

IN THE SUPREME COURT OF MISSOURI

No. SC89416

ANDREA BECHTEL, by her next friend BARBARA BECHTEL,

Petitioner - Appellant,

v.

DEPARTMENT OF SOCIAL SERVICES, STATE OF MISSOURI,

Respondent.

**On Appeal from the Circuit Court of St. Louis County
Honorable Robert S. Cohen**

REPLY BRIEF OF APPELLANT

**AMERICAN CIVIL LIBERTIES UNION OF
EASTERN MISSOURI**

Anthony E. Rothert, #44827
454 Whittier Street
St. Louis, Missouri 63108
(314) 652-3114
(314) 652-3112 Facsimile

SINDEL & EMMEL
Nancy E. Emmel, #32524
7711 Bonhomme, Ste. 815
Clayton, Missouri 63105
(314) 727-5533
(314) 727-5464 Facsimile

Attorneys for Petitioner-Appellant
ORAL ARGUMENT REQUESTED

TABLE OF CONTENTS

TABLE OF AUTHORITIES	2
ARGUMENT	4
CONCLUSION	25

TABLE OF AUTHORITIES

CASES

Hargrave v. Vermont,

340 F.3d 27 (2d Cir. 2003) _____ 19

McJunkin v. McJunkin,

896 So.2d 962 (Fla.App. 2005) _____ 17

PGA Tour, Inc. v. Martin,

532 U.S. 661 (2001) _____ 12

School Bd. of Nassau County, Fla. v. Arline,

480 U.S. 273 (1987) _____ 12

Tennessee v. Lane,

541 U.S. 509 (2004) _____ 18

Wong v. Regents of the University of California.,

192 F.3d 807 (9th Cir. 1999) _____ 22, 23

STATUTES

42 U.S.C. § 12101 _____ 18

RSMo § 178.661 _____ 14

RSMo § 178.666 _____ 14

RSMo § 208.900 _____ 4, 8

RSMo § 208.152 _____	8
RSMo § 475.010 _____	13
RSMo § 475.050 _____	17
RSMo § 475.079 _____	13
RSMo § 475.120 _____	16
RSMo § 475.336 _____	16
REGULATIONS	
28 C.F.R. § 35.130 _____	12, 21
5 C.S.R. § 90-7.100 _____	14
13 C.S.R. § 70-91.010 _____	<i>passim</i>
19 C.S.R. § 15-8.100 _____	9
19 C.S.R. § 15-8.200 _____	10
19 C.S.R. § 15-8.300 _____	5
19 C.S.R. § 15-8.400 _____	7

ARGUMENT

I. SECTION 208.900.1 VIOLATES FEDERAL ANTI-DISCRIMINATION LAWS BECAUSE THE ALTERNATE PROGRAM FROM WHICH ANDREA MIGHT RECEIVE SOME SERVICES IS NOT EQUAL, THE STATE MUST ASSESS WHETHER ANDREA AS AN INDIVIDUAL IS ABLE TO SELF-DIRECT CARE WITHIN THE PROGRAM'S PARAMETERS, AND THERE IS NO EVIDENCE THAT THE ACCOMODATION ANDREA SEEKS IS UNREASONABLE

In its brief before this Court, Respondent—for the first time in this case—asserts that the state has not really excluded Andrea Bechtel from receiving the personal care assistance she needs in her home; rather, the state has categorically removed all persons under guardianship from one program and placed them in a separate program.¹ Although excluded from the personal care program in which she successfully participated for more than

¹ In the case *sub judice*, the state merely argued that Andrea was ineligible to continue participating in the program because of RSMo § 208.900.1. L.F. 65-71. Andrea challenges the validity of the statute; she is not arguing the statute itself was interpreted or applied incorrectly.

five years, Andrea and other persons under guardianship might remain eligible for some personal care service under the MO HealthNet program.² The state claims the programs are equal. From these premises, the state urges that it is merely protecting Andrea from potential abuse.

Respondent's argument should fail because (a) federal disability anti-discrimination laws require equal opportunity, not merely the opportunity to join another, different program; (b) Andrea is entitled to an individualized assessment to show that she meets the essential requirements of the self-

² It is not clear that Andrea is even eligible for the MO HealthNet program. It appears she is not. The financial requirements to remain eligible are also not the same between the two programs. *Compare*, 13 CSR 70-91.010.1 (requiring proof of Medicaid eligibility under Title XIX of the Social Security Act) *with* 19 CSR 15-8.300.1 (excepting requirement of proof of Medicaid eligibility under Title XIX of the Social Security Act). The parties stipulated and the trial court found that Andrea does not qualify for Medicaid and is not eligible for personal care benefits from any other source. L.F. 75. If Andrea cannot participate in the MO-HealthNet program for financial reasons, then the state's arguments lose any plausibility they may have.

directed program because not having a guardian is not essential to the program; and (c) Andrea is entitled to a reasonable accommodation, if necessary, to continue her participation in the program.

A. Disqualification from the program under which Andrea was receiving personal care assistance coupled with allowing her participation in a separate program fails to provide her with equal opportunity

Assuming, *arguendo*, Andrea is eligible for the MO HealthNet program, its benefits are not equal to the program in which Andrea participated in previously. *See n.2, supra*. The state suggests that the only difference between the program from which Andrea was excluded starting in 2005 and the MO HealthNet program from which the state says she might receive benefits is that the former is consumer-directed while the latter is agency-directed.³ The separate programs, however, do not provide equal

³ Referring to the Personal Care Assistance program as consumer-directed and the MO HealthNet program as agency-directed is an inaccurate over-simplification. Both programs require joint supervision by both the agency and the consumer. The MO HealthNet program requires that the personal care plan be “developed in collaboration with and signed by the recipient,” and that the recipient (or another responsible person) sign daily to

benefits. Contrary to the state's claim, there has been a change in benefits, not merely in the method of supervising the benefits.⁴

confirm that the services have been received. 13 C.S.R. 70-91.010.1(B)(3), .4(A)(2)(F). MO HealthNet requires only one on-site supervisory visit per year to evaluate the worker's performance and the adequacy of the care plan; otherwise, the supervision is the monitoring of paperwork. 13 C.S.R. 70-91.010.3(H)(3). On the other hand, consumers are not left entirely to themselves in the Personal Care Assistance program. Vendors have responsibilities, including collecting timesheets and certifying their accuracy. 19 CSR 15-8.400.2.

⁴ Since the state has waited until its brief in this Court to argue that inclusion in a separate program is a sufficient accommodation of Andrea under the federal anti-discrimination statutes, there is no evidence in the record regarding whether the number of hours, quality of care, and number of services provided under the alternative program are equivalent. As demonstrated herein, they are not equal, as a matter of law. Nevertheless, the state ought not at this late date be permitted make a factual assertion of equality without the ability to point to any actual evidence in support of its claim.

One difference between the benefits offered by the respective programs is who can be the care provider paid by the state. Under the program in which Andrea participated before being excluded, the personal care attendant could be any person other than the consumer's spouse. RSMo § 208.900.6. Under the MO HealthNet program, which the state now claims could provide services, *no* family member can be the care provider. RSMo § 208.152.1(14); 13 C.S.R. 70-91.010(K)(4). This difference is very real for Andrea because her mother has been her life-long care provider. L.F. 74.

As the state itself admits, Andrea had a series of non-family care providers paid for by the state. It should not be surprising that a family member would be more likely to remain in a position of providing in-home care for an individual with significant physical disabilities at a nominal wage, than is a stranger who nets even less. This is not glamorous work, and it is not a remarkable observation that family members are more willing to provide this type of care on a long-term basis than strangers. Andrea and others with guardians are entitled to the same benefit the state offers to those without guardians: the stable care provided by a family member when it is appropriate and available. The Personal Care Assistance program's allowance of family member caregivers is more effective as well. For instance, although Andrea can talk, her articulation makes it difficult for

persons other than her mother to understand her. L.F. 52. Care will necessarily be better when the care provider can understand the wants and needs articulated.

There are additional differences in the benefits provided. Under the Personal Care Assistance program, for instance, Andrea would be eligible for assistance with any unmet shopping and transportation needs. 19 C.S.R. 15-8.100(O)(6). Andrea would not be provided this benefit in the MO HealthNet program into which the state now wishes to steer her.

The programs have different aims, so it is no wonder the extent of benefits is not the same. The Personal Care Assistance program provides assistance with “[a]mbulation, housekeeping, or other functions of daily living based on an independent living philosophy...” (19 C.S.R. 15-8.100(O)(8)), whereas the MO HealthNet program permits “[m]edically related household tasks, including approved homemaker and chore tasks.” 13 C.S.R. 70-91.010.2(B)(7). Such medically related care must be approved by a physician and the amount of services dictated by the level-of-care determination and assessment. 13 CSR 70-91.010.1(B)(1),(4). The personal care services offered under MO HealthNet are only those that are “medically-oriented.” 13 CSR 70-91.010.2. The Personal Care Assistance program is more flexible and intended to provide consumers with what it

takes for them to live independently, which is not the same as a program that provides medically necessary care. 19 CSR 15-8.200(4)(B)(2)(units of PCS “provided based on the consumer’s unmet needs” related to functions of daily living). Indeed, the program to which the state wishes to consign Andrea is not geared exclusively toward promoting independent living in the community but rather and is designed to provide medically necessary benefits not only to individuals in their homes but also in residential care facilities. 13 CSR 70-91.010 (“PURPOSE”).

Although the MO HealthNet program does not, in reality, provide equality, the state’s brief suggests how a program that addressed any concerns about the ability of persons under guardianship to self-direct their care under the Personal Care Assistance program would look. The state could, as it claims it does, merely provide for minimally increased agency supervision in those cases where an individual has limitations on the ability to self-direct as a result of mental disability but otherwise provide identical benefits. There is no evidence that doing so would alter the fundamental nature of the Personal Care Assistance program or be cost prohibitive. That might well be a reasonable accommodation, but it is not what the state has done here. The benefits provided—not merely the method of supervision—are different.

Based solely on Andrea being appointed a guardian, the state has removed the benefits of the Personal Care Assistance program in which she had successfully received services for more than five years and requires her to receive any benefits instead from a MO HealthNet program that provides different benefits. Unlike the existing program under which Andrea was receiving benefits, the MO HealthNet program is not an independent program designed to promote independent living for persons with severe disabilities by providing in-home assistance with unmet needs related to the performance of activities of daily living (whether medically related, or not). It is an entirely separate program with a different purpose and different benefits. The federal anti-discrimination statutes require the state to offer Andrea an equal opportunity to receive benefits; offering her instead the opportunity to participate in another program is not enough.

B. Andrea is entitled to an individualized assessment to show that she meets the essential requirements of the self-directed program

The state does not meaningfully explain why it should be excused from providing Andrea with an individualized assessment of her ability to self-direct the care provided in her home. The state has already repeatedly assessed Andrea's ability to self-direct and found that she *is* capable of self-

directing care; nevertheless, the state has decided that an entire category of people with mental disabilities cannot possibly self-direct their care.

The federal anti-discrimination statutes require an individualized assessment of whether a particular person can meet the requirements for participation in a program. *See* 28 C.F.R. § 35.130(b)(8) (requiring that for eligibility requirements that screen out handicapped individuals to be valid, they must be necessary for the provisions of the program); *see also School Bd. v. Arline*, 480 U.S. 273, 287 (1987) (Rehabilitation Act requires an individualized inquiry to determine an otherwise qualified candidate); *PGA Tour, Inc. v. Martin*, 532 U.S. 661, 690 (2001) (applying “the ADA’s basic requirement that the need of a disabled person be evaluated on an individual basis”).

Even under the arguments the state now advances, it is the alleged inability to self-direct care, *not* the appointment of a guardian, that the state uses to justify Andrea’s exclusion from the program in which she previously participated. But the use of guardianship as a proxy to determine the ability, or inability, to self-direct care is over-inclusive.⁵ It is over-inclusive in that

⁵ To the extent there is a legitimate state interest in discriminating amongst persons with disabilities, the use of guardianship as a proxy is under-inclusive as well. Even the person with the most serious mental and

the reasons for appointment of a guardian may have nothing to do with the ability to self-direct a personal care attendant in the home. A probate court is required to place an individual under guardianship if it finds the individual “incapacitated.” RSMo § 475.079.1. An individual is “incapacitated” when he is “unable by reason of any physical or mental condition to receive and evaluate information or to communicate decisions to such an extent that he lacks capacity to meet essential requirements for food, clothing, shelter, safety or other care.” RSMo § 475.010(9). A person may be placed under guardianship, for example, because of his inability to manage money or find appropriate housing. These limitations, sufficient to require appointment of a guardian, say nothing about an individual’s ability to self-direct care.⁶

While the requirement challenged in this case – *i.e.*, that a person not

physical disabilities may avoid being appointed a guardian if he has, for example, executed a power of attorney that allows decision to be made on his behalf or has family members who otherwise manage to meet his needs without appointment of a guardian.

⁶ The connection is even more attenuated when a person is removed from the program on the basis of having been appointed a conservator to make financial decisions and thereby irrebuttably presumed to be unable to self-direct care.

have a guardian – is new, the requirement of being able to self-direct care is not. *See* RSMo. § 178.661.7 (predecessor statute providing for participant-directed services), §178.666 (predecessor statute stating that client is responsible for direction of care attendant). During the more than five years Andrea participated in the program, her continued suitability for the program was assessed at least annually. *See* 5 CSR 90-7.100. There was no change in Andrea’s condition. The change was from an individualized assessment already required under the rules to a statutory blanket exclusion of all persons with guardians.

The state justifies its discriminatory treatment of persons with mental disability by assuring this Court that it is merely trying to protect persons with disabilities from abuse. The state accurately notes,

[P]eople with disabilities are 4 to 10 times more likely to become a victim of violence, abuse, or neglect than persons without disabilities. This victimization can occur anywhere; however, two of the most common places for victimization are in hospitals and at home. Victims usually know the person who harms them, and family members as well as personal home care aides have been

reported to perpetrate both emotional abuse and sexual violence against persons with disabilities.

Respondent's Brief at 15 (internal citations omitted). While it is an unfortunate fact that persons with disabilities are too often abused, this fact is not a legitimate basis for depriving a sub-group of disabled persons (*i.e.*, those with mental disabilities) the equal opportunity to participate in a program. The state points to no evidence that persons with mental disabilities are any more likely to be subjected to abuse than persons with physical disabilities, yet the state discriminates only against persons with mental disabilities by excluding them from the program. There is no empirical justification for the discrimination between persons with mental disabilities and persons with physical disabilities. To the extent the potential for abuse might justify requiring additional safeguards in Personal Care Assistance program, those safeguards must be implemented in a non-discriminatory manner.⁷

⁷ Persons with mental disabilities requiring appointment of a guardian, including Andrea, participated in the Personal Care Assistance program for many years. The state has presented not a shred of evidence that persons with mental disabilities have in fact been subject to abuse under the program or abused with any greater frequency than persons with only physical

Concerns about abuse also do not warrant the restrictions on who can act as caregiver. As discussed, *supra.*, Andrea is not allowed to have her mother and guardian as a caregiver under the MO HealthNet program although her mother was (and would be) permitted to provide care under the Personal Care Assistance program. While family members and in-home personal aides have too often been perpetrators of abuse, there is no evidence to suggest that replacing a family member with a non-family personal care aide decreases the likelihood of abuse.

The appointment of a guardian is itself a safeguard against abuse that should be encouraged in appropriate cases rather than discouraged by being grounds for elimination from a program. The probate court retains jurisdiction over the guardian and her ward and requires detailed reports from the guardian. RSMo § 475.336. A guardian is charged with, *inter alia.*, assuring that her ward receives medical care and other needed services as well as promoting and protecting her ward's care, safety, health, and welfare. RSMo § 475.120. Respondent's policy argument that it must eliminate persons with guardians from the Personal Care Assistance program is in direct conflict with the fundamental reason a guardian is appointed: to protect a vulnerable ward.

disabilities.

There is likewise no rational relationship between the elimination of benefits when one is moved from the Personal Care Assistance program to the MO HealthNet program and the proffered purpose of protecting persons under guardianship from abuse. The barring of family members as caregivers contradicts the probate statute's preference for family members as guardians. *See* RSMo § 475.050. The elimination of assistance with shopping and transportation also does nothing to protect a person with mental disabilities from abuse. Indeed, allowing persons with disabilities a means of getting out into the community and interacting with others is a prophylactic against the isolation that allows abuse to go undetected.

As other courts have noted, "In our present day paternalistic society we must take care that in our zeal for protecting those who cannot protect themselves we do not unnecessarily deprive them of some rather precious individual rights." *McJunkin v. McJunkin*, 896 So.2d 962 (Fla.App. 2005). This is precisely the type of unequal treatment based on unwarranted assumptions that the Americans with Disabilities Act was designed to ameliorate. Congress recognized that

"individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history

of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.”

Tennessee v. Lane, 541 U.S. 509, 516, 124 S.Ct. 1978 (2004) (*quoting* 42 U.S.C. § 12101(a)(7)). Title II of the ADA, at issue here, was enacted in response to “pervasive unequal treatment in the administration of state services and programs, including systematic deprivations of fundamental rights.” *Id.* at 524.

The state’s justification for excluding persons with guardians from the Personal Care Assistance program, while cloaked in caring terms, is further evidence that the decision is premised on the type of paternalistic assumptions based on stereotypes that the Americans with Disabilities Act was designed to combat. In other words, Andrea is excluded from participation in the program because of her disability. An adjudication of incapacity and the accompanying appointment of a guardian necessarily rest on a determination that the individual is substantially limited in the

performance of routine activities because of a disability. Andrea was appointed a guardian because of her mental disabilities and, without those disabilities, she would not require a guardian. The very reason Andrea has been excluded from the Personal Care Assistance program is because she has a condition that is a “disability” under the ADA and the Rehabilitation Act. Exclusion on the basis of the determination that she is disabled is, as a logical and legal matter, exclusion “by reason of” disability. *See Hargrave v. Vermont*, 340 F.3d 27, 26 (2d Cir. 2003)(state law that applied only to individuals civilly committed because of their mental illness discriminated on basis of disability). Persons with mental disabilities need equal treatment and access to a program with equal benefits, not to be consigned to an alternate program with fewer benefits for their own purported protection.

To the extent the state can exclude Andrea and others from participation in the Personal Care Assistance program based on an inability to self-direct care, federal anti-discrimination laws require the decision to be made based on an individual’s actual, personal inability to self-direct. The state says the essential aspect of the program addressed by the exclusion of persons with guardians from the program is that the person receiving services be able to self-direct. But the state has repeatedly found Andrea to be capable of self-directing care when her ability to do so was determined

individually rather than assumed based upon her membership in a group. Instead of providing an individualized determination of ability, the state now uses guardianship as a proxy and excludes an entire category of persons without assessing any one person's ability to self-direct care—with, or even without, an accommodation. The state has moved in the opposite direction contemplated by federal anti-discrimination laws.

C. The accommodation proposed by Andrea would allow her to maintain the same benefits and address any legitimate concerns the state may have without altering the character of the program

Based on the evidence in the record, Andrea may not need an accommodation of her disability. If she is provided an individualized inquiry into her ability to self-direct care, she may be found to have the ability to self-direct.⁸

Notably absent from Respondent's brief is a consideration of the accommodation proposed by Appellant or a satisfactory explanation of how the accommodation that would allow her to remain in the program is

⁸ It is unclear whether Andrea received services under the program for five years because she was deemed eligible after being assessed individually or because her disability was accommodated in the same manner she proposes it should be now.

inappropriate. The reasonable accommodation sought is for the state to alter its definition of “self-direct” so that it requires only that the consumer have the means to provide for the direction of her care, which could include direction of care with the assistance of a guardian where a person has a mental disability necessitating such assistance but is otherwise qualified for the program.

The state is required to modify its program to prevent disability discrimination unless doing so would fundamentally alter the program.

A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.

28 C.F.R. § 35.130(b)(7) (2001)(accommodation requirements under the Rehabilitation Act).

Because the state chose not to address the merits of Andrea’s ADA and Rehabilitation Act claims in the case *sub judice*, Respondent’s brief in this Court offers the only glimpse of why the state believes it can lawfully

exclude Andrea from further participation in the Personal Care Assistance program. The arguments are wholly insufficient, however, to overcome Andrea's assertion that she is entitled to – if nothing else—an accommodation of her mental disability. Generally the question of whether a proposed accommodation is reasonable “depends on the individual circumstances of each case” and “requires a fact-specific, individualized analysis of the disabled individual's circumstances and the accommodations that might allow him to meet the program's standards.” *Wong v. Regents of the Univ. of Cal.*, 192 F.3d 807, 818 (9th Cir.1999). In this case, the facts are not disputed. Andrea successfully participated in the participant-directed Personal Care Assistance program with a guardian for more than five years and all she asks is that she not now be excluded from the program. Again, the state presents no evidence that the program was not working.

Andrea bore the initial burden of producing evidence that a reasonable accommodation was possible. *Wong*, 192 F.3d at 816-17. In this case the possibility that Andrea could receive benefits under the Personal Care Assistance program is not speculative; it is based on an actual five-year experience that the state does not deny. Andrea has met her burden.

Once Andrea met her burden of showing a reasonable accommodation was possible, the burden shifted to the state to show the requested

accommodation was not reasonable. *Wong*, 192 F.3d at 817. The state has produced no evidence that it cannot operate its program while accommodating Andrea's disability.

This case is not typical in at least one significant respect. The state's participant-directed Personal Care Assistance program at issue has apparently already provided for many years the accommodation Andrea seeks. Andrea, and others whose mental disabilities required the appointment of a guardian, were able to benefit from the Personal Care Assistance program until the state decided to categorically exclude them from participation. If the state's decision was based on evidence that the program could not function while accommodating persons with mental disabilities resulting in appointment of a guardian or – as the state proclaims in its brief—a legitimate concern about abuse of persons under guardianship within the population of persons with disabilities, then that evidence has not made its way to the record in this case.

Andrea has proposed a reasonable accommodation to the state's program. The state has not made a showing that the accommodation is unreasonable. To the contrary, until relatively recently the state apparently had no problem providing the very accommodation Andrea seeks. There is not a basis in the record for declining a request for a reasonable

accommodation.

CONCLUSION

For the foregoing reasons, as well as those in her opening brief, Appellant requests this Court reverse the judgment of the Circuit Court, declare § 208.900.1 RSMo (Supp. 2005) invalid because it violates federal law, remand the case with directions to reinstate Appellant's benefits and determine the appropriate back pay and attorneys' fees, and grant Appellant such other and further relief as is just and proper under the circumstances.

Respectfully submitted,

ANTHONY E. ROTHERT, #44827
American Civil Liberties Union
of Eastern Missouri
454 Whittier Street
St. Louis, Missouri 63108
(314) 652-3114
(314) 652-3112 *facsimile*

NANCY E. EMMEL, #32524
Sindel & Emmel
7711 Bonhomme, Ste. 815
Clayton, Missouri 63105
(314) 727-5533
(314) 727-5464 *facsimile*

ATTORNEYS FOR PETITIONER-APPELLANT

CERTIFICATE OF COMPLIANCE

The undersigned hereby certifies that pursuant to Rule 84.06(c), this brief: (1) contains the information required by Rule 55.03; (2) complies with the limitations in Rule 84.06; (3) contains 4,320 words, exclusive of the sections exempted by the rules, determined using the word-count feature of Microsoft Office Word 2003. The undersigned further certifies that the accompanying floppy disk has been scanned and was found to be virus-free.

CERTIFICATE OF SERVICE

The undersigned hereby certifies that two copies of this brief and a copy of the brief of floppy disk were served upon the counsel identified below by United States Mail, postage prepaid, on September 18, 2008:

Lasandra Fae Morrison

Assistant Attorney General

615 E. 13th, Ste. 401

Kansas City, Missouri 64106
