determination-of-Decisional-Incapacity.pdf.

Importantly, decisional capacity can be fluid, so healthcare providers should “[a]ssum[e] decisional capacity in adults while recognizing a spectrum of developing, partial, complete, fluctuating, and diminishing decisional capacities; and “[r]ecogniz[e] and employ[] ways to enhance decisional capacity.” *Id*. at 3. Because capacity is task specific in that “a person has or lacks capacity for a particular decision at a particular time and under a particular set of circumstances…[a]ttention must be given to enhancing capacity before reaching a determination of incapacity.” *Id*. Measures to enhance capacity may include identifying times and environmental conditions that are more likely to enhance capacity, ameliorating the effects of medication or psychological and physiological stressors, and overcoming communication barriers related to one’s disability. *Id*. at 5. “Factors that diminish [] capacity may include physiological dysfunction, psychological disorders, and medication effects.” *Id*. at 4. Because of this fluidity, "[e]valuations for decisional capacity must be repeated over time and in varying circumstances to reach a confident conclusion." *Id*.

Courts are recognizing that findings of incapacity remove a person's right to self-determination. In a case where parents sought a guardianship over their adult son with Down syndrome, the New York Surrogate Court held that petitioners had not shown evidence of their son's inability to make medical decisions, other than conclusory statements by doctors. *In re D.D., supra*, at 3. In assessing an individual's capacity, the court held "the standard here is not whether the petitioners can make better decisions than D.D., it is whether or not D.D. has the capacity to make decisions for himself with the support that he abundantly has." *Id.* at 676. What the New York court recognized is that a finding of capacity requires consideration of supports and modifications that can assist the person in enhancing capacity.

IV. THE SUPERIOR COURT CORRECTLY PROHIBITED THE USE OF SECTION 1418.8 TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT

With respect to end-of-life decisions, the lower court ordered that the decision to remove or withdraw life-sustaining care may no longer be implemented through the section 1418.8 statutory process, unless it is also consistent with the resident's individual health care instructions and other wishes, but does not prohibit the use of the statutory process for comfort or hospice care that is not inconsistent with the individual's health care instructions and other wishes. (*Id.* at 4.)

A. Disability Rights California's Experiences And Expertise In Investigating Abuse And Neglect In Facilities Support The Need For Protections In End-of-Life Decision-Making

The Superior Court correctly held that Section 1418.8 should not apply to situations involving end-of-life decisions; this holding should be extended to decisions involving hospice or comfort care. Any decision regarding end-of-life care and treatment can have irreversible consequences and thus should be subject to the same protections and limitations discussed above. To rule otherwise would ignore Constitutional and statutory rights that underscore the need for due process protections at these critical treatment stages.

Disability Rights California is mandated under state and federal law to investigate allegations of abuse and neglect of people with disabilities, and advocate on their behalf. 42 U.S.C. § 15001 *et seq*., 29 U.S.C. § 794e *et seq.*; 42 U.S.C. § 10801 *et seq*., Welf. & Inst. Code § 4900 et seq. Both Congress and the California Legislature have given Disability Rights California broad authority to ensure that Californians with disabilities are free from abuse and neglect. Using this authority, we have investigated hundreds of cases of abuse and neglect involving residents of nursing homes and other long term care facilities and worked to implement reform measures to ensure such incidents do not reoccur.

The details of one Disability Rights California investigation involving a tragic and avoidable end-of-life decision by a substitute decision-maker are reported in *The Deadly Failure of a Hospital to Follow a Patient's Decisions about his Medical Care (Lew and Morrison, Disability Rights California* (2013) http://www.disabilityrightsca.org/pubs/702601.pdf. This report involves a nursing facility resident, Mark Turner, who died when physicians overruled his end-of-life wishes after declaring that he lacked capacity.

Mr. Turner was a 56-year-old man with end stage renal disease living in a nursing home. His long period of isolation in a nursing home partially contributed to him losing all contact with family and close personal friends. Mr. Turner's renal functioning was inadequate so, several times a week, he left the nursing home to receive dialysis. At times, Mr. Turner would have periods of confusion because of the toxins accumulating in his body between dialysis treatments. When he was lucid, he and his doctors talked about his prognosis and what he wanted to have happen in the event of the inevitable health crisis. Mr. Turner gave clear and consistent, explicit instructions that he wanted to live and to have all possible life saving measures.

Following a medical crisis, Mr. Turner's physician concluded that he lacked the capacity for medical decision making. His care team then decided that continued dialysis was futile and ordered his dialysis stopped. Without dialysis, Mr. Turner would die. The care team also ordered that resuscitation not be attempted and that Mr. Turner receive comfort care only. Several days later, Mr. Turner died, alone. Medical staff later claimed that Mr. Turner had changed his mind regarding his end-of-life choices, but there was no evidence of this in any of the medical records or physician notes.

Disability Rights California's report found that medical staff's decision to discontinue dialysis directly caused Mr. Turner's premature death and that staff had no authority to discontinue his life-sustaining dialysis or to execute new orders contrary to his written instructions regarding resuscitative measures. The report also found that the Department of Public Health erred in not citing the hospital for violating state law despite its determination that the facility had violated his right to make medical and end-of-life care decisions.

In its report, Disability Rights California recommended that health care facilities seek court approval or appointment of a legal representative before foregoing life sustaining treatment of a patient who lacks capacity when there are questions regarding his/her end of life decisions and no designated representative. Disability Rights California further recommended that the Department of Public Health enforce compliance with state law and protect patients' rights to make medical and end-of-life decisions, including when the patient subsequently loses capacity.

Mr. Turner’s case is not isolated. Disability Rights California’s investigations of abuse and neglect in facilities have uncovered other instances in which physicians have made presumptions of incapacity and, against the expressed wishes of the patient or conservator, have changed patients’ code status from full resuscitation to a do not resuscitate (DNR) status. In one example, a 45-year old man with intellectual disabilities made his desire for full resuscitation clear prior to routine hernia surgery. Prior to surgery, he sustained a kidney injury, which caused a buildup of potassium in his blood, a deadly condition if left untreated. Believing that the individual lacked capacity due to his intellectual disability, his physician questioned his decision making ability and deemed him incompetent, and changed his code status from full resuscitation to a DNR status and comfort care only. Medication that cleared his body of excess potassium was discontinued and he died days later. The hospital never contacted staff at his residential facility where he had lived for years to ascertain his decision making capacity or his end-of-life wishes. In another example, Disability Rights California intervened in a case in which hospital staff changed the code status of a patient with intellectual disabilities who was hospitalized with treatable pneumonia, against the express wishes of his conservator.

These cases are cautionary examples of why Section 1418.8 should not apply to circumstances in which an individual is facing an end-of-life situation, even in cases involving hospice or comfort care.

B. Applying Section 1418.8 to End-of-Life Decisions Circumvents Laws That Protect Decision Making Consistent with a Person's Expressed Wishes

Section 1418.8 stands in direct contrast to the principles of personal bodily autonomy embodied in California law to protect individuals' autonomy in medical decision making. The fundamental right to bodily autonomy requires Constitutional protections. *Conservatorship of Wendland* (2001) 26 Cal.4th 519, 524. However, Section 1418.8 does not require adherence to legal safeguards that the Legislature has enacted to protect an individual's right to govern his or her own medical care in the event of incapacity.

For example, under Probate Code section 4670, an adult having capacity may give an individual health care instruction. The individual instruction, oral or written, may be limited to take effect only if a specified condition arises. In addition, Probate Code section 4780 sets out the legal authority for an individual to make decisions regarding life-sustaining treatment including resuscitative measures in the case that he or she subsequently loses capacity. These directives for care are known as a Physician Orders for Life Sustaining Treatment, or a POLST. These orders specify the individual's decision to have or refuse cardiopulmonary resuscitation (CPR) and the extent of life-sustaining medical intervention and nutritional support desired. Health care providers are required to treat an individual in accordance with the POLST. Prob. Code § 4780.

Given the potentially irreversible consequences following the withdrawal of life-sustaining treatment, existing law requires independent oversight of a physician or legal representative when they are acting contrary to the directives of an incapacitated patient with regard to medical decision making. When a conservator instructs a nursing facility to withhold life-sustaining measures for their conservatee, Probate Code section 2355 requires a trier of fact to determine whether the decision of a conservator concurs with what the conservatee would have wanted. Similarly, a physician may not modify an existing POLST or issue a new POLST unless she has consulted with the individual or the individual's legally recognized health care decision-maker. Cal. Prob. Code §§ 4780, 4781.2.

The California Supreme Court in *Wendland*, interpreting the application of Probate Code section 2355, held that, "a conservator may not withhold artificial nutrition and hydration from such a person absent clear and convincing evidence the conservator's decision is in accordance with either the conservatee's own wishes or best interest." *Wendland, supra,* 26 Cal.4th at 524. Thus, before allowing a conserved patient without capacity to die based on the consent of his conservator, the law requires *clear and convincing evidence* that this outcome is either (1) what the conservatee wants or (2) in his best interest. *Id*. As Justice Werdegar explained for the California Supreme Court, “the importance of the ultimate decision and the risk of error are manifest. So too should be the degree of confidence required in the necessary findings of fact. The ultimate decision is whether a conservatee lives or dies, and the risk is that a conservator, claiming statutory authority to end a conscious conservatee's life ‘in accordance with the conservatee's . . . wishes,’ . . . will make a decision with which the conservatee subjectively disagrees and which subjects the conservatee to . . . death.” *Wendland, supra,* 26 Cal.4th at 547 (internal citation omitted).

Section 1418.8 stands in direct contrast to the principles of personal bodily autonomy and expressed wishes of the individual that underlie Probate Code sections 4780, 4670, and 2355, and cannot be reconciled with these statutory protections. In the light of this, and the fact that section 1418.8 lacks the due process protections required when a fundamental right is implicated, as here, the court correctly held that Section 1418.8 should not apply to end-of-life decisions. This Court should go further and order that section 1418.8 also not apply to hospice or comfort care.

V. CONCLUSION

For the foregoing reasons, *amicus curiae* Disability Rights California respectfully requests that this Court rule in favor of Plaintiffs/Appellants, adopt the arguments and reasoning of *amicus curiae* American Civil Liberties Union, and further find that:

(1) Section 1418.8 runs afoul of the ADA and other anti-discrimination laws and that people with disabilities are entitled to effective communication and reasonable modifications to ensure their meaningful participation in medical decision making;

(2) The fundamental right to self-determination requires meaningful notice of determinations of incapacity; and

(3) Section 1418.8 should not apply to end-of-life decisions, hospice and comfort care.

Respectfully submitted,

Dated: October 2, 2017 DISABILITY RIGHTS CALIFORNIA

By: /s/ Katherine Mathews
Katherine Mathews
Attorneys on Behalf of Applicant

CERTIFICATE OF COMPLIANCE

I, Katherine Mathews, hereby certify that the attached brief uses 14 point Times New Roman font. According to the word processing program I used to prepare this brief, the text of this entire filing contains 7912 words in length.

Dated: October 2, 2017 DISABILITY RIGHTS CALIFORNIA

By: <u>/s/ Katherine Mathews</u>
Katherine Mathews
Attorneys on Behalf of Applicant

PROOF OF SERVICE

Re: California Advocates for Nursing Home Reform v. Smith
California Court of Appeal, First Appellate District
Case No. A147987

I, Jamie C. Parkin, declare that I am over 18 years of age, and not a party to the within cause; my business address is 1330 Broadway, Suite 500 Oakland, CA 04612.

On October 2, 2017, I served a true copy of the:

NOTICE OF ERRATA RE: [PROPOSED] *AMICUS CURIAE* BRIEF BY DISABILITY RIGHTS CALIFORNIA IN SUPPORT OF PLAINTIFFS AND APPELLANTS; APPLICATION BY DISABILITY RIGHTS CALIFORNIA IN SUPPORT OF PLAINTIFFS AND APPELLANTS; [PROPOSED] *AMICUS CURIAE* BRIEF BY DISABILITY RIGHTS CALIFORNIA IN SUPPORT OF PLAINTIFFS AND APPELLANTS

on the parties listed on TrueFiling, via electronic service as in compliance with the Court.

I declare under penalty of perjury that the foregoing is true and correct.

Executed on October 2, 2017

/s/ Jamie C. Parkin
Paralegal/Declarant

Court of Appeal, First Appellate District
Diana Herbert, Clerk/Administrator
Electronically FILED on 10/19/2017 by C. Hoo, Deputy Clerk

STATE OF CALIFORNIA
Court of Appeal, First Appellate District

PROOF OF SERVICE

(Court of Appeal)

Case Name: **California Advocates For Nursing Home Reform(CANHR) v. Chapman**
Court of Appeal Case Number: **A147987**
Superior Court Case Number: **RG13700100**

1. At the time of service I was at least 18 years of age and not a party to this legal action.

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I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

10-02-2017
Date

/s/Salma Enan
Signature

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Disability Rights California
Law Firm