

STATE OF WISCONSIN
IN SUPREME COURT

Case No. 2014 AP 135

DISABILITY RIGHTS WISCONSIN,
Plaintiff-Appellant-Petitioner,

v.

UNIVERSITY OF WISCONSIN HOSPITAL AND CLINICS, DONNA KATEN-BAHENSKY,
UW SCHOOL OF MEDICINE AND PUBLIC HEALTH, BOARD OF REGENTS OF THE
UNIVERSITY OF WISCONSIN SYSTEM AND KEVIN P. REILLY,
Defendants,

GREGORY P. DEMURI, M.D., MARGO HOOVER-REGAN, M.D., NORMAN FOST, M.D.,
JIM MUEGGENBERG, M.D. AND JULIA WRIGHT, M.D.

Defendants-Respondents.

AMICUS CURIAE BRIEF IN SUPPORT OF PETITION FOR REVIEW OF THE AUTISTIC
SELF ADVOCACY NETWORK, NOT DEAD YET, ADAPT, AMERICAN ASSOCIATION OF
PEOPLE WITH DISABILITIES, ASSOCIATION OF PROGRAMS FOR RURAL
INDEPENDENT LIVING, AUTISM WOMEN'S NETWORK, BAZELON CENTER FOR
MENTAL HEALTH LAW, NATIONAL ASSOCIATION OF THE DEAF, NATIONAL
COUNCIL ON INDEPENDENT LIVING, NATIONAL DISABILITY RIGHTS NETWORK,
QUALITY TRUST FOR INDIVIDUALS WITH DISABILITIES, UNITED SPINAL
ASSOCIATION, AND WISCONSIN BOARD ON DEVELOPMENTAL DISABILITIES

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ARGUMENT IN SUPPORT OF REVIEW

A. The Long History of Disability-Based Deprivation of Medical Treatment Argues for Granting the Petition for Review.

The Circuit Court's determination — that people with disabilities have no rights under the Wisconsin Constitution in the context of decisions to withdraw life-preserving medical treatment — raises critical human rights concerns that merit review by this Court. Individuals with disabilities have experienced a long history of deliberate deprivation of medical care for the purpose of hastening death, often over the explicit objection of the individuals and those who are most familiar with their lives. By holding that state-employed physicians can deliberately bring about the death of an individual with a disability by withholding appropriate treatment that they would have routinely provided to similarly situated, non-disabled patients, the Circuit Court has denied justice to a large number of individuals with disabilities whose lives have been, or will be, cut short as a result of disability bias.

Such conduct is directly at issue in this case. Patient 1 was a teenaged boy with developmental disabilities who lived in a nursing facility. He had a history of swallowing difficulties that at times led to respiratory infections and pneumonia, but with appropriate treatment he had recovered each time. Defendant Hoover-

Regan, in consultation with Dr. Fost and Patient 1's parents, developed a plan to withhold *all* medical care the next time Patient 1 fell ill. Under the plan, Patient 1 would be deprived of not only antibiotics or other medications to treat his immediate symptoms, but also of food and water. Defendants' plan to withdraw care was based not on the belief that such care would be futile or ineffective. Instead, they planned to withdraw medications because they believed they *would* be effective at prolonging his life and that Patient 1's life was not worth living as a result of his disability.¹ Defendants failed to seek guidance on whether Patient 1's guardians had the legal authority to order withdrawal of treatment, particularly in light of the fact that Patient 1 was neither diagnosed with a terminal illness nor in a persistent vegetative state.

When Patient 1 developed signs of suspected pneumonia, the staff at the facility where Patient 1 lived refused to withhold antibiotics, food, and water. Unlike Defendants or even Patient 1's parents, facility staff interacted with Patient 1 on a daily basis and disagreed that Patient 1's quality of life was poor. Defendants arranged to have Patient 1 transferred to the University of Wisconsin Hospital Center for the purpose of withdrawing medications, food, and water and

¹ Numerous studies have shown that nondisabled individuals, including doctors, routinely underestimate the "quality of life" of people with disabilities in comparison with those individuals' own assessments of their quality of life. See Sam Bagenstos, *Hedonic Damages, Hedonic Adaptation, and Disability*, 60 VANDERBILT L.J. 745, 749 (2007).

transferring him to hospice care. Within a day of his transfer, Patient 1—dehydrated, ill, and dosed with morphine—stopped breathing and died.

Defendants repeated this process two years later when Defendant Wright encouraged the family of Patient 2 – a woman with developmental disabilities who also had a respiratory infection – to withdraw routine antibiotic treatment for the purpose of causing death. As with Patient 1, this decision was based on Defendants’ assumptions about Patient 2’s quality of life as a person with a disability, without any input from Patient 2 herself or from the people who interacted with her every day. Fortunately, Patient 2 began to recover on her own, prompting her family to resume treatment. Even after her family resumed treatment, however, Defendant Wright continued to insist on placing Patient 2 in hospice care despite the fact that she was suffering from a terminal illness.

Withdrawal of medical treatment, food, and water from people with disabilities for the purpose of causing or hastening death – even when the person with a disability is conscious and objects to withdrawal of treatment – is disturbingly common. In a recent report, the National Disability Rights Network (“NDRN”), an association of Protection and Advocacy organizations such as Disability Rights Wisconsin, discussed numerous cases in which doctors or guardians withheld potentially lifesaving medical care from people with disabilities who were neither

dying nor in a pervasive vegetative state or coma.² Both exemplars in this action were included in NDRN's report.³

Many of the individuals discussed in NDRN's report gained access to medical treatment as a result of the intervention of their state Protection and Advocacy organization. For example, the North Dakota Protection and Advocacy Project successfully helped one man with end-stage liver disease fight against his guardian's imposition of a "no code," which barred doctors from providing lifesaving care in the event of a medical emergency. The individual strongly objected to the "no code," but it was only after legal advocacy by the Protection and Advocacy organization that it was lifted.⁴ Fortunately, legal intervention occurred before any medical emergency.

As in the case of Patient 1, however, withdrawal of lifesaving treatment can cause death within hours or days and well-before a legal challenge of the withdrawal can be mounted. Patient 1 was a teenager with a curable infection who died less than 24 hours after he was withdrawn from antibiotics, nutrition, and hydration. Even though the nursing staff who interacted with him every day

² NATIONAL DISABILITY RIGHTS NETWORK, DEVALUING PEOPLE WITH DISABILITIES: MEDICAL PROCEDURES THAT VIOLATE CIVIL RIGHTS 17, 26-30 (2012), available at http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf.

³ *Id.* at 17.

⁴ *Id.* at 28.

voiced strong objections to withdrawal of care, there was no meaningful opportunity for legal advocates to intervene and enforce Patient 1's rights.

B. The Petition for Review Raises Important Questions of Self-Determination in Medical Contexts and the Limits of Guardians' Authority to Refuse Life-Preserving Care.

At the heart of many withdrawal-of-care cases is the right to self-determination of people with disabilities. Both plaintiffs in these cases were individuals with disabilities who, due to disability, minority, or both, were considered incapable of making decisions about their own medical care. As a result, the decision to withdraw medical treatment was made by legal guardians. However, Defendants made no effort to determine the wishes of the wards themselves or to ensure that the guardians actually had the legal authority to request withdrawal of treatment.

In part due to widespread under-treatment of people with disabilities, state and federal courts have long recognized limitations on parents' and guardians' authority to withhold medical treatment from people with disabilities. As NDRN notes, these limitations stemmed from recognition that doing what parents, guardians and care providers deemed was in the best interest of an individual with a disability often conflicts with the expressed interests of the individual or is based on incorrect assumptions about the person's disability.⁵ Studies have shown that

⁵ *Id.* at 14.

nondisabled individuals often dramatically underestimate the quality of life of people with disabilities in comparison with disabled individuals' own ratings of their quality of life.⁶ Acknowledging these same concerns, the Wisconsin Supreme Court recognized in 1981 that:

Those who normally would speak for the incompetent — parents, guardians, or even social workers — may in actuality speak, consciously or unconsciously, in their own interests: Diminished worry, convenience, a wish to be relieved of responsibility for close supervision, or frustration at their inability to deal with a most difficult problem.

Eberhardy v. Circuit Court for Wood County, 102 Wis.2d 539, 573 (Wis. 1981).⁷

Disability rights experts and medical ethicists overwhelmingly agree that there must be some legal limits to the authority of parents and guardians to withhold medical treatment from people with disabilities. Even Dr. Fost, one of the physician defendants in this action, has acknowledged that parents or guardians of people with disabilities should not enjoy complete discretion to withhold medical care.⁸

Although Wisconsin law acknowledges limits on guardians' authority to make life-or-death decisions on behalf of the people entrusted to their care, the Appeals

⁶ Bagenstos, *supra* note 1.

⁷ Less than two years ago, the Supreme Court of Wisconsin also recognized that parents and guardians lacked absolute authority to refuse lifesaving medical treatment for their non-disabled children. *Wisconsin v. Neumann*, 832 N.W.2d 560, 592 (Wis. 2013).

⁸ Norman Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 CRITICAL CARE CLINICS 145, 155-156 (1986), available at <https://mywebspace.wisc.edu/rstreiffer/web/CourseFolders/MHB558S06/Fost%20-Treatment%20of%20Critically%20Ill%20Newborns.pdf>.

Court held that third parties — such as doctors and hospitals — are not bound to recognize these legal limitations. Such a holding effectively nullifies the protections the Wisconsin Supreme Court intended to create when it recognized limitations on guardians’ authority. Depending on the nature of a person’s health condition, people may die within minutes, hours, or days of the decision to withhold or withdraw treatment – long before social services or law enforcement could be notified or conduct an investigation into whether the decision was consistent with the patient’s expressed wishes and/or within the scope of the decision-maker’s authority. Patient 1 died less than one day after UWHC staff removed him from artificial nutrition and hydration, before Disability Rights Wisconsin could intervene to protect his rights. If the North Dakota man discussed in NDRN’s report had experienced a medical emergency while the North Dakota Protection and Advocacy Project was still working to have the “no code” removed from his medical record, he could have died before it was lifted.

The Appeals Court’s decision also failed to take into account the significant and active role that the state-employed physician Defendants took in advising the patients’ families to withdraw basic care for the purposes of ending the patients’ lives and in designing and implementing “comfort care” plans. Families and guardians rely on physician recommendations when making medical decisions on behalf of their loved ones. Indeed, in his article discussing end-of-life decision-making regarding children with disabilities, Fost acknowledged that public support

for ending the lives of children with disabilities by withdrawing artificial nutrition and hydration is “largely affected by the support of physicians and hospitals” for such a course of action.⁹ In the case of Patient 1, Defendants even facilitated the transfer of the patient to the hospital from a facility that had been providing Patient 1 with food, water, and medication, for the express purpose of withdrawing treatment.

In light of the active role the state-employed physician Defendants played in encouraging and enabling the patients’ guardians to withdraw care, it is crucial that the Court recognize their concurrent obligation to avoid using their authority in a manner that is in conflict with patients’ constitutional, civil and other legal rights. At the very least, state-employed doctors should have an obligation to determine the scope of guardians’ legal authority before implementing a course of action, and should not use their position at a state-run facility to persuade parents, guardians, and families to acquiesce in an unlawful course of action. Otherwise, people with disabilities will lack any legally enforceable right to be free from unlawful decisions made on their behalf without their consent.

⁹ See generally Norman Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 CRITICAL CARE CLINICS 145, 154 (1986), available at <https://mywebspaces.wisc.edu/rstreiffer/web/CourseFolders/MHB558S06/Fost%20-Treatment%20of%20Critically%20Ill%20Newborns.pdf>.

CONCLUSION

Based on all the foregoing, and in conjunction with the arguments presented in Appellant's Petition for Review, *amici* Autistic Self Advocacy Network, Not Dead Yet, ADAPT, American Association of People with Disabilities, Association of Programs for Rural Independent Living, Autism Women's Network, Bazelon Center for Mental Health Law, National Association of the Deaf, National Council on Independent Living, National Disability Rights Network, Quality Trust for Individuals with Disabilities, United Spinal Association, and Wisconsin Board on Developmental Disabilities respectfully request that the court grant Disability Rights Wisconsin's petition for review.

Dated this 26th day of January, 2015.

Respectfully submitted,

BY:

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Attorneys for Amici

CERTIFICATION

I hereby certify that this brief conforms to the rules contained in Wis. Stat. § 809.19(8)(b) and (c) for a nonparty brief. The length of this brief is 1,910 words.

Dated this 26th day of January, 2015.

Signed:



Samantha Crane
Attorney *pro hac vice*

Roy Froemming
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**CERTIFICATION OF COMPLIANCE WITH
RULE 809.19(12)**

I hereby certify that I have submitted an electronic copy of this brief, excluding the appendix, if any, which complies with the requirements of Wis. Stat. § 809.19(12). I further certify that this electronic brief is identical in content and format to the printed form of the brief filed as of this date.

A copy of this certificate has been served with the paper copies of this brief filed with the court and served on all opposing parties.

Dated this 26th day of January, 2015.

Signed:

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