#### No. 02-35587

## IN THE UNITED STATES COURT OF APPEALS FOR THE NINTH CIRCUIT

OREGON, et al.,

Plaintiffs-Appellees

V.

JOHN ASHCROFT, in his official capacity as United States Attorney General, et al.,

Defendants-Appellants.

## ON APPEAL FROM THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF OREGON

BRIEF OF AUTONOMY, INC., CASCADE AIDS PROJECT, GAY MEN'S HEALTH CRISIS, THE SEATTLE AIDS SUPPORT GROUP, THE AIDS PROJECT AT LAMBDA, AND PROJECT INFORM: On Behalf Of Their Members or Supporters With Disabilities and Terminal Illnesses; AND Evan Davis, Michael Stein, Hugh Gregory Gallagher, Camilla Lee, and Ram Dass (hereafter "The AUTONOMY Disability Brief")

## AS AMICUS CURIAE IN SUPPORT OF PLAINTIFFS-APPELLEES

THANE W. TIENSON LANDYE BENNETT & **BLUMSTEIN** 3500 Wells Fargo Center Portland, OR 97201 Telephone: (503) 224-4100 Facsimile: (503) 224-4133

ANDREW I. BATAVIA 2845 Prairie Avenue Miami Beach, FL 33140

RICHARD F. ZIEGLER CURTIS K. TAO JEFFREY H. JORDAN KATHERINE E. JOHNSON CLEARY GOTTLIEB STEEN & **HAMILTON** One Liberty Plaza New York, New York 10006 Telephone: (212) 225-2000

Facsimile: (212) 225-3999

Attorneys for Amicus Curiae AUTONOMY, Inc. et al.

# **TABLE OF CONTENTS**

			<u>P</u>
TAB	LE OF	AUTHORITIES	
CON	SENT	OF THE PARTIES	
COR	PORA	TE DISCLOSURE STATEMENT	
INTE	EREST	S OF AMICI CURIAE	
SUM	IMAR`	Y OF ARGUMENT	
ARG	UME	NT	
I.	THA INTE	GON'S DEATH WITH DIGINITY ACT RECOGNIZES T TERMINALLY ILL INDIVIDUALS HAVE A STRONG EREST IN THE ABILITY TO HASTEN IMMINENT TH WITH THE ASSISTANCE OF THEIR PHYSICIANS	
	A.	Competent Terminally Ill Adults Have A Strong Liberty Interest In The Right To End Their Suffering By Hastening Their Own Imminent Deaths	
	В.	The Citizens of Oregon Have Sovereign Authority To Allow Assisted Dying For Terminally Ill Individuals And The Attorney General May Not Usurp This Authority By Administrative Fiat	
		1. The Public Interest Is Better Served By Continuing To Permit Physicians To Use Those Medications Necessary To Allow Their Patients With Terminal Illnesses To Exercise ThisLiberty Interest	
		2. Available Data Demonstrate That A Substantial Majority Of People With Disabilities Supports The Right Of Terminally Ill Individuals To Hasten Death With The Assistance Of Their Physicians	

П.	THE	OREGON ACT STRIKES THE APPROPRIATE
	BAL	ANCE BETWEEN THE INTERESTS OF TERMINALLY
	ILL	INDIVIDUALS AND THE LEGITIMATE INTERESTS OF
	THE	STATE WITHOUT DENYING PERSONS WITH
	DISA	ABILITIES ANY RIGHTS OR PROTECTIONS UNDER
	FED	ERAL LAW
	A.	The Death With Dignity Act Is Narrowly Drawn So That
		Only Individuals With Terminal Illnesses May Avail
		Themselves Of Its Provisions
		1. There Is No Evidence That People With Disabilities Have
		Been Harmed In Any Way Under The Oregon Act
		2. The Oregon Act Is Consistent With The ADA And
		Federal Law
	B.	When Weighed Against The Liberty Interests At Stake,
		Government Interests Are Minimal In Cases Of Physician
		Assisted Dying Under The Oregon Law
CO1	<b>VCLUS</b>	SION

# **TABLE OF AUTHORITIES**

	Page(s)
Rules and Statutes	
20 U.S.C. § 1400	5
42 U.S.C. § 12101	6
42 U.S.C. § 12102(2)	4
42 U.S.C. § 12111-12181	5
Oregon Death With Dignity Act, Or. Rev. Stat. § § 127.800-127.995 (2001)	1, 15-16,17
<u>Cases</u>	
Bragdon v. Abbott, 524 U.S. 624 (1998)	4
Cruzan v. Director Missouri Dep't of Health, 497 U.S. 261 (1990)	9
<u>Garger v. New Jersey,</u> 429 U.S. 922 (1976)	23
<u>Ingraham v. Wright,</u> 430 U.S. 651 (1977)	9
In re Marriage of Carney, 598 P.2d 36 (Cal. 1979)	5
<u>In re Quinlan,</u> 355 A.2d 647 (N.J.), <u>cert. denied,</u> 429 U.S. 922 (1976)	23
<u>Lee v. Oregon,</u> 107 F.3d 1382 (9th Cir.), <u>cert. denied,</u> 522 U.S. 927 (1997)	10
New State Ice Co. v. Liebmann, 285 U.S. 262 (1932)	12

	Page(s)
Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999)	5
Olmstead v. United States, 277 U.S. 438 (1928)	8
Oregon v. Ashcroft, 192 F. Supp. 2d 1077 (D.Or. 2002)	9
Philadelphia Citizens in Action v. Schweiker, 669 F.2d 877 (3d Cir. 1982)	11
Relf v. Weinberger, 372 F.Supp. 1196 (D.C. Cir. 1974)	5
Washington v. Glucksberg, 521 U.S. 702 (1997)	2,8-10,15
<u>Youngberg v. Romeo,</u> 457 U.S. 307 (1982)	5
Other Authorities	
Andrew I. Batavia, <u>The Ethics of PAS: Morally Relevant</u> Relationships Between Personal Assistance Services	
and Physician-Assisted Suicide, Archives of Physical Med. and Rehab. (2001), 12 Suppl. 2:S25-31	6
Andrew I. Batavia, <u>The Relevance of</u> Data on Physicians and Disability on the Right to	
Assisted Suicide, 6 Psych. Pub. Pol'y L. 552	13
Almost Dead: Buck v. Bell and the Sterilization of Handicapped  Persons, 50 TEMP. L.Q. 995 (1977)	6
Pamela Fadem et al., <u>Attitudes of People With Disabilities</u> Toward Death with Dignity/Physician Assisted Suicide	
Legislation: Broadening the Dialogue (2001)	13

	Page(s)
Mark Nagler, Perspectives on Disability (2d ed. 1993)	22
Susan Okie, "I Should Die the Way I Want To":  Oregon Doctors, Patients Defend Threatened  Assisted Suicide Law, Wash. Post, Jan. 1, 2002	21
David Orentlicher, <u>The Supreme Court and Terminal Sedation</u> , 24 Hastings Const. L.Q. 947 (1997)	19
Susan Stoddard Pflueger, <u>Independent Living: Emerging</u> <u>Issues in Rehabilitation</u> , (Dec. 1997) (unpublished report, on file with the Institute for Research Utilization)	5
Dr. Timothy Quill, <u>Ashcroft's Ruling Usurps</u> States' and Voters' Rights, Rochester Dem. Chron., Dec. 12, 2001	16,19
Stein, M. From Crippled to Disabled: The Legal Empowerment of Americans With Disabilities, 43 Emory L.J. 24 (1994)	5
Stein, M. Mommy Has a Blue Wheelchair: Recognizing the Parental Rights of People With Disabilities, 60 Brooklyn L. Rev. 1069 (1994)	6
Kathryn Tucker, <u>The Death with Dignity Movement:</u> <u>Protecting Rights and Expanding Options after</u> <u>Glucksberg and Quill</u> , 82 Minn. L. Rev. 923 (1998)	18-19
Implementing The Americans With Disabilities Act: Rights And Responsibilities Of All Americans (Lawrence O. Gostin & Henry A. Beyer eds., 1993)	22
The Americans With Disabilities Act: From Policy to Practice (Jane West ed., 1991)	22

	Page(s)
Implementing the Americans With Disabilities Act (Jane West ed., 1996)	22
Hastings Center Report, <u>Vitalism Revitalized: Vulnerable Populations</u> , <u>Prejudice</u> , and <u>Physician-Assisted Death</u>	17
Fourth Annual Report on Oregon's Death With Dignity Act (Feb. 6, 2002)	19,20
Three Years of Legalized Physician Assisted Suicide (Feb. 2001)	20-21
Hearings before the Oregon Senate Committee on Health Insurance and Bioethics on SB1141 (April 30, 1991) (Statement of Richard A. Wise, ACLU of Oregon)	10
Mem. from Ashcroft to Hutchinson, published at 66 Fed. Reg. 56 (Nov. 9, 2001)	2
Harris Poll Data from December 2001, <a href="http://www.harrisinteractive.com/harris_poll/index.asp?PID=278">http://www.harrisinteractive.com/harris_poll/index.asp?PID=278</a>	14
http://www.AUTONOMY-NOW.org	3

## **CONSENT OF THE PARTIES**

AUTONOMY has received consent from all parties to file this brief.

## **CORPORATE DISCLOSURE STATEMENT**

Each Amici organization is a non-profit corporation or unincorporated association. None has parent corporations nor issues stock. No publicly held company owns an interest in any Amici.

## **INTERESTS OF AMICI CURIAE**

Amici represent people with a broad array of disabilities who support the right of mentally competent, terminally ill individuals to choose to end their suffering with medications prescribed by their physicians to achieve a humane and peaceful death. While there is ongoing debate regarding the availability of this choice, Amici believe that the substantial majority of people with disabilities support it. We believe that the people of Oregon have appropriately addressed this issue by passing the Oregon Death with Dignity Act (hereafter, "the Oregon Act" or "the Act"), Or. Rev. Stat. § § 127.800-127.995 (2001).

<sup>&</sup>lt;sup>1</sup> The Oregon Death With Dignity Act was a citizen's initiative first voted into law by Oregon voters in 1994. Implementation was delayed by a legal injunction, which was ultimately lifted by this Court. In 1997, Oregon voters were asked to repeal the Act, but they declined to do so by a margin of 60% to 40%.

Since 1997, the Act has allowed terminally ill Oregon residents to request and obtain a lethal prescription from their physicians if they are diagnosed to have less than six months left to live. The Act contains numerous safeguards that ensure the Act will be used only for its limited intended purpose, which does not include assisting people with non-terminal conditions.

We are deeply offended by the decision of Attorney General Ashcroft (hereinafter, "the Ashcroft directive) to punish physicians who comply with the Oregon Act <sup>2</sup>, and believe that the Ashcroft directive is at odds with the Supreme Court's ruling in Washington v. Glucksberg, 521 U.S. 702 (1997). The beliefs of a few federal government officials should not be imposed arbitrarily to supercede the democratic will of the people of Oregon.

Several organizations join this brief as Amici. AUTONOMY, Inc. is a national disability rights organization incorporated and based in Oregon, representing the interests of individuals with disabilities who believe that people with disabilities should be able to exercise choices in all aspects of their lives. The Board of Directors of AUTONOMY includes some of the most prominent individuals in the disability community, including a former executive director of the National Council on Disability, one of the world's foremost rehabilitation physicians, a noted Oregon disability rights activist, an award-winning author and historian, the former director of the National Institute on Disability and

On November 6, 2001, Attorney General Ashcroft announced that he was reversing the decision of his predecessor, stating that "assisting suicide is not a 'legitimate medical purpose' within the meaning of 21 C.F.R. § 1306.04 (2001)" and "prescribing, dispensing, or administering federally controlled substances to assist suicide violates the CSA [Controlled Substances Act]." As such, Ashcroft directed that "[s]uch conduct by a physician registered to dispense controlled substances may 'render his registration . . . inconsistent with the public interest' and therefore subject to possible suspension or revocation under 21 U.S.C. 824(a)(4)." Mem. from Ashcroft to Hutchinson, published at 66 Fed. Reg. 56,607 (Nov. 9, 2001).

Rehabilitation Research and a former editor of the Harvard Law Review who has served as the president of the National Disability Bar Association. All have substantial disabilities.<sup>3</sup>

The other Amici organizations represent people with terminal or potentially terminal illnesses. Cascade AIDS Project is dedicated to helping individuals in the northwest United States who have HIV or AIDS. Gay Men's Health Crisis is a New York based organization dedicated to providing compassionate care to individuals with AIDS, educating the public, and advocating for fair and effective public policies. The Seattle AIDS Support Group is an organization that provides free, confidential emotional support for people with HIV or AIDS. The AIDS Project at LAMBDA Legal Defense and Education Fund advocates nationally for people with HIV and AIDS through impact litigation, education and public policy work in the context of the struggle for civil rights of lesbians, gay men, bisexuals, the transgendered, and people living with HIV and AIDS. Project Inform is a national nonprofit, community based organization working to end the AIDS epidemic through education and advocacy. Each of these organizations firmly supports the continued implementation of the Oregon Act. The leaders of these organizations have submitted letters of support and statements of interest, which are provided in Appendix I.

<sup>&</sup>lt;sup>3</sup> See http://www.AUTONOMY-NOW.org.

In addition, several individual Amici from the disability community join this brief in their individual capacities and support the people of Oregon in this case. Evan Davis is a partner with a major national law firm who had polio at age five. Hugh Gregory Gallagher, who is also a survivor of polio, is a pioneer of the disability rights movement, one of the world's foremost authorities on the Nazi "Euthanasia" Program, and Vice President of AUTONOMY. Michael Stein is a person with paraplegia, and is a former president of the National Disability Bar Association and currently serves on the Board of Directors of AUTONOMY. Camilla S. Lee is a woman with Chronic Progressive Multiple Sclerosis and is a supporter of AUTONOMY. All have disabilities but not terminal illnesses. Their personal statements are also attached in Appendix I.

## The Disability Rights Movement

The interests of Amici reflect the interests of millions of people with disabilities, including people with terminal illnesses, throughout the country.<sup>4</sup>

The ADA defines "disability" very broadly as "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual [e.g., seeing, hearing, speaking, walking, dressing, feeding oneself, working, learning, etc.].; (B) a record of such an impairment; or (C) being regarded as having such an impairment." 42 U.S.C. § 12102(2). In Bragdon v. Abbott, 524 U.S. 624, 631 (1998), the Supreme Court found that courts must (1) determine whether the plaintiff's condition is an impairment; (2) "identify the life activity upon which the [plaintiff] relies"; and (3) "ask whether the impairment substantially limited the major life activity." Because virtually all terminal illnesses impose a substantial limitation in at least one major life activity, most people with terminal illnesses are included as people with disabilities under the ADA.

Although the personal circumstances of people with disabilities vary substantially, they share a common interest in having choices in all aspects of their lives and being able to maintain control over their lives. This interest is the cornerstone of the disability rights movement.<sup>5</sup> Judy Heumann, one of the pioneers of the movement, expressed the driving spirit of the movement best in an early policy report: "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent on a 'normal' body." Over time, the movement has been successful in recognizing a broad array of rights for people with disabilities and establishing a presumption in our society that individuals with disabilities should be allowed to make their own independent choices about their lives.<sup>7</sup> After decades of political

<sup>&</sup>lt;sup>5</sup> The terms "disability rights movement" and "independent living movement" are often used interchangeably by members of the disability community. Whether they are two separate social movements or two names for basically the same movement is a matter of debate. For purposes of this brief, the broader term "disability rights movement" is used to refer to both.

<sup>&</sup>lt;sup>6</sup> Susan Stoddard Pflueger, <u>Independent Living: Emerging Issues in Rehabilitation</u>, foreword ii (Dec. 1977) (unpublished report, on file with the Institute for Research Utilization).

<sup>&</sup>lt;sup>7</sup> <u>See Youngberg v. Romeo</u>, 457 U.S. 307 (1982); the right to be free of involuntary sterilization, <u>Relf v. Weinberger</u>, 372 F. Supp. 1196 (D.C. Cir. 1974); the right to raise a child, <u>In re Marriage of Carney</u>, 598 P.2d 36 (Cal. 1979); the right to have access to public streets, public transportation, schools, public services, privately owned places of public accommodation and places of employment, 42 U.S.C. §§ 12111-12181; the right to a free and appropriate education, 20 U.S.C. §1400 <u>et seq.</u>, and the right to be free from unjustified institutionalization and to live in the community; <u>Olmstead v. L.C. ex rel. Zimring</u>, 527 U.S. 581, 596 (1999). <u>See also Stein</u>, M. <u>From Crippled to Disabled: The Legal Empowerment of Americans With Disabilities</u>, 43 *Emory L.J.* 24 (1994);

struggle, Congress passed the Americans with Disabilities Act of 1990 (the "ADA")<sup>8</sup>, demonstrating the nation's progress and commitment in respecting the right of people with disabilities to exercise control over their lives in the mainstream of society.

The conditions of most individuals with disabilities are not life-threatening and will never reach a terminal phase. To these individuals, issues concerning assisted dying are the same as those for anyone else, except that some will have a greater need for assistance due to functional limitations. Other individuals with disabilities have conditions that are or may become life-threatening, such as the individuals with AIDS represented by several Amici organizations.

All Amici, however, want a wide range of end-of-life choices if they someday become terminally ill, including the right to hasten death if they determine that life during their remaining few days is no longer bearable. Further, they want the security of knowing that they can exercise this choice safely, effectively, and legally with the professional assistance of their physicians. They

Stein, M. Mommy Has a Blue Wheelchair: Recognizing the Parental Rights of People With Disabilities, 60 *Brooklyn L. Rev.* 1069 (1994); Robert L. Burgdorf, Jr. & Marcia P. Burgdorf, The Wicked Witch Is Almost Dead: Buck v. Bell and the Sterilization of Handicapped Persons, 50 TEMP. L.Q. 995 (1977).

<sup>&</sup>lt;sup>8</sup> The Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq.

<sup>&</sup>lt;sup>9</sup> Andrew I. Batavia, <u>The Ethics of PAS: Morally Relevant Relationships</u> <u>Between Personal Assistance Services and Physician-Assisted Suicide</u>, Archives of Physical Med. and Rehab. (2001), 12 Suppl. 2:S25-31 (discussing the implications

do not want their disabilities to be used by others to justify a wholesale denial of this right to all people with terminal illnesses. Amici believe that the decision to hasten death is a uniquely personal, moral, and religious choice, one that primarily affects the individual involved and their loved ones. Most importantly, it is a decision that the State of Oregon has empowered them to make for themselves without undue federal interference.

## SUMMARY OF ARGUMENT

This brief expresses the interests of people with disabilities, represented by Amici, who support the continued implementation of the Oregon Act and the District Court's decision to recognize the democratic will of the people of Oregon. The purpose of this brief is to offer a disability rights perspective in support of the Oregon Act and the District Court's decision, and in opposition to the Ashcroft Directive.

In Part I of this brief, Amici discuss the substantial autonomy and liberty interests of people with terminal illnesses in making end-of-life decisions without undue government interference, and the sovereign right that the citizens of Oregon have to enact legislation asserting this right.

In Part II, Amici demonstrate that the Oregon Act strikes an appropriate balance between the rights of terminally ill people and governmental interests in

for some individuals who, due to their disabilities, cannot use their hands and arms

preserving life. The Oregon Act was carefully drafted to guard against potential abuses, and as a result there has been no evidence of improper application of its provisions, nor of a discriminatory effect on individuals with disabilities.

## **ARGUMENT**

There is no reason to think the democratic process will not strike the proper balance between the interests of terminally ill, mentally competent individuals who would seek to end their suffering and the State's interests in protecting those who might seek to end life mistakenly or under pressure.

Justice O'Connor in Glucksberg, 521 U.S. at 737.

I.
OREGON'S DEATH WITH DIGNITY ACT RECOGNIZES THAT
TERMINALLY ILL INDIVIDUALS HAVE A STRONG INTEREST IN
THE ABILITY TO HASTEN IMMINENT DEATH WITH THE
ASSISTANCE OF THEIR PHYSICIANS

A. Competent Terminally Ill Adults Have A Strong Liberty Interest In The Choice To End Their Suffering By Hastening Their Own Imminent Deaths

The United States Constitution confers on individuals, "as against the [G]overnment, the right to be let alone -- the most comprehensive of rights and the right most valued by civilized men." Olmstead v. United States, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting). The right of any individual to choose the circumstances of his own death when that death is imminent is perhaps the most personal incarnation of the right to be left alone. In Glucksberg, while the

or who cannot swallow pills).

Supreme Court did not go so far as to recognize a constitutionally protected right to physician-assisted dying, it acknowledged that there are important elements of individual freedom involved in end-of-life decisions. The <u>Glucksberg Court was</u> aware of the importance its decision would have on individual liberty and was very careful to issue an opinion that would leave the choice of whether to grant a right to physician-assisted dying to the individual states. The District Court correctly understood the <u>Glucksberg Court</u>'s objective, and its decision in favor of individual autonomy should be upheld. <u>See Oregon v. Ashcroft</u>, 192 F.Supp.2d 1077 (D.Or. 2002).

B. The Citizens Of Oregon Have Sovereign Authority To Allow Assisted Dying For Terminally Ill Individuals And The Attorney General May Not Usurp This Authority By Administrative Fiat

The U.S. Supreme Court also recognized in <u>Glucksberg</u> that "Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician assisted suicide" and encouraged "this debate to continue,

Justice Stevens noted in his concurrence that the state's "interest in the preservation of human life . . . is not a collective interest that should always outweigh the interests of a person who because of pain, incapacity, or sedation finds her life intolerable, but rather, [is] an aspect of individual freedom." 521 U.S. at 746 (citation omitted). He also stated that "[t]here are situations in which an interest in hastening death is legitimate . . ." and that "there are times when it is entitled to constitutional protection." The U.S. Supreme Court has also recognized that a liberty interest is implicated when a state inflicts pain and suffering (as prolonging a terminally ill patient's life against his will would do) and when a competent adult refuses life-saving medical treatment. See, e.g., Ingraham v. Wright, 430 U.S. 651, 674 (1977); Cruzan v. Director Missouri Dep't of Health, 497 U.S. 261 (1990).

as it should in a democratic society."<sup>11</sup> After years of intense debate, the Death With Dignity Act survived all political and legal challenges.<sup>12</sup> The message from the people of Oregon was clear: we have struggled with, considered and debated this difficult policy question, and we have chosen to provide those members of our community who face imminent death with a humane and compassionate way to eliminate their suffering.

The legislative record for the policy determination underlying the Oregon Act is replete with evidence that the state was guided by Oregon's medical community, disability community, family members of terminally ill people, and bio-ethicists. Input from diverse members of society is a hallmark of our democratic process. The policy determination underlying the Oregon Act resulted from a participatory process in which the interests of people with disabilities were considered, and represents a balance between the need to ease the suffering of terminally ill people and the need to provide safeguards against abuse.

<sup>&</sup>lt;sup>11</sup> Washington v. Glucksberg, 521 U.S. 702, 735 (1997).

<sup>&</sup>lt;sup>12</sup> <u>Lee v. Oregon</u>, 107 F.3d 1382 (9th Cir.), <u>cert. denied</u>, 522 U.S. 927 (1997).

<sup>13</sup> See, e.g., Hearings before the Oregon Senate Committee on Health Insurance and Bioethics on SB1141 (April 30, 1991) (statement of Richard A. Wise, ACLU of Oregon) (stating that individuals should have the right to control their own bodies and lives so long as they don't harm anyone else and that society should intervene only to make sure that the person has considered all other options) (statement of Peter Goodwin, Department of Family Medicine, Oregon Health

In contrast, by unilaterally issuing his directive without providing an opportunity for public comment, the Attorney General is attempting to nullify the Oregon Act without affording the people of Oregon the opportunity to voice their needs and concerns. Had he sought public comment prior to issuing the directive, many people with terminal illnesses and other people with disabilities, including Amici, would have helped to explain why this law is so important. Instead, by reversing his predecessor's standing directive without formal notice or opportunity to comment, the Attorney General ignored the basic precept "that the public interest is served by a careful and open review of the proposed administrative rules and regulations." The Attorney General's actions do not represent the will of the people directly affected by the Oregon Act, and should not be permitted to usurp the sovereign authority of the state of Oregon.

1. The Public Interest Is Better Served By Continuing To Permit Physicians to Use Those Medications Necessary To Allow Their Patients With Terminal Illnesses To Exercise Their Liberty Interest

Prohibiting physician assistance in dying for terminally ill individuals will not serve the public interest. In most cases, such governmental interference will only prolong pain and suffering on the part of terminally ill individuals and their

Sciences University) (stating that the time has come to address this issue because individuals need a process for making life-ending requests).

<sup>14 &</sup>lt;u>See Philadelphia Citizens in Action v. Schweiker</u>, 669 F.2d 877, 881 (3d Cir. 1982).

families, who will be forced to bear witness to the slow and agonizing death of their loved ones. In other cases, such a prohibition will not prevent terminally ill people from taking their lives at all; it will merely force them to do so without the help of physicians.

In contrast, permitting physician-assisted dying under the Oregon Act benefits our nation. An important attribute of our federalist system is that, in the absence of a valid and constitutional federal regulation, individual communities are left free to experiment with solutions to the difficult problems that confront our society from time to time. See New State Ice Co. v. Liebmann, 285 U.S. 262, 311 (1932) ("It is one of the happy incidents of the federal system that a single courageous state may, if its citizens choose, serve as a laboratory, and try novel social and economic experiments without risk to the rest of the country.") (Brandeis, J., dissenting). The Supreme Court has expressly recognized the rights of states to conduct this experiment in the field of physician-assisted dying. The Attorney General seeks to end this democratic process at its inception, thereby impeding the potential for progress in the field of end-of-life care for all Americans.

2. Available Data Demonstrate That A Substantial Majority Of People With Disabilities Supports The Right Of Terminally Ill Individuals To Hasten Death With The Assistance Of Their Physicians

When considered in aggregate, the available data demonstrate that a substantial majority of people with disabilities supports the right to assisted dying for terminally ill individuals. Studies show that between 63% and 90% of people with terminal illnesses support the right to physician-assisted dying and want this choice available to them. <sup>15</sup>

A recent in-depth study of 45 individuals with disabilities suggests that, among people with disabilities, a "[t]remendous breadth and diversity of opinion exists with respect to attitudes toward death with dignity legislation." Virtually all respondents advocated self-determination and autonomy in how people with disabilities live and die. Disturbingly, many respondents indicated that they felt significant social pressure not to support the right to assisted dying, and many received misleading information from opponents of this right.

Disability on the Right to Assisted Suicide, 6 Psych. Pub. Pol'y L., at 552-53 (citing W. Breibart et. al., Interest in Physician Assisted Suicide Among Ambulatory HIV Infected Patients, 153 Am. J. Psychiatry, 238-42 (1996), B. Trindall et al., Attitudes to Euthanasia and Assisted Suicide in a Group of Homosexual Men with Advanced HIV Disease, 6 J. of Acquired Immune Deficiency Syndrome, 1069 (1993)).

<sup>&</sup>lt;sup>16</sup> Pamela Fadem et al., <u>Attitudes of People with Disabilities Toward Death with Dignity/Physician Assisted Suicide Legislation: Broadening the Dialogue</u> (2001).

The most recent Harris poll data from December 2001 provide the most compelling evidence that a substantial majority of Americans with disabilities support the right to assisted dying generally and the Oregon Act in specific.<sup>17</sup> It found that Americans with disabilities support the right to physician-assisted dying by a margin of more than two-to-one. Specifically, 68% of adults with disabilities believe "the law should allow doctors to comply with the wishes of a dying patient in severe distress who asks to have his or her life ended." Sixty-eight percent of people with disabilities who were read a description of Oregon's assisted dying law indicated that they favored implementation of such a law in their own state.<sup>18</sup>

While individual rights and civil liberties should not depend exclusively on the will of the majority, the fact that individuals with disabilities support the Oregon Act is notable for two reasons. First, it indicates that the state of Oregon is not forcing its will on persons with disabilities. Second, the substantial support for the Act by individuals with disabilities suggests that the Act reinforces, rather than detracts from, their autonomy interests.

<sup>17</sup> See http://www.harrisinteractive.com/harris poll/index.asp?PID=278

http://www.harrisinteractive.com/harris\_poll/index.asp?PID=278

Interestingly, based on the results of the 2001 Harris survey, the support among the disability community for the right to assisted dying is even slightly higher than support among the general population, which is still a substantial majority of 61%. See

# THE OREGON ACT STRIKES THE APPROPRIATE BALANCE BETWEEN THE INTERESTS OF TERMINALLY ILL INDIVIDUALS AND THE LEGITIMATE INTERESTS OF THE STATE WITHOUT DENYING PERSONS WITH DISABILITIES ANY RIGHTS OR PROTECTIONS UNDER FEDERAL LAW

The people of Oregon drafted the Oregon Act to recognize and balance the twin interests enunciated by Justice O'Connor in <u>Glucksberg</u> -- those of terminally ill persons in ending their suffering and those of the state in protecting individuals who might seek to end their lives mistakenly or under pressure. To protect individuals with disabilities who may be vulnerable to discrimination, coercion, and mistake, the people of Oregon narrowly tailored the Act to ensure that the touchstone of a request for life-ending medication is terminal illness accompanied by imminent death, and not disability generally. In contrast, government interest in preserving life is minimal under these circumstances because of the short amount of life left for terminally ill individuals.

A. The Death With Dignity Act Is Narrowly Drawn So That Only Individuals With Terminal Illnesses May Avail Themselves Of Its Provisions

The Oregon Act permits terminally ill individuals the opportunity to request and receive from their physicians a prescription for medication that they may use, at their own discretion, to hasten imminent death in a "humane and dignified manner." Or. Rev. Stat. § 127.805. The Act expressly provides that "[n]o person

<sup>&</sup>lt;sup>19</sup> See Glucksberg, 521 U.S. at 735.

shall qualify under the provisions of [the Act] solely because of age or disability." Or. Rev. Stat. § 127.805. The drafters narrowly tailored the Act to ensure that only competent adults with terminal illness, and <u>not</u> people with general non-terminal disabilities, will be able to avail themselves of the Act. If a person with a disability (<u>e.g.</u>, spinal cord injury) is in the terminal stage of an illness (<u>e.g.</u>, cancer), she can avail herself of the Oregon Act; if she is not in the terminal stage of an illness, she cannot.

There are significant differences between the effect of loss of mobility or bodily functions on independence in the case of a person with a stable disability and this loss of independence in a terminally ill person. Many people with disabilities maintain very independent lifestyles despite major physical limitations. Although their lives may not be easy, most individuals with disabilities adjust to their disabilities and maintain what they assess as a high quality of life.<sup>20</sup>

Terminally ill individuals, however, face very different challenges.

Debilitating terminal illnesses often result in a rapid deterioration of physical capabilities that may present increasing frustration and limitations with each day that passes, culminating in death.<sup>21</sup> This deterioration, often accompanied by extreme pain and the lack of any hope for recovery, puts terminally ill individuals

<sup>&</sup>lt;sup>20</sup> See discussion of disability rights movement, *supra*, 6-8.

<sup>&</sup>lt;sup>21</sup> <u>See</u> Dr. Timothy Quill, <u>Ashcroft's Ruling Usurps States' and Voters'</u> <u>Rights</u>, Rochester Dem. Chron., Dec. 12, 2001

in a very different situation from individuals with disabilities, who have long lives ahead of them. Those who oppose the right to physician-assisted dying based on concerns about individuals with non-terminal conditions (i.e., stable disabilities) tend to incorrectly equate these two very different situations.

Due to the rigorous procedures for obtaining a prescription under the Oregon Act, the rights granted to terminally ill individuals in Oregon are even less prone to abuse than the rights of individuals seeking palliative care or withdrawal of life support in other states.<sup>22</sup> Under the Oregon Act, physicians may grant a prescription only to an individual who satisfies the Act's narrow criteria, and only after the individual completes an extensive approval process.<sup>23</sup> Compared with aggressive palliative care, which is legal and in many states results in *de facto* physician-assisted dying, the Oregon Act has substantially more procedures for

<sup>&</sup>lt;sup>22</sup> <u>See</u> Hastings Center Report, <u>Vitalism Revitalized: Vulnerable</u> <u>Populations, Prejudice, and Physician-Assisted Death</u> at 31 (arguing that "right-to-die" legislation does not increase risk of premature death for individuals with disabilities because legislation such as the Oregon Act provides additional safeguards not currently in place when patients elect to forego life-prolonging treatment).

Only competent adults with less than six months to live may request a prescription, and they must make two oral requests separated by at least 15 days, as well as one written request signed by two witnesses. At this point, two physicians must confirm the diagnosis and prognosis and refer the individual for a psychological examination if they believe the patient's judgment is impaired. In addition, the prescribing physician must inform the individual of other feasible alternatives to hastening death, and request that the individual notify her next-of-kin of the request. In 1999, an additional safeguard was added to the legislation, requiring that the pharmacist be notified of the purpose of the prescription, providing a final check by an objective party. Or. Rev. Stat. §§ 127.800-127.897.

evaluating the individual's capacity and respecting the individual's wishes. A person eligible for assistance under the Oregon Act is even less likely to be abused or taken advantage of than a person in a coma or permanent vegetative state. A person seeking physician assistance in dying under the Oregon Act must be conscious and able to make an independent decision, whereas families of comatose or otherwise vegetative individuals may withdraw life support while the patient is unconscious and unable to express his desires.<sup>24</sup> Moreover, the Oregon Act requires each prescribing physician to inform every individual requesting a prescription of additional options for end of life care, to ensure that each individual's request is in fact a choice and not a decision forced upon him for lack of other options.

Although any legal right can be abused, there is no reason to believe that the Oregon Act will be extended to persons or situations for which it was not intended. Well-crafted legislation provides adequate safeguards to prevent the rights it grants from being used for unintended purposes, and the Oregon Act does just that. Indeed, In the first four years of its existence, the Act has been used infrequently. In 2001, an estimated 7 out of every 10,000 deaths in Oregon resulted from the ingestion of medications prescribed under the Act. Data from previous years

<sup>&</sup>lt;sup>24</sup> <u>See</u> Kathryn Tucker, <u>The Death with Dignity Movement: Protecting</u> <u>Rights and Expanding Options after Glucksberg and Quill</u>, 82 Minn. L. Rev. 923,

provide similar percentages. <sup>25</sup> The Act's precise definitions of who can request a physician's assistance in hastening imminent death, together with its substantial procedural requirements for the fulfillment of a request, ensure that the Act will be used only for its intended purpose.

1. There Is No Evidence That People With Disabilities Have Been Harmed In Any Way Under The Oregon Act

Given its strict provisions, it is not surprising that there have been no known instances of discrimination against people with disabilities under the Oregon Act.

Nor is there any evidence of any abuse occurring under the Act during its first four years. Detailed reports of the Act's procedures and results have been published since its inception, and the fierce scrutiny of the Act by its opponents offers assurance that any misuse of the Act's provisions would not have gone unnoticed.

931 n.41(1998); David Orentlicher, <u>The Supreme Court and Terminal Sedation</u>, 24 Hastings Const. L.O. 947 (1997).

Fourth Annual Report on Oregon's Death With Dignity Act at 9 (Feb. 6, 2002) (http://www.ohd.hr.state.or.us/chs/pas/ar-index.htm).

Rights, Rochester Dem. Chron., Dec. 12, 2001; Fourth Annual Report on Oregon's Death With Dignity Act (Feb. 6, 2002). Opponents of the Oregon Act also equate the hastened deaths that may occur under the Act with a wide variety of illegal physician-assisted deaths that have occurred in other jurisdictions. The examples used, ranging from the forced "euthanasia" program employed by the Nazis, to the controversial actions of Dr. Kevorkian (whose acts violated the laws of the states where he practiced and typically would have violated the Oregon Act as well), are not relevant to the function, purpose, and reality of the Oregon Act, and the Court should be careful not to allow opposing amici to confuse these very different situations.

The Act requires the Oregon Health Division ("OHD") to develop a reporting system for monitoring and collecting information on hastened deaths under the Act.<sup>27</sup> The legislature created this monitoring requirement in order to evaluate concerns that the option of physician-assisted dying would be used disproportionately by the poor, uneducated, uninsured or otherwise disadvantaged people. After four years, the OHD annual reports offer no indication that the Act has resulted in discrimination against people with disabilities. In fact, the OHD data have consistently shown that individuals who hasten their imminent death under the Act are demographically comparable to other Oregonians dying of similar diseases.<sup>28</sup> The only notable demographic difference is that those who have sought assistance under the Act have tended to be more educated than those who do not, placating concerns that people will choose to hasten their deaths under the Act due to ignorance of other options for dealing with the end of life.<sup>29</sup>

Pursuant to this requirement, the OHD requires each physician who writes a prescription for lethal medication to submit information documenting his or her compliance with the law. The OHD then reviews all physician reports and contacts physicians if any data is missing. The OHD collects the death certificates that correspond to the physicians' reports to confirm that the deaths actually occurred and to collect demographic information about the patients. For the third and fourth year reports, the OHD also conducted telephone interviews with all of the prescribing physicians. Oregon's Death with Dignity Act. See Three Years of Legalized Physician Assisted Suicide at 8 (Feb. 2001); Fourth Annual Report at 7 (Feb. 6, 2002).

The most common underlying illness is cancer (86% in 2001), followed by heart and lung disease. Fourth Annual Report, Table 1 (Feb. 6, 2002).

<sup>&</sup>lt;sup>29</sup> People with a college education were eight times more likely to seek assistance in dying than people without a high school education. Patients with

Information gathered from prescribing physicians indicates that people who choose to request physician assistance in hastening death tend to be knowledgeable and demanding. "When you talk to doctors, what comes through is, this is an unusual group of people. They place a high value on control and independence. Compromise is not in their vocabulary. Nobody who knows them is surprised by the request."<sup>30</sup>

There is substantial agreement that the health care treatment of individuals with disabilities is often far from perfect. Imperfections in the system, however, provide no legitimate basis for denying the right of persons in the terminal stage of illness to control the final phase of their lives. The people of Oregon took these imperfections into consideration when drafting the Act and enacted a law with extensive procedural safeguards to protect potentially vulnerable groups. In the absence of any evidence of abuses during the first four years of the Oregon Act's existence, this Court should accept the Oregon Act for what it is -- a careful, responsible piece of legislation that creates rights without causing harm to any vulnerable groups of people.

post-baccalaureate education were 19 times more likely to seek assistance than people without a high school education. Three Years of Legalized Physician Assisted Suicide at 4.

<sup>&</sup>lt;sup>30</sup> See Susan Okie, "I Should Die the Way I Want To": Oregon Doctors, Patients Defend Threatened Assisted Suicide Law, Wash. Post, Jan. 1, 2002 (citing survey conducted by Linda Ganzini, professor of psychiatry at the Oregon Health Services University).

## 2. The Oregon Act Is Consistent With The ADA and Federal Law

As noted above, overarching goal of the disability rights movement is to help people with disabilities achieve autonomy and independence in all aspects of their lives. Until recently, however, a paternalistic attitude towards people with disabilities was prevalent in our society, and many people with disabilities were forced to cede control of their lives to other people, often to their detriment.

Through the bipartisan enactment of the ADA, our nation developed a consensus that competent adults with disabilities can and should exercise control of their lives in the mainstream of our society.<sup>31</sup>

Consistent with the disability rights movement's goal of autonomy for its constituents is the right to control one's own death when it is imminent.<sup>32</sup> While Amici certainly do not dispute that prejudice and discrimination exist among physicians and within the medical community, the Oregon Act does not give the decision-making power to physicians. In fact, precisely the opposite is true: the

Practice (Jane West ed., 1991); Implementing The Americans With Disabilities

Act (Jane West ed., 1996); Mark Nagler, Perspectives On Disability (2d ed. 1993);

Implementing The Americans With Disabilities Act: Rights And Responsibilities

Of All Americans (Lawrence O. Gostin & Henry A. Beyer eds., 1993).

<sup>&</sup>lt;sup>32</sup> The argument that the Oregon Act discriminates against people with disabilities by denying them the protection of suicide prevention laws and medical practice standards afforded non-disabled persons in violation of the ADA and the Equal Protection Clause is entirely without merit. *Specifically, nothing in the Oregon Act denies anyone any rights under the Constitution, the ADA, or any other law.* The Oregon Act grants rights to people with terminal illnesses; it does not grant rights or deny rights on the basis of disability generally.

Act empowers dying persons with terminal illnesses to make decisions about their own fates. This is consistent with the goal of individual autonomy that the disability rights movement has been working toward since its inception. The Oregon Act grants an additional end-of-life option to individuals with terminal illness without discriminating against people with disabilities, thereby increasing the individual autonomy of all Oregonians without compromising any rights already guaranteed under federal law.

B. When Weighed Against The Liberty Interests At Stake, Government Interests Are Minimal In Cases Of Physician Assisted Dying Under the Oregon Act

For the reasons discussed above, terminally ill individuals have an extremely significant interest in maintaining autonomy in making end-of-life decisions. In contrast, the federal government's interests in preventing physician-assisted dying are minimal. While the state has a legitimate interest in preserving life, that interest diminishes as the potential for life diminishes. Garger v. New Jersey, 429 U.S. 922 (1976); In re Quinlan, 355 A.2d 647, 664 (N.J.), cert. denied, 429 U.S. 922 (1976). The Oregon Act is implicated only in the case of an individual who, based on reasonable medical judgment, has less than six months of life left to live. At this point, the dying patient's interest in controlling the time and manner of her death is at its maximum, and the government's interest in preserving that life is minimal. However, the government always maintains a great interest in ensuring

that the patient's wishes are protected, an interest that is maintained right up to the moment of death.

When physically healthy people attempt suicide, the government has an interest in intervening based on the possibility that such actions may be the product of mental illness. However, the only legitimate governmental interest in preventing terminally ill individuals from controlling the circumstances of their own deaths is an interest in preventing abuses of this policy that might result in violations of other rights. The Oregon Act already protects this interest with exactly the type of narrowly tailored restrictions that due process envisions, i.e., procedural safeguards ensuring that the people making this decision are fully informed, fully competent, and not under any coercion. See discussion infra II.A. Because the government's minimal interests are accommodated by the protections of the Act, the relative balance of interest in the case of patients seeking to hasten death under the Oregon Act is clearly in favor of the patient.

## **CONCLUSION**

On behalf of the people with disabilities whose interests we represent, Amici respectfully request that this Court affirm the decision below.

Dated: November 12, 2002 LANDYE BENNET & BRUMSTEIN LLP

By:\_\_\_\_

Thane W. Tienson 3599 Wells Fargo Center Portland, OR 97201 (503) 224-4100

CLEARY, GOTTLIEB, STEEN & HAMILTON Richard F. Ziegler One Liberty Plaza New York, New York 10006 (212) 225-2000

Attorneys for *Amicus Curiae* AUTONOMY, Inc. *et al*.

## **CERTIFICATE OF COMPLIANCE**

Pursuant to Fed. R. App. P. 29(d) and 9th Cir R. 32-1, the attached amicus brief is proportionately spaced, has a typeface of 14 points or more and contains 7000 words or less, inclusive of all headings, footnotes, and quotations. The word count was generated by using the word-processing system used to prepare this Brief pursuant to Rule 32(a)(7)(C).

Date: November 12, 2002

Thane W. Tienson

# **APPENDIX I**

PERSONAL STATEMENTS