

97-6027

IN THE
UNITED STATES COURT OF APPEALS
FOR THE SECOND CIRCUIT

**CONCETTA DESARIO and BETTY EMERSON, Individually and
o/b/o all persons similarly situated, *Plaintiffs-Appellees*,
CAROLINE STEVENSON, THOMAS SLEKIS, and HOWARD
WOLAN, Individually and o/b/o all persons similarly situated,
Intervenor-Plaintiffs-Appellees,**

versus

**JOYCE A. THOMAS, Commissioner, Connecticut Department of
Social Services, *Defendant-Third Party Plaintiff-Appellant*;
DONNA SHALALA, Secretary of the United States,
Department of Health & Human Services, *Third Party Defendant***

**ON APPEAL FROM THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF CONNECTICUT**

BRIEF, PURSUANT TO FED.R.APP.P., RULES 29, 35, & 40 OF:

**NATIONAL MULTIPLE SCLEROSIS SOCIETY; UNITED
CEREBRAL PALSY ASSOCIATIONS; NATIONAL PARKINSON'S
FOUNDATION; UNITED STATES SOCIETY FOR
AUGMENTATIVE AND ALTERNATIVE COMMUNICATION;**

[list of *amici* organizations continues on next page]

**AS *AMICUS CURIAE* IN SUPPORT OF PLAINTIFFS-
APPELLANTS' PETITION FOR REHEARING OR
REHEARING *IN BANC***

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ASSOCIATIONS OF NEW YORK STATE; NATIONAL
ORGANIZATION OF RARE DISORDERS; CYSTIC FIBROSIS
FOUNDATION; SICKLE CELL DISEASE ASSOCIATION OF
AMERICA; NATIONAL COUNCIL ON INDEPENDENT LIVING;
NATIONAL HEALTH LAW PROGRAM; CENTER ON
DISABILITY AND HEALTH; NATIONAL CFIDS FOUNDATION;
CFIDS ASSOCIATION OF AMERICA; MEDICAL SOCIETY OF
THE STATE OF NEW YORK; CONNECTICUT STATE MEDICAL
SOCIETY; UNITED CEREBRAL PALSY
ALS ASSOCIATION, GREATER NEW YORK CHAPTER;
COMMUNICATION INDEPENDENCE FOR THE
NEUROLOGICALLY IMPAIRED; GAY MEN'S HEALTH CRISIS;
NEW YORK AIDS COALITION; CONNECTICUT UNION OF
DISABILITY ACTION GROUPS; VERMONT CENTER FOR
INDEPENDENT LIVING; VERMONT STATEWIDE
INDEPENDENT LIVING COUNCIL; DISABILITY RESOURCE
CENTER OF FAIRFIELD COUNTY; VERMONT
DEVELOPMENTAL DISABILITIES PLANNING COUNCIL;
VERMONT COALITION FOR DISABILITY RIGHTS; GREATER
CONNECTICUT CHAPTER, NATIONAL MULTIPLE SCLEROSIS
SOCIETY; WESTERN CONNECTICUT CHAPTER, NATIONAL
MULTIPLE SCLEROSIS SOCIETY; HARTFORD COMMISSION
ON DISABILITY ISSUES; CITY OF NORWICH, CONNECTICUT,
DEPARTMENT OF SOCIAL SERVICES; HIV ACTION
INITIATIVE; CONNECTICUT ASSOCIATION OF DIRECTORS
OF HEALTH; NATIONAL ORGANIZATION FOR WOMEN,
CONNECTICUT CHAPTER; UNITED SENIORS IN ACTION;
COUNCIL OF VERMONT ELDERS; CONNECTICUT CFIDS
ASSOCIATION; BRIDGEPORT CHILD ADVOCACY
COALITION; BRAIN INJURY ASSOCIATION OF
CONNECTICUT; OFFICE OF PROTECTION AND ADVOCACY
FOR PERSONS WITH DISABILITIES; DISABILITY LAW
PROJECT; CONNECTICUT LEGAL SERVICES, INC.; GREATER
UPSTATE LAW PROJECT, INC.; ADVOCACY, INC.; SOUTHERN
POVERTY LAW CENTER; OREGON ADVOCACY CENTER

TABLE OF CONTENTS

	Page
Table of Contents	i
Table of Authorities	ii
Interests of the <i>Amici</i> Organizations	iv
Statement of the Case	1
Summary of Argument	2
ARGUMENT	3
I. IMPLEMENTATION OF THE <u>DESARIO</u> PANEL-S HOLDING WILL LEAD TO NEEDLESS DEATHS	3
A. Mechanical Ventilators	3
B. Surgical Insertion of Pacemakers	5
C. Treatment for AIDS-Related Conditions	5
D. Treatment for Uterine and Bladder Cancer	6
II. IMPLEMENTATION OF THE <u>DESARIO</u> PANEL-S DECISION WILL CAUSE NEEDLESS HARM AND SUFFERING	7
A. Environmental Control Devices	7
B. Augmentative Communication Devices	8
C. Home Health Care Assistance to the Elderly	10
D. Ex-sufflicator	11
CONCLUSION	12
Certificate of Service	

TABLE OF AUTHORITIES

	<u>PAGE</u>
<i>Statutes</i>	
42 U.S.C. ' 1396(2)	7, 11n.12
Rule 35(a)(2), Fed.R. App. P.	1
<i>Regulations</i>	
42 C.F.R. ' 440.230(b)	13
<i>Federal Cases</i>	
<u>DeSario v. Thomas</u> , No. 97-6027 Slip Op. (2d Cir. Feb. 24, 1998)	<i>Passim</i>
<u>Detsel v. Sullivan</u> , 895 F.2d 58 (2d Cir. 1990)	3, 4
<u>Fred C. v. Texas Health & Hum. Serv. Comm'n</u> , 924 F.Supp. 788 (W.D.Tex. 1996), <u>vacated &</u> <u>remanded</u> 117 F.3d 1416 (5th Cir. 1997)(Table), <u>on remand</u> , 1997 WL 809210 (W.D.Tex. 1997) <u>appeal pending</u>	10n.10
<u>Hunter v. Chiles</u> , 944 F.Supp. 914 (S.D.Fl. 1996)	10n.10; 10
<u>Meyers v. Reagen</u> , 776 F.2d 241 (8th Cir. 1985)	10n.10; 11n.12
<u>Myers v. State of Mississippi</u> , 3:94 CV 185 LN Mem. Op. & Order (S.D.Miss. June 23, 1995)	10n.10
<u>N.Y.S. Dept. of Social Services v. Bowen</u> , 846 F.2d 129 (2d Cir. 1988)	1
<u>Skandalis v. Rowe</u> , 14 F.3d 173 (2d Cir. 1994)	12
<u>Skubel v. Fuoroli</u> , 113 F.3d 330 (2d Cir. 1997)	4
<i>State Cases</i>	

Steelman v. Comm'r, Minn. Dept. of Hum. Serv.,
55-CO-95-2888 Order (Minn Dist.Ct. Olmsted Co.
July 25, 1996) 8n.6

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Statistical Update 27 (1997) 5n.3

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viruses & Opportunistic Infections (February 1998) 6n.4

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& 80, submitted in Myers v. State of Mississippi,
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1995) 9n.7

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1996, filed in In re: J. Moriarity, Case No.
656-8141 (Conn. Dept. of Social Services) 12n.13

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P-O-E-T-R-Y," *N.Y. Times*, March 16, 1991 9n.8

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In re: Julia Tavalaro, FH # 0993049J (NYS Dept.
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Statistical Abstract of the United States (1996) 6n.5;
11n.11

INTERESTS OF THE *AMICI* ORGANIZATIONS

Amici are 14 national and 32 state and community-based agencies, organizations, coalitions, and professional associations which are concerned about protecting the health and rights of persons with disabilities. All *amici* organizations have devoted substantial resources to ensure that persons with disabilities obtain health services that meet their needs.

The *amici* organizations believe the panel's decision in DeSario raises extremely important issues regarding the ability of persons with disabilities to obtain necessary health care. The *amici* organizations are particularly concerned that the panel's decision authorizes Medicaid program to impose treatment limitations and exclusions that serve no purpose, not even that of saving money, and can result in needless, preventable suffering or death. That such results can have devastating consequences for persons who are poor, who have disabilities and who are elderly, and who must rely on Medicaid programs for the medical care necessary to preserve their lives and maintain and improve their health, is of predominant concern for the *amici* organizations. Consequently, the *amici* organizations support Plaintiffs-appellees petition for rehearing, and urge this Court to rehear this case *in banc*.

The *amici* organizations submit this brief in order to bring to the Court's attention examples of the types of health consequences that will be authorized if the panel's decision is allowed to stand. These effects will not be addressed by the parties themselves.

Based on their experience and training, the *amici* organizations bring to this matter an enormous wealth of experience and expertise relating to the needs of persons with disabilities and the most appropriate care and treatment to meet those needs.

National Organizations

National Multiple Sclerosis Society

The National Multiple Sclerosis Society is a not-for-profit organization, founded in 1946, which is devoted to finding effective treatments for, and supporting the health and welfare of the more than 300,000 Americans with Multiple Sclerosis, one of the two most common neurological diseases affecting young adults. The National Multiple Sclerosis Society's 144 chapters and branches throughout the country serve more than 500,000 persons with Multiple Sclerosis and their families per year. Its services include bio-medical research, public education and information, legislative and public policy advocacy, and limited, direct health services. The NMSS= direct health care services are offered to persons with Multiple Sclerosis who have no other means of obtaining necessary health care.

Many thousands of persons with Multiple Sclerosis are poor and Medicaid eligible. The National Multiple Sclerosis Society recognizes that for persons with Multiple Sclerosis who are Medicaid eligible, there is no alternative source of assistance able to meet their medical needs. By comparison, the scope and scale of the NMSS's direct health care services could never be considered an adequate or appropriate substitute for Medicaid program coverage of these devices and services.

United Cerebral Palsy Associations, Inc.

The United Cerebral Palsy Associations, Inc., is a Washington, D.C. based, not-for-profit corporation that was incorporated in 1948. Today it represents 150 affiliates in 43 states with a mission to advance independence, productivity and community participation of the 500,000 children and adults with cerebral palsy in the United States and of persons with other severe disabilities. UCPA and its affiliates advocate for and provide services to over 50,000 children and adults annually. Services include early intervention, physical therapy, occupational therapy, and speech-language pathology services, special education, in home and family supports, home modifications, durable medical equipment and other assistive devices, residential services, summer camps, day treatment, housing, transportation and employment services. Many of these services overlap with services provided by state Medicaid programs and in some states, UCPA affiliates serve as Medicaid providers of these services. UCPA also has been selected by the U.S. Department of Education, pursuant to the Technology Related Assistance for Individuals with Disabilities Act, 29 U.S.C. ' 2201 *et seq.*, to provide national technical assistance to individuals with disabilities, their families, services providers and advocates concerning their efforts to expand, *inter alia*, state Medicaid program coverage of durable medical equipment and other assistive devices. UCPA knows Medicaid programs' central role in providing durable medical equipment and other services to people with disabilities and it is greatly concerned that the panel's decision in this case can authorize coverage limitations and exclusions even for devices or services that fit the criteria of a covered Medicaid service and also are the only form of treatment that will be of benefit to a Medicaid recipient.

National Parkinson's Foundation

The National Parkinson's Foundation, founded in 1957, is headquartered in Miami, Florida. NPF is the largest organization serving people with Parkinson's disease and their families throughout the world. Its mission is to find the cause of and cure for Parkinson's disease and related neurological disorders through research; to educate practitioners to detect early warning signs of Parkinson's disease; to educate patients, their caregivers and the general public; to provide diagnostic and therapeutic services; and to improve the quality of life for both patients and their families. To implement this mission statement, NPF sponsors bio-medical research and educational conferences, and publishes and disseminates educational information to medical professionals, patients and caregivers.

Parkinson's disease affects more than 1 million persons in the United States, with age 60 as the average age for the onset of symptoms. It is a slowly progressive neurological disorder which has debilitating effects on a person's ability to control voluntary movement. The disabling effects of Parkinson's disease include balance and mobility impairments, loss of voice power and of other voluntary motor control. While there currently is no known cure for Parkinson's disease, there are many effective medical devices and services that address the physical limitations it causes. Medicaid programs throughout the country are a major source of funding for these devices and services and NPF is extremely concerned that the panel decision in this case authorizes Medicaid programs to reduce or eliminate their scope of coverage for these essential services.

United States Society for Augmentative and Alternative Communication (USSAAC)

The United States Society for Augmentative and Alternative Communication is the only national association with a specific commitment to enhancing the lives of children and adults whose ability to speak and to be understood in normal conversation is severely impaired by disability, and who can benefit from high-, low-, and no-technology augmentative communication systems. USSAAC is the United States chapter of the International Society for Augmentative And Alternative Communication (ISAAC). USSAAC is a comprehensive, multi-disciplinary association devoted to expanding the base of knowledge about expressive communication disabilities, developing effective means of assessment and treatment for those disabilities, and assisting persons who need AAC intervention to obtain appropriate devices, services and as necessary, funding assistance. The inability to communicate one's thoughts, needs, and wishes is one of the most devastating of all functional impairments, affecting every aspect of a person's life. Augmentative communication devices and services provide effective treatment that will overcome those limitations. USSAAC's members come from every state and include augmentative communication consumers and their families, as well as clinical professionals such as speech-language pathologists, occupational therapists, educators, physical therapists, physicians, researchers, manufacturers and equipment vendors.

USSAAC publishes a peer-reviewed professional journal AAC, sponsors continuing education conferences, and through its national office staff, and annually provides ongoing information and referral about augmentative communication treatment and about sources of

funding for that treatment to thousands of persons throughout the country. USSAAC's experience is that state Medicaid programs are the *only* available funding source for thousands of persons who require AAC devices and services, and its members have worked tirelessly for more than 20 years to explain AAC intervention to Medicaid policy makers and thereby expand the scope of coverage nationwide. For these reasons, USSAAC is extremely concerned that any Medicaid program may refuse to cover or be given authority to exclude AAC devices and services.

RESNA

RESNA is the Rehabilitation Engineering and Assistive Technology Society of North America, based in Arlington, Virginia. RESNA is an inter-disciplinary association comprised of more than 2,000 individuals and organizations with a common interest in the use of technology to overcome disability. RESNA's membership includes persons with disabilities as well as professional services providers, such as occupational therapists, physical therapists, speech-language pathologists and rehabilitation engineers. RESNA publishes a semi-annual journal *Assistive Technology*, as well as a bi-monthly *RESNA News*. It operates the RESNA Press, which published M. Morris & L. Golinker, *Assistive Technology: A Funding Workbook* (1991), one of the most widely used resources related to Medicaid funding of durable medical equipment and other assistive devices and services. RESNA also sponsors an annual educational conference attended by thousands of Rehabilitation professionals, people with disabilities and their families, and others. The RESNA Technical Assistance Project was selected by the U.S. Department of Education to provide national technical assistance to federally funded Assistive Technology Projects in every state, pursuant to the Technology Related Assistance for Individuals with Disabilities Act, 29 U.S.C. ' 2201 *et seq.* That statute mandates that Assistive Technology Projects pursue "systems change" activities that will expand Medicaid program coverage of assistive devices because, as Congress found, the provision of these services can reduce the overall costs of care for persons with severe disabilities. RESNA seeks to participate as *amicus curiae* in the petition for rehearing in this case because it believes the panel decision, if allowed to be implemented, will be devastating to the needs of persons with disabilities and is contrary to public policy.

National Spinal Cord Injury Association

The National Spinal Cord Injury Association, founded in 1948, was created to improve the medical care for the approximately 400,000 persons in the United States with spinal cord injuries and/or disease, and to foster research towards a cure for paralysis. Its mission is to enable people with spinal cord injuries to make choices and take actions to achieve their highest level of independence and personal fulfillment. The NSCIA operates through 32 community-based chapters, 13 developing chapters and 10 support groups serving thousands of members throughout the country. NSCIA also serves more than 2,000 individual members who reside in rural communities and other areas in which there are no organized chapters or support groups. NSCIA disseminates information to more than 1,200 callers per month, including information about medical research, the availability of medical care needed by persons with spinal cord injuries

and sources of funding for that care. NSCIA distributes approximately 95,000 *Fact Sheets* about spinal cord injury annually, and publishes *SCI Life*, a quarterly magazine which is distributed to 35,000 people.

Persons with spinal cord injury and/or disease are consumers of a wide range of medical care, and because many are poor, NSCIA knows that state Medicaid programs are significant sources of funding for the medical care needed by people with spinal cord injuries. NSCIA also knows that Medicaid program funding of a broad scope of treatment options, including durable medical equipment, is essential to the life, health, independence and quality of life for people with spinal cord injuries.

National Organization of Rare Disorders

The National Organization of Rare Disorders, founded in 1983, is based in New Fairfield, Connecticut. It is dedicated to the identification, treatment and cure of rare or Orphan® diseases. This phrase is given to conditions that affect so few people that the bio-medical and pharmaceutical industries do not believe it will be commercially cost-effective to conduct research to find treatments and cures. NORDD was created following the successful legislative advocacy by its individual member organizations to enact the Orphan Drug Act, which provides federal financial assistance to support research related to treatment for these conditions. It is now a federation of more than 140 not-for-profit, voluntary health organizations dedicated to helping people with these Orphan® diseases. Some of the better known of these conditions include Cystic Fibrosis, Duchenne Muscular Dystrophy, Hemophilia, and Amyotrophic Lateral Sclerosis, or Lou Gehrig's Disease. NORDD provides information, advocacy, and referrals to sources of medical assistance to more than 800,000 persons with rare disorders and their families, medical professionals, government officials, and funding program policy and decision makers, per year. NORDD also sponsors bio-medical research and distributes selected Orphan drugs.®

By definition, the conditions which comprise Rare disorders® will not be common in the Medicaid population in any state, yet, Medicaid programs are an essential source of medical care services to persons with rare disorders. Medicaid also is the program of last resort, where care can be obtained only after all other sources of assistance have been exhausted. Thus, it is essential to the lives, health and quality of life of persons with rare disorders that Medicaid programs not limit or exclude coverage of specific treatments simply because their need may arise infrequently, because they benefit people with rare diseases or are costly. Medicaid programs, consistent with their role as programs of last resort, must offer a sufficient scope of individual treatments among its covered services to ensure that the only form of treatment that fits within the scope of a covered service and that is capable of benefiting a recipient, will be available.

Cystic Fibrosis Foundation

The Cystic Fibrosis Foundation, established in 1955, and headquartered in Bethesda, Maryland, seeks to assure the development of the means to cure and control Cystic Fibrosis and

to improve the quality of life for the 30,000 children and young adults with the disease. It is the most common fatal genetic disease in the United States. Cystic Fibrosis causes the body to produce an abnormally thick, sticky mucous, which clogs the lungs and leads to fatal infections. The mucous also obstructs the pancreas, preventing enzymes from reaching the intestines to digest food. Cystic Fibrosis is not a disease common in the population, and the Cystic Fibrosis Foundation is extremely concerned that the panel's decision in this case will permit Medicaid programs, on which many children and young adults with Cystic Fibrosis depend for their medical care, will not cover and make available the treatments necessary to maintain their health and extend their lives.

Sickle Cell Disease Association of America, Inc.

The Sickle Cell Disease Association of America is a national organization formed to call attention to, and seek solutions for, problems created by sickle cell disease. Sickle Cell Disease is an inherited condition that affects 70,000 African Americans and 1 in 4,000 Americans in the general population. The health consequences of Sickle Cell Disease include anemia, damage to and blockage of blood vessels, which reduces oxygen flow to organs and tissues, unpredictable episodes of severe pain, as well as stroke, leg ulcers and decreased resistance to infection. The SCDA has 65 community based member organizations to provide limited financial aid, public and professional education, screening, counseling and supportive services for individuals and their families.

The vast majority of persons with Sickle Cell Disease come from traditionally poor and medically under-served minorities. As a result, they rely heavily on Medicaid programs to meet the costs of their medical care. The SCDA is extremely concerned that Medicaid programs not be permitted to limit their scope of coverage of treatments to those that are common in the Medicaid population, which may adversely affect the ability of persons with Sickle Cell Disease to obtain necessary items and services.

National Council on Independent Living

The National Council on Independent Living (NCIL) is a not-for-profit organization formed in 1992, with headquarters in Arlington, Virginia. NCIL is a national membership association of Centers for Independent Living and people with disabilities. NCIL engages in legislative and executive policy development advocacy to expand the rights of and the scope of assistance available to persons with disabilities so that they may enjoy full integration and participation in society, and also seeks the development, improvement and expansion of Centers for Independent Living. NCIL is aware of the critically important role of Medicaid programs in meeting the health care needs of persons with disabilities. Providing assistance so that persons with disabilities can access Medicaid funding for necessary items of durable medical equipment and other services is a principal activity of its members.

The broad scope of Medicaid funding for these items and services is essential. Although many NCIL members have the ability to provide funding for items and services necessary to

support the independent living of persons with disabilities, pursuant to the Rehabilitation Act, 29 U.S.C. ' 701 *et seq.*, these funds are profoundly inadequate to meet the needs of persons with disabilities even in states where Medicaid funding is widely available. In no way can these funds be seen as an effective or adequate alternative to the Medicaid program.

National Health Law Program

The National Health Law Program (NHeLP) is a national public interest law firm, based in Washington, D.C. that seeks to improve health care for America's working and unemployed poor, minorities, elderly and people with disabilities. NHeLP serves legal services programs, protection and advocacy offices, community-based organizations, the private bar, providers and individuals who work to maintain a health care safety net for millions of uninsured or underinsured low-income people. NHeLP monitors Medicare, Medicaid and other publicly-funded health care programs, seeks remedies when laws and policies are ignored, and helps Americans receive needed medical care. NHeLP seeks to participate as *amicus curiae* in this case because the panel's decision is significantly at odds with long-settled precedent in the Medicaid program and, if allowed to be implemented, can have significant adverse effects on the ability of many Medicaid recipients to obtain necessary, even life-sustaining health care. NHeLP has an interest in preserving long-standing precedent in the Medicaid program that ensures poor people, regardless of the frequency of their conditions or treatment needs among the Medicaid population as a whole, have access to treatment that is medically necessary.

Center on Disability and Health

The Center on Disability and Health is not-for-profit, Washington, D.C. based research, education and advocacy organization founded in 1994. The Center on Disability and Health is dedicated to ensuring that as national and state health care policy is developed and reformed, consideration is given to the impact of those policies on health care consumers. The mission of the Center on Disability and Health is to increase understanding of the changes needed in the financing and delivery of health care to better meet the needs of persons with disabilities and other chronic conditions. The Center has conducted research and produced educational materials on numerous subjects of health care reform, including the Oregon Medicaid waiver, which replaced the state Medicaid program with a prioritized list of covered medical conditions and treatments selected on the basis of the medical severity of the conditions and the effectiveness of the treatments. The Center's research identified aspects of Oregon's initial waiver proposal that discriminated against persons with disabilities by de-valuing the benefits of treatment they utilize, and which were later identified by the federal government as grounds to deny the initial waiver application. The Center is aware of the efforts of Medicaid programs throughout the country to reform their systems and is concerned that the standard established by the panel decision in this case, which segregates the concepts of coverage from medical need, is inconsistent with basic principles which guided the Medicaid program for more than 30 years, and currently guide states' Medicaid reform efforts.

National CFIDS Foundation

CFIDS Association of America

The National CFIDS Foundation, with headquarters in Needham, Massachusetts, and the CFIDS Association of America, with headquarters in Charlotte, North Carolina, are organizations that provide information, referral and advocacy services to the more than 500,000 persons with Chronic Fatigue-Immune Dysfunction Syndrome throughout the United States. The CFIDS Foundation also sponsors research into the causes of this condition. CFIDS is a poorly understood and often disabling condition. It impairs a person's ability to function normally in life and for many people with CFIDS, a wide array of medical services and devices are needed, including wheelchairs, TENS machines (for chronic pain management), oxygen and other medical supplies. Many people with CFIDS are Medicaid eligible and rely on Medicaid for access to these items and services. The National CFIDS Foundation and The CFIDS Association of America are both concerned that Medicaid programs not be permitted to reduce the scope of their covered treatments for persons whose conditions or treatment needs are not common to large numbers of recipients. Persons with CFIDS who rely on Medicaid programs for their health care have no other sources from which they can obtain that care.

State and Local Organizations

Medical Society of the State of New York

The Medical Society of the State of New York was organized in 1807 and is incorporated and operated under New York State's Not-For-Profit Corporation Law. The Society has approximately 27,000 member physicians, representing physicians in all specialties. The purposes of the Medical Society include: to enhance the delivery of medical care of high quality to all people in the most economical manner, and to act to promote and maintain high standards in medical education and in the practice of medicine in an effort to ensure that quality medical care is available to the public. The Medical Society is extremely concerned that the panel decision in this case will adversely affect our member physicians' ability to effectively care for their Medicaid patients. Contrary to the panel decision's conclusions, a rational medical decision making process for selecting covered treatments requires consideration of the severity of a patient's medical condition and the ability of an available item or service to effectively treat that condition.

Connecticut State Medical Society

The Connecticut State Medical Society (CSMS) was incorporated and chartered by the Connecticut General Assembly in 1792. CSMS has more than 6,800 members, representing over 90 percent of private practicing physicians in Connecticut. Among the Society's purposes, as expressed in the organization's By-Laws, is to enlighten and direct public opinion so that the profession shall become increasingly useful to the public in the prevention and care of disease and in prolonging and adding comfort to life.® CSMS members provide treatment to Medicaid

recipients in Connecticut and are acutely aware of the unavailability of other sources from which these persons will be able to obtain necessary health care if Medicaid programs limit or exclude treatments as has been authorized by the DeSario panel's decision. The CSMS also recognizes the error in the panel's approach that Medicaid services will be rationally distributed if the program makes coverage decisions regarding the scope of available treatment without appropriate medical professional input, and without consideration of the medical necessity for, and effectiveness of those treatments.

United Cerebral Palsy Associations of New York State

The United Cerebral Palsy Associations of New York State (UCPA of NYS) is one of the leading advocacy and service organizations for individuals with a wide variety of disabilities in New York State. Together with its 24 affiliates and divisions, UCPA of NYS provides programs and services to over 30,000 individuals with disabilities and their families in every county of the state. As the largest member of the national United Cerebral Palsy Associations, Inc., UCPA of NYS is active in ensuring appropriate health care is available to persons with disabilities through legislative advocacy, education, and individualized services for consumers. UCPA of NYS provides extensive direct health care services to recipients of New York State Medicaid, and receives payment from Medicaid for many of these services. UCPA of NYS recognizes that New Yorkers who are poor and who have disabilities are dependent on Medicaid to meet the costs of necessary health care services and that there are no alternative sources of assistance that will be effective to meet their needs.

ALS Association, Greater New York Chapter

The ALS Association, Greater New York Chapter is the local chapter of the national ALS Association in New York State. It serves persons with Amyotrophic Lateral Sclerosis, also known as "Lou Gehrig's Disease" throughout the metropolitan New York City region. Its mission is to discover the cause of and cure for ALS through research, while providing patient support, information/ education to health care professionals and the general public, and advocacy for ALS research and health care concerns. ALS is characterized by a degeneration of motor cells in the brain and spinal cord leading to progressive paralysis of the voluntary muscles. As the disease progresses, the ALS patient loses the ability to move, speak, swallow and eventually to breathe. Once diagnosed, the average life span of a person with ALS is 2-5 years. During this period of physical functional deterioration, the mind remains intact and unaffected. In addition to Lou Gehrig, the late Senator Jacob Javits and the actor David Niven both had ALS, as does the physicist Stephen Hawking. The ALS Association, Greater New York Chapter provides a variety of services, including clinical services at the Beth Israel Medical Center, educational programs on research and patient care, information and counseling, an equipment loan program, augmentative communication services, monthly support group meetings that serve more than 500 people, and telephone referrals that respond to more than 200 inquiries per month. Among the questions most frequently raised is for assistance finding sources of medical care and for information about funding for assistive devices and other items and services. Many times, the response provided is to explain how the person can become eligible for Medicaid and thereby be

able to access its services. For this reason, the ALS Association, Greater New York Chapter is extremely concerned that the panel's decision in this case may permit Medicaid programs to restrict or exclude necessary treatment for persons with ALS. The direct care services it provides cannot be seen as an effective substitute for Medicaid, and for persons with ALS who rely on Medicaid, there are no other resources that will meet their needs.

Communication Independence for the Neurologically Impaired

Communication Independence for the Neurologically Impaired (CINI), established in 1993, is a New York City based not-for-profit services and advocacy organization dedicated to assuring persons with severe neurological impairment, such as ALS, are able to obtain necessary augmentative communication devices (ACDs) and services so that they will be able to maintain the ability to communicate throughout the progress of the disease. CINI provides direct augmentative communication services to persons with ALS as well as information and referral assistance to assist persons with ALS find sources of health care and funding for ACDs. CINI seeks to participate as *amicus curiae* in this petition for rehearing because it knows that communication impairments rob people of their ability to control their lives, at the very point when important decisions about their health, finances, and family relations are of paramount concern. CINI is extremely concerned that Medicaid programs may be authorized by the panel's decision in this case to exclude coverage for AAC devices and services, a step that will have devastating consequences to persons with ALS and other progressive neurological impairments.

Gay Men's Health Crisis

Gay Men's Health Crisis is the nation's oldest and largest AIDS service organization. GMHC serves more than 9,000 men, women and children living with AIDS and their families. GMHC provides meals and nutritional advice, emotional support and case management, legal and financial aid, and other special services for families. GMHC seeks to participate as *amicus curiae* in this case because it knows that even though the State of New York has mounted a vigorous response to the AIDS epidemic, its safety-net is by no means equipped to provide needed care if the Medicaid program is allowed to shift the cost of unusual treatments for atypical conditions to charities or other sources of care. The epidemic has already strained the already fragile Medicaid safety-net of clinics and public and private hospitals that provide the overwhelming majority of AIDS treatment services. If directed to treatments for AIDS related conditions, the panel's decision that authorizes Medicaid programs to exclude coverage for costly and unusual treatments would impose a death sentence on persons with AIDS.

New York AIDS Coalition

The New York AIDS Coalition is comprised of more than 200 HIV/AIDS community-based organizations in New York. These organizations are part of New York's infrastructure for delivering a range of care to persons living with HIV/AIDS. The services these organizations provide are often the main life-lines for New Yorkers living with the disease. The NYAC assists its member organizations and their clients by promoting public policies that address the needs of

persons with HIV/AIDS and the communities in which they live. The panel's decision in this case directly contradicts and interferes with the mission of the NYAC. By concluding issues of treatment coverage and medical need are "distinct concepts," the panel has authorized Medicaid programs to exclude treatments that are not commonly needed by the Medicaid population as a whole. The NYAC seeks to participate as *amicus curiae* in this case to urge this court to insist that Medicaid programs apply a standard for selecting covered treatments that requires consideration of the effectiveness of treatments to preserve life and restore health.

Connecticut Union of Disability Action Groups, Inc.

The Connecticut Union of Disability Action Groups, Inc., (CUDAG), founded in 1988, is a grassroots coalition of persons with disabilities. Its mission is to provide a statewide organization through which grassroots groups can act to secure full participation for persons with disabilities in every aspect of our society. CUDAG now has 17 member organizations representing persons with a wide range of disabilities and whose collective membership is more than 6,000 persons. The majority of these persons are poor and rely on public sources of financial assistance for their necessary living expenses as well as Medicaid to meet their health care costs. CUDAG seeks to participate as *amicus curiae* in this action because many of its members have unusual and expensive equipment and services needs that appear to be excludable under the panel decision's standard.

Vermont Center for Independent Living (VCIL)

The Vermont Center for Independent Living, established in 1979, is Vermont's first and only cross-disability center promoting independent living for persons with disabilities and the first organization in the State of Vermont to be directed and staffed by a majority of persons with diverse disabilities. Through its offices in Montpelier, Bennington and Brattleboro, Vermont, and field-based offices in every Vermont county, VCIL helps people with significant disabilities gain more control over their lives and access the tools and services, including Vermont Medicaid program covered services, that will improve their potential to live independently, rather than in more costly and restrictive institutional settings such as nursing facilities. Selected as one of the best centers for independent living in the country in 1997, VCIL serves more than 2,500 Vermonters annually. A constant focus of VCIL's activities is to ensure Vermonters with disabilities have access to as broad a scope of durable medical equipment, prosthetic devices, and other services through Vermont Medicaid as is possible. These devices and services are essential to the health and quality of life of Vermonters with disabilities: in our state, there are no other public or private programs or resources that can substitute for Medicaid coverage of these necessary items and services.

Vermont Statewide Independent Living Council

The Vermont Statewide Independent Living Council is a policy advisory council appointed by the Governor to carry out the mandates of the federal Rehabilitation Act, 29 U.S.C. ' 701. Its primary responsibility is to develop and oversee the implementation of the State Plan for

Independent Living and to monitor programs that help people with disabilities live with independence and dignity in their own homes, as opposed to in nursing facilities or other institutions. Central to the mission of the Vermont Statewide Independent Living Council is ensuring that persons with disabilities have broad access to durable medical equipment, prosthetic devices and other assistive devices necessary to preserve life, maintain and improve health, functional status, and ensuring opportunities exist for ongoing independent living. The Council is particularly concerned that the panel's decision in this case does not appropriately require Medicaid programs, one of, if not the largest provider of items and services to persons with disabilities in Vermont, to consider the medical necessity and effectiveness of items and services before deciding whether they are to be covered.

Disability Resource Center of Fairfield County

The Disability Resource Center of Fairfield County, Connecticut, is a Center for Independent Living, with offices in Stratford and Stamford, that provides information and referral and other services to persons with disabilities. The Center's clients are largely Medicaid recipients with disabilities who seek medical services in order to improve their health, functional status and to live more independently. The Center is extremely concerned that the panel decision in this case authorizes the Connecticut Medicaid to continue to use its exclusive list of durable medical equipment even though that list was not developed with consideration to the costs -- to recipients and to the program itself -- when a non-listed item is simply denied. For many clients of the Disability Resource Center those costs are significant, because items and services they need to maintain their independence will not be provided.

Vermont Developmental Disabilities Planning Council

The Vermont Developmental Disabilities Planning Council was created pursuant to Public Law 104-183, the Developmental Disabilities Assistance and Bill of Rights Act. The DDPC engages in systemic change, capacity building and advocacy activities on behalf of the 10,000-12,000 Vermonters with developmental disabilities. The DDPC's mission is to assist persons with developmental disabilities achieve independence, productivity, integration, and inclusion in to the community. Most adults with developmental disabilities in Vermont are Medicaid eligible and many, based on their conditions, require substantial amounts of medical services. These include a range of assistive devices, such as augmentative communication devices, specialized lifts, and special aids to vision. These Vermonters depend completely on Medicaid to provide these items and services, without which their health, independence and quality of life will be significantly compromised. The DDPC also knows that no other resources exist in Vermont to address these needs if Medicaid is not required to provide these services.

Vermont Coalition for Disability Rights

The Vermont Coalition for Disability Rights is a coalition of 29 organizations, representing the interests of Vermonters who are blind and visually impaired, deaf and hearing impaired, spinal cord injured, traumatic brain injured, and who have other disabilities and chronic impairments.

The Coalition's member organizations represent the interests of people with many low incidence conditions and conditions requiring unusual and costly medical treatments. The Coalition for Disability Rights is the major state-wide disability advocacy organization in Vermont. Because of the importance of the Medicaid program to people with disabilities, the Coalition's member organizations are intimately involved with systems design, oversight and policy development of the Vermont Medicaid program. Its members serve on numerous Vermont Medicaid advisory and oversight boards and task forces, including those related to development of Vermont's managed care regulations. The Coalition's member organizations are extremely concerned that the panel decision's conclusions that Medicaid programs may exclude coverage for treatments that address the needs of people with rare conditions, or who have unusual and costly treatment needs will have significant adverse effects on the health and well being of Vermonters with disabilities, and will interfere with Vermont's public policy initiatives to provide less costly, community based as opposed to institutionalized care.

*Greater Connecticut Chapter, National Multiple Sclerosis Society
Western Connecticut Chapter, National Multiple Sclerosis Society*

The Greater Connecticut Chapter of the National Multiple Sclerosis Society serves the needs of more than 10,000 persons with Multiple Sclerosis and their families in Hartford, New Haven, Middlesex, New London, Tolland and Windham, Connecticut. The Western Connecticut Chapter of the National Multiple Sclerosis Society serves more than 1,200 persons in Fairfield and Litchfield Counties. Both organizations provide information and referral services and are acutely aware of the needs persons with Multiple Sclerosis have for a broad range of durable medical equipment and other services. Many of the persons served by these organizations are Medicaid recipients whose lives and independence will be compromised if Connecticut Medicaid is authorized to select which items of durable medical equipment to cover without consideration of the medical significance or of the effectiveness of the devices. These organizations also know that Medicaid is the last resource available for these persons and their families; no others are able to effectively meet the needs of Medicaid recipients with Multiple Sclerosis.

Hartford Commission on Disability Issues

The Hartford Commission on Disability Issues, created by City of Hartford ordinance, is a public, voluntary group of 15 persons who work to improve the quality of life for persons with disabilities in Hartford, Connecticut. Commissioners are appointed by the Mayor and are responsible to make policy recommendations to the Mayor, Common Council, and City Manager which will give persons with disabilities opportunities for full participation in all aspects of community life. Based on this mission, the Hartford Commission on Disability Issues is extremely concerned that the panel's decision in this case permits Medicaid to operate its exclusive list of durable medical equipment without consideration of the medical or independent living significance, of the effectiveness, or even the cost-effectiveness of a requested item or service.

City of Norwich, Connecticut, Department of Social Services

The City of Norwich, Connecticut, Department of Social Services is a governmental agency that is responsible for implementing the General Assistance program for Norwich residents who are not eligible for Medicaid. Although the General Assistance program provides valuable services to persons who are poor and those who are disabled in Connecticut, it cannot be seen as another community resource that will meet the needs of Medicaid recipients who are unable to acquire the medical treatment they need from that program.

HIV Action Initiative, Inc.

The HIV Action Initiative, created in 1991 and based in Hartford, Connecticut, is a regional coalition of business and community leaders, services providers, health care institutions and people living with HIV. Its mission is to address community-wide issues in the greater Hartford area related to HIV care and service delivery, prevention, public awareness, public policy and research. The HIV Action Initiative seeks to participate as *amicus curiae* in this case so that the court recognizes that in the Greater-Hartford area, there are no other community-based resources to meet the needs of persons with HIV, if the Medicaid program is given the authority to reduce or eliminate treatments regardless whether they are medically necessary.

Connecticut Association of Directors of Health

The Connecticut Association of Directors of Health, (CADH) is a not-for-profit organization of 60 health directors representing the vast majority of Connecticut's rural, suburban and urban residents. CADH is extremely concerned that the panel's decision in this case authorizes Connecticut Medicaid to exclude coverage of the treatments needed by persons with rare conditions, or unusual and costly treatment needs. Such a policy clearly runs contrary to the concept of equal access to health care which CADH believes is an inherent concept in the Medicaid program.

National Organization for Women, Connecticut Chapter

The National Organization for Women, Connecticut Chapter, (CT NOW), is a women's rights organization with more than 2,000 members. CT NOW's mission is to take action to bring women into full participation in the mainstream of American society now. CT NOW seeks to participate as *amicus curiae* in this action because the panel's holding that Connecticut Medicaid can exclude coverage of treatments that do not arise sufficiently often can have significant life-threatening to women, particularly impairments that affect the female reproductive tract such as treatment for uterine cancer. The possible exclusion of treatment for conditions such as this will have a devastating impact on the health and lives of women and their families.

United Seniors in Action

United Seniors in Action (USA), founded in 1984, is a Connecticut-wide coalition of community groups, seniors centers and union retiree groups which provides information, referral and advocacy assistance regarding health care and sources of funding for health care services to Connecticut's 46,000 seniors on Medicaid. USA has worked to educate its member organizations about Connecticut's proposed state-wide Medicaid waiver and other issues related to the Medicaid program. It is aware that for the elderly poor, there are no health services funding programs other than Medicaid that will be able to meet their needs. If necessary care is not provided through Medicaid, the life, health and independence of the elderly poor in Connecticut will be jeopardized.

Council of Vermont Elders

The Council of Vermont Elders (COVE) promotes the dignity, security, and well being of all Vermont senior citizens. Its membership includes organizations, individual senior citizens, and younger persons who share in the specific mission of providing information and legislative advocacy on issues which affect the lives of Vermont's senior citizens. COVE focuses special attention on the needs of those most vulnerable because they are frail, low income and/or isolated. Access to appropriate health care is one of the most important concerns for senior citizens in Vermont, in particular access to medical devices and services that will aid mobility, communication and independent living. The Medicaid program plays a crucial role in assuring those health care services are provided. COVE is crucially interested in ensuring that the scope of Medicaid services is not reduced such that the needs of senior citizens in Vermont are not going to be met. COVE is greatly concerned, therefore, that the panel's decision in this case authorizes Medicaid programs to make decisions about coverage for durable medical equipment and other services without considering the medical need or the potential benefits of the requested item or service.

Connecticut CFIDS Association

The Connecticut CFIDS Association, headquartered in Enfield, Connecticut, like its national counterpart, The CFIDS Association of America, provides information, referral and advocacy assistance to persons with Chronic Fatigue Syndrome and related conditions. Most frequent among the information requests received is for assistance finding sources of appropriate medical care and sources of funding for that care. The Connecticut CFIDS Association frequently provides information regarding how persons with CFIDS can become eligible for Connecticut Medicaid, so that they can access the treatments available through that program. The Connecticut CFIDS Association is aware of the lack of other resources in our communities able to meet the needs of persons with CFIDS if Medicaid programs are permitted to exclude treatments that are not common in the Medicaid population.

Bridgeport Child Advocacy Coalition

The Bridgeport Child Advocacy Coalition, founded in 1985, is comprised of 62 member organizations committed to improving the health and well-being of Bridgeport, Connecticut's 37,000 children and to ensuring children are safe and receive the education and skills to reach their full potential. BCAC members provide research, community planning, advocacy, education and community mobilization services. Many BCAC members provide direct services to families who are Medicaid eligible, such as children with special needs. BCAC and its member organizations recognize there is no source that will be effective to meet the health needs of children who are poor or who have disabilities other than Connecticut Medicaid.

Brain Injury Association of Connecticut

The Brain Injury Association of Connecticut, founded in 1982, is a not-for-profit organization that serves as the Connecticut state chapter of the National Brain Injury Association. BIAC is committed to helping survivors of brain injuries obtain necessary rehabilitation and other services that will support their independence, productivity, and quality of life. Many brain injury survivors have severe disabilities that require interventions such as durable medical equipment to aid mobility, speech, vision, hearing and other impaired functional abilities. Equally true, the residual care needs of many brain injury survivors cause them to exhaust all other available insurance and family resources and they become Medicaid eligible. Medicaid is clearly the last resort for obtaining necessary medical care for these families: there are no other sources available. For this reason, BIAC is extremely concerned that Medicaid programs not be permitted to determine the scope of covered treatments without consideration of their medical need or effectiveness.

Office of Protection and Advocacy for Persons with Disabilities

The Office of Protection and Advocacy for Persons with Disabilities is a state agency, created by Connecticut statute, Conn. Gen.Stat. ' 46a-11 and various federal laws, *e.g.*, Technology Related Assistance for Individuals with Disabilities Act, 29 U.S.C. ' 2201 *et seq.* (*Tech Act*), and the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. ' 6042, to protect and advocate for rights of individuals with mental and physical disabilities. The Office of Protection and Advocacy pursues legal, administrative and other remedies which ensure individuals with disabilities who are eligible for treatment and services from the Connecticut Medicaid program receive the items and services they need to preserve their lives, maintain or improve their health, and support their ability to live independently. In the Tech Act, Congress recognized that durable medical equipment, prosthetic devices and other forms of assistive devices and services can be of great benefit to the health and quality of life of persons with disabilities. It recognized as well that the provision of these devices and services can increase the independent functioning of people with disabilities and thereby reduce the overall costs of their care. For these reasons, Congress directed the Office of Protection and Advocacy to pursue *expansion* of Medicaid program obligations to cover and provide these assistive devices, including augmentative communication aids and environmental control devices. Thus, the Office of Protection and Advocacy is particularly concerned that the panel's decision in this case will permit

Medicaid to limit or restrict these same devices and services, contrary to clear expressions of national public policy as well as to the needs of individuals with disabilities in this State.

Disability Law Project

The Disability Law Project, founded in 1976, provides legal protection and advocacy services to persons with disabilities throughout Vermont. Its mission is to increase awareness of, provide enforcement for and work to expand the civil rights, entitlement and services for people with disabilities. The Disability Law Project engages in direct representation of people with disabilities and also works vigorously as a legislative and administrative policy advocate, often on issues related to health care in general and the scope of the Vermont Medicaid program in particular. For clients eligible for Medicaid, it is clearly the payor of last resort: there are no alternative sources of health care able to effectively meet their needs. Therefore, it is essential the Medicaid program be obligated to fulfill its role as the lifeline to the independence, health, productivity, and in some cases, the survival of people with disabilities. For example, the Disability Law Center recently succeeded in requiring Medicaid to provide a closed circuit television device to aid the vision of a 70 year old recipient who is legally blind and who suffers from numerous other impairments. The severity of her vision impairment made this the only type of magnification device that will meet her needs. Absent this device, our client would not be able to read the prescription labels necessary to control her other health conditions, and would no longer be able to live independently. Her only alternative would be to move to a nursing facility at much higher cost to Medicaid. In re: Brisson, 702 A.2d 405 (VT. 1997). In another case, the Disability Law Center represented a 38 year old man, who is married with two teenage children, and who suffered a stroke and lost the ability to speak. The Disability Law Center was able secure an augmentative communication device from Medicaid which allows him to direct his care, including state-funded attendant care services, which reduces his need for other Medicaid funded services. Each of these devices were obtained because Medicaid recipients were able to assert the essential nature of these devices to address their particular needs. The Disability Law Center seeks to participate as *amicus curiae* in this case because the panel's decision concludes that medical need and coverage are distinct concepts, and that coverage decisions for items and services do not have to take into consideration the degree of a recipient's need for treatment or the effectiveness of an item or service to meet those needs.

Connecticut Legal Services, Inc.

Connecticut Legal Services, is a state-wide organization with 6 offices, which provides legal representation, advice, education and referrals to low income persons. CLS serves more than 5,458 persons per year by means of advice and/or representation and more than 20,000 persons per year by means of education services. In 1997, CLS represented 309 persons on matters involving Connecticut Medicaid. CLS is aware that the Medicaid program in Connecticut is an irreplaceable resource for low income persons and persons with disabilities. No other community-based resources exist that can substitute for Medicaid. CLS seeks to participate as *amicus curiae* in this case because the panel's decision does not require Medicaid to make choices about coverage of individual medical devices and other treatments on the basis of either the

degree of the recipient's medical necessity for the treatment, the likely effectiveness of the treatment in meeting those needs, or the possible consequences to the recipient -- in terms of human suffering or even Medicaid program expenses -- if the requested treatment is denied.

Greater Upstate Law Project, Inc.

The Greater Upstate Law Project is a not-for-profit law firm that provides free civil legal representation, legislative and administrative advocacy, training and technical support to low-income residents of New York State, and to other legal services programs and community groups working to improve the lives of New York's poor, on matters of importance to their lives, including the provision of quality health care. In that capacity, GULP has represented thousands of New Yorkers in several seminal Medicaid cases before this Court and others, including Catanzano v. Wing, 103 F.3d 223 (2d Cir. 1996) and 60 F.3d 113 (2d Cir. 1995). GULP is concerned that the panel's decision in this case may have significant adverse effects on the abilities of poor New Yorkers to obtain necessary medical services from New York's Medicaid program.

Advocacy, Inc.

Advocacy, Inc. is the protection and advocacy program for the State of Texas. It serves approximately 25,000 individuals with disabilities each year, including persons seeking durable medical equipment, prosthetic devices and other items and services from the Medicaid program. Advocacy, Inc. is counsel for the plaintiff in Fred C. v. Texas Health & Human Services Commission, 924 F.Supp. 788 (W.D.Tex. 1996), *vacated and remanded* 117 F.3d 1416 (5th Cir. 1997)(Table), *on remand*, 1997 WL 809210 (W.D.Tex. 1997), *appeal pending*. This case seeks to overturn Texas Medicaid's refusal to provide an augmentative communication device to an adult, even though the state concedes it meets all the coverage criteria of durable medical equipment in Texas, the plaintiff is homebound and therefore eligible for home health care services (through which durable medical equipment is accessed), and that the requested device is the least costly medically necessary device. Even after all of these criteria are satisfied, the state claims it has the residual discretion not to cover this device. Advocacy, Inc. seeks to participate as *amicus curiae* because the panel's decision in this appeal expressly rejected 30 years of settled law in the Medicaid program and created a conflict among the circuits that could adversely affect people with disabilities throughout the country.

Southern Poverty Law Center

Founded in 1971, the Southern Poverty Law Center is a non-profit organization based in Montgomery, Alabama, dedicated to protecting victims of injustice. The Center pursues legal action to protect the civil rights of minorities, women, people who are poor and in need of health care, persons with mental illness, and others subject to unfair treatment based on their membership in a disadvantaged group. The Southern Poverty Law Center currently is representing clients in Alabama who seek access to augmentative communication devices from Medicaid, and whose ability to acquire those vitally necessary devices may be jeopardized by the panel's decision in this case. The Southern Poverty Law Center seeks to participate as *amicus*

curiae in this case because the panel's decision does not require state Medicaid programs to ensure that covered services are not arbitrarily rendered meaningless to individual recipients, by prohibiting Medicaid programs to exclude coverage of the only form of treatment within a covered category of care that will be of benefit to a recipient.

Oregon Advocacy Center

The Oregon Advocacy Center is the protection and advocacy system for the State of Oregon. It provides legal representation for a broad range of persons with disabilities who are having difficulty obtaining medical services from the Oregon Medicaid program, including durable medical equipment. The Oregon Advocacy Center seeks to participate as *amicus curiae* in this case because the panel's decision establishes a standard for determining the sufficiency of coverage of individual Medicaid items and services that is inconsistent with settled law in the Medicaid program and even inconsistent with the unique state-wide waiver that governs Oregon's Medicaid program. Oregon has prioritized medical conditions and treatments according to the medical severity of the condition and the likely effectiveness of the treatment. This method for determining coverage is itself at odds with the panel's conclusion in this case that concepts of coverage and medical need are distinct. For Oregon Medicaid recipients, these concepts are inextricably intertwined. In addition, although the prioritized list of conditions and treatments governs the Medicaid program as a general matter, Oregon Medicaid still offers a "safety-valve" exception when a person's unique disability makes a non-listed treatment necessary for an otherwise covered condition. This too is a direct contrast to the panel's decision which will permit Medicaid to determine coverage based on whether the treatment needs are common to the Medicaid population as a whole. The Oregon Advocacy Center is concerned that the panel's decision raises issues under other statutory protections for persons with disabilities, such as the Americans with Disabilities Act, and, if allowed to be implemented, may encourage Oregon to weaken the essential protections for people with disabilities and unusual conditions and treatment needs.

STATEMENT OF THE CASE

Amici support Plaintiffs-appellees in their petition to this Court to rehear DeSario v. Thomas, No. 97-6027, *in banc*.

Rehearing *in banc* is essential to address a question of exceptional importance. Rule 35(a)(2), Fed.R.App.P. The DeSario panel held that state Medicaid programs can deny treatment that is unquestionably medically necessary to preserve an individual recipient's life, or to maintain or improve health, as long as the Medicaid population as a whole is given "adequate" coverage. *Slip Op.* at 38-44. Even though the Medicaid program is the health insurer of "last resort," N.Y.S. Dept of Social Serv. v. Bowen, 846 F.2d 129, 133 (2d Cir. 1988), Medicaid recipients with serious medical needs who are not fortunate enough to suffer from medical problems common to large numbers of others, and whose treatment needs are costly, will have "to look for other sources of assistance." *Slip Op.* at 38. The panel concludes that the denial of treatment will be justified regardless of its effects, even when it causes unrelieved suffering and/or death to Medicaid recipients. *Id.* at 35.

The *amici* organizations represent persons in these desperate situations. A first group includes those with fatal conditions, a class of conditions not common among the Medicaid population as a whole. Yet for persons with AIDS, Cystic Fibrosis, and genetic impairments, meaningful treatment is now available for the first time ever, offering the alternative of health and life for what had historically been death sentences by diagnosis.

A second group includes persons with Cerebral Palsy, dysarthria (an impairment of the nerves and muscles controlling speech), Multiple Sclerosis, and Muscular Dystrophy. These disabling, chronic conditions also are not common among the Medicaid population as a whole.

Nonetheless, these recipients seek assistive devices that will provide improved or restored function, and will reduce their need for other more expensive medical services, for example, by permitting independent living instead of institutional care.

A third group has impairments that are otherwise common. Cardiovascular disease, for example, is the impairment with the highest prevalence in the United States population. But some treatments for this condition, although of lifesaving significance, are nonetheless not typical. Examples include surgical insertion of a pacemaker.

In sum, despite differences in age, condition and the specifics of their needed treatments, the individuals represented by the *amici* organizations all seek access to effective treatments that will sustain their lives or improve or maintain their health. Under the DeSario panel's decision, however, their lives are expendable, and many of them will die because their conditions are not common or they have unusual and costly treatment needs.

Consequently, the *amici* organizations urge this Court to rehear DeSario *in banc* and to correct the panel's conclusion under which these individuals= suffering and death will result from a "reasonable" interpretation of Medicaid program standards. The individuals whom the *amici* organizations represent rely on the Medicaid program for their health and their very lives, and they know, first hand, the hollowness of the panel's suggestion that "other resources in the community" (*Slip Op.* at 38) will substitute for Medicaid coverage of their treatment needs.

SUMMARY OF ARGUMENT

The DeSario panel reviewed Connecticut Medicaid's use of an exclusive list of durable medical equipment. Durable medical equipment is an extremely small part of all government

spending on health care, representing only 3 percent of all expenditures in 1994.¹ The DeSario panel's holding, however, is not limited to the durable medical equipment benefit. Rather, it held that Medicaid programs may select which individual treatments to cover in *any* category of service based on how often they are needed or sought by the Medicaid population as a whole. *Slip Op.* at 38-44. One result of the panel's conclusion is that Medicaid programs are authorized to exclude treatments for recipients with rare conditions or unusual and costly treatment needs. *Id.* at 38. This holding is arbitrary and irrational. If allowed to be implemented, it could lead to unnecessary, preventable suffering and death, as illustrated in the examples provided below.

ARGUMENT

I

IMPLEMENTATION OF THE DESARIO PANEL'S HOLDING WILL LEAD TO NEEDLESS DEATHS

There are endless examples of how the panel's decision could lead to the unconscionable deprivation of critically needed medical care. The following are merely illustrations of the implications of the panel's decision.

A. Mechanical Ventilators

¹ U.S. Dept of Commerce, Bureau of the Census, Statistical Abstract of the United States, Table 156, p. 112 (1996).

A variety of conditions cause people to be unable to breathe on their own, and as a result, to be dependent on a ventilator. Melissa Detsel, who had multiple congenital anomalies, is one ventilator-dependent Medicaid recipient whose impairments have been reviewed by this Court. Detsel v. Sullivan, 895 F.2d 58 (2d Cir. 1990). (The actor Christopher Reeves, who is unable to breathe on his own due to a spinal cord injury, is perhaps the nation's best known ventilator user, although not a Medicaid recipient.) Other conditions associated with the need for mechanical ventilation are Cystic Fibrosis, and Amyotrophic Lateral Sclerosis (more commonly known as ALS or Lou Gehrig's Disease). None of these conditions is common in the Medicaid population as a whole.²

For these people, however, a ventilator is a life-line. (Without the device, its users would die in a matter of minutes.) Ventilators also play other roles. As this Court recognized in Detsel, the development and availability of portable ventilators have made it possible for many people who cannot otherwise breathe on their own to lead full, ordinary lives. In Detsel, and more recently in Skubel v. Fuoroli, 113 F.3d 330 (2d Cir. 1997), this Court held that Medicaid recipients who rely on ventilators have the freedom to come and go to wherever their normal life activities may require. Detsel, 895 F.2d at 66. For Melissa Detsel, now deceased, this meant attending school and enjoying other activities of her childhood and teen years. For Christopher Reeves, it means serving as a spokesperson for research to find a cure for spinal cord injuries and continuing his career in the arts. For persons with Cystic Fibrosis, typically young adults in their

² Nationwide, the number of technology dependent children like Melissa Detsel was estimated in 1988 at no more than 17,000, of which approximately 1,000-2,000 were estimated to live in New York State. Only a very small minority of persons with spinal cord injuries have them at the C,2-3 level, as does Christopher Reeves. For Cystic Fibrosis and ALS, only 30,000 persons have each of these conditions, nationwide.

20's, and for those with ALS, most often young adults, these devices are life extenders: they delay the fatal consequences of these progressive conditions.

Ventilators currently are covered by Connecticut Medicaid. But the panel's decision does not require that coverage because the need for these devices is rare. However, absent a duty on Medicaid programs to pay for the ventilators these recipients must have, state Medicaid agencies can deny the possibility of a normal life. Detsel and Skubel will be effectively nullified.

B. Surgical Insertion of Pacemakers

Pacemakers are surgically inserted devices that control the rhythm of the heartbeat for persons (such as the late Ella Fitzgerald and Mr. Justice Douglas) with cardiovascular disease.

Pacemakers are life-saving prosthetic devices that currently are covered, but are not needed by the Medicaid population as a whole, or even by a majority of persons with cardiovascular disease.³

As a result, the panel's decision may not require them to be covered in the future.

Pacemakers are not a new form of treatment: they were developed in 1958 and are routinely covered and funded by Medicare and commercial health insurance programs. But longstanding, routine acceptance is not a factor the DeSario panel requires to be considered in

³ Although cardiovascular disease is the most common impairment among the United States population, the surgical insertion of pacemakers is not typical of the needs of all persons with this condition. In 1995, pacemakers represented only 2.8 percent of all cardiovascular disease surgeries, which is only one of many different forms of cardiovascular disease treatment. American Heart Assoc. 1998 Heart & Stroke Statistical Update 27 (1997).

Medicaid coverage decisions. And, neither is the fact that, absent a pacemaker, those Medicaid recipients for whom one is necessary will die.

C. Treatment for AIDS-Related Conditions

Applying the DeSario panels standard, Medicaid programs could exclude coverage of treatments for AIDS-related conditions. Cytomegalovirus (CMV), for example, causes disease in many parts of the body; CMV of the retina is the most common manifestation. If untreated, it will lead to blindness, severe neurological complications and ultimately, death. In the past, CMV was treated with intravenous infusions, an extremely costly and ineffective approach. In 1996, the FDA approved an innovative eye-implant device, the Vitrasert implant. The implant is effective, but costly. It must be replaced every 5 - 8 months at a cost of \$ 4,000 per implant, plus \$ 2,000 for the procedure.

Failure to provide this medical breakthrough treatment would turn back the clock on AIDS treatment. This unconscionable result would be particularly irrational in light of the recent studies that report, for the first time, there are treatments that can achieve significant decreases in AIDS-related deaths.⁴

D. Treatment for Uterine & Bladder Cancer

Uterine cancer and bladder cancer represented only 2.5 percent and 3.9 percent, respectively, of all new cancer diagnoses in 1994. Absent treatment, both of these cancers are fatal, but, when treated, both have five-year survival rates of approximately 58 percent.⁵

⁴ See Fndn for Retro virology & Human Health, Abstracts of the Fifth Conference on Retro viruses & Opportunistic Infections (February 1998).

⁵ Statistical Abstract, *supra*, Table 223, at p. 145.

Utilizing the standard approved by the panel decision, however, treatment for uterine and bladder cancer may be excluded because they are not sufficiently common. Although the rates of survival for uterine and bladder cancer are relatively high, the DeSario panel did not require the effectiveness of treatment to be considered in Medicaid coverage decision-making. Applying the panel's standard, many Medicaid recipients with these cancers face needless, preventable suffering and death.

II

IMPLEMENTATION OF THE DESARIO PANEL'S DECISION WILL CAUSE NEEDLESS HARM AND SUFFERING

Unnecessary death is not the only potential consequence of the DeSario panel decision. Its lack of reasonableness and irrationality is proved as well by another measure, the needless, preventable, de-humanizing harm that also could result from implementation of the panel's decision.

A. Environmental Control Devices

Environmental control devices (ECD's), the device sought by Plaintiff DeSario, are another excludable treatment under this standard. These devices are needed by persons with quadriplegia; ECD's are prosthetic devices which substitute for their users' impaired functional abilities. Their purpose is to enable Medicaid recipients with quadriplegia to live safely and independently, outside of an institutional setting and its attendant high costs. See 42 U.S.C. ' 1396(2).

Their importance is starkly demonstrated by the facts applicable to Dana Steelman, a woman in her late 30's who became a quadriplegic as a result of a car accident and who is a

Minnesota Medicaid recipient. Due to her injuries, Ms. Steelman has limited use of her arms and no use of her hands. She also lost the ability to control her internal body temperature, making her prone to heat stroke and hypothermia. On one occasion, she had to be hospitalized due to heat stroke. She requires an environmental control device to enable her to control the temperature and ventilation in her apartment. Also, despite her impairments, Ms. Steelman lived in an apartment, independently and alone. Thus, she required and ECD that allows her to lock her doors and operate the telephone in an emergency.

When a male acquaintance of Ms. Steelman left her apartment following an argument, she was unable to lock the door. He later returned and re-entered her apartment, but she had no environmental control device to activate the telephone by voice and call for help. Even after she was raped, she was unable to obtain help until a care giver arrived, through the still unlocked door, hours later.⁶

The significance of environmental control devices will never be demonstrable on the basis of the number of persons who need them. On the other hand, a standard for selecting covered treatments that ignores the value of these devices to save Medicaid expenses by supporting independence over nursing home care, and which further ignores the health and safety needs of people like Ms. Steelman, cannot be deemed reasonable.

B. Augmentative Communication Devices

Augmentative communication devices (ACDs) supplement or replace the ability to speak for persons whose speech is not understandable due to injury or disease. Dysarthria, an

⁶ See Steelman v. Comm'r, Minn. Dept. of Hum. Serv., 55-CO-95-2888 Order (Minn Dist.Ct. Olmsted Co. July 25, 1996).

impairment of the nerves which control the muscles and other speech-producing organs, is the speech-related impairment most often associated with ACD need and use. Typically, ACD users also have impairments that limit use of their hands, so that writing messages also is not an option.

Stephen Hawking, the internationally acclaimed physicist, needs an ACD as a consequence of dysarthria caused by ALS. Other conditions associated with ACD need are stroke, traumatic brain injury, and Cerebral Palsy, the impairment which affects Howard Wolan, one of the DeSario plaintiffs. None of these conditions is common to the Medicaid population as a whole. Nationwide, only a few thousand ACDs are purchased by Medicaid programs, per year.

The ability to speak and use language is recognized as the single physical, functional characteristic distinguishing human beings from other species. The loss of this ability can have severe consequences, including severe and grievous harm, yet this result is easily preventable. For instance, the mother of a young adult Medicaid recipient in New York State reported the preventable tragedy that befell her son: "Andrew has a burn scar on his hand which occurred because he could not tell his attendants at school that they had pushed him up against a radiator and locked his wheels in a position where his hand was trapped to sear until the flesh melted off."⁷

The inability to communicate also can lead to mis-diagnoses and delays or denials of appropriate care. An example is that of Julia Tavalaro, a woman who suffered a severe stroke and was considered brain dead. For seven years she remained in the back ward of an institution where she had no input related to any aspect of her life. Ms. Tavalaro, a New York City

⁷ Affidavit of Judith Frumkin, February 11, 1995, & 80, submitted in Myers v. State of Mississippi, 3:94 CV 185 LN Mem. Op. & Order (S.D.Miss. June 23, 1995).

Medicaid recipient who now uses an ACD, has become an accomplished poet and published author.⁸

⁸ See In re: Julia Tavalaro, FH # 0993049J (NYS Dept. of Social Serv. May 7, 1987)(awarding ACD); D. Martin, "When Paralysis is no Match for P-O-E-T-R-Y," *N.Y. Times*, March 16, 1991; J. Tavalaro, Look Up For Yes (1997)(describing post-stroke experiences).

Sadly, Ms. Tavalaro's experiences are not unique. One doctor, writing in support of his Medicaid-eligible patient's request for an ACD, described his difficulties obtaining information in these shocking terms: ACurrent inability to communicate has greatly limited his access to medical care and indeed has reduced it to approximately veterinary proportions.⁹ ACD's are the only item of durable medical equipment that will be of any benefit to a person with severe dysarthria. Moreover, the effectiveness of ACDs is well established, yet Connecticut Medicaid still refuses to cover them.¹⁰

The extraordinary potential of ACDs to provide vital benefits to persons like the DeSario plaintiff, Howard Wolan, and to protect against unnecessary suffering and harm is now in jeopardy. The DeSario panel's decision does not require consideration of whether the device

⁹ In re: Anonymous, Case No. 851-0107314, Slip op at 10 (Ohio Dept of Human Services Dec. 7, 1988).

¹⁰ They have been covered by Medicaid programs and private insurance for many years. At least 25 Medicaid programs, including New York's, have specific ACD funding guidelines. In the few coverage disputes about ACDs that have been resolved by federal courts, the decisions have uniformly recognized the ability to speak is "vital" and have required ACDs to be covered. Hunter v. Chiles, 944 F.Supp. 914 (S.D.Fl. 1996); Fred C. v. Texas Health & Hum. Serv. Comm'n, 924 F.Supp. 788 (W.D.Tex. 1996), vacated & remanded 117 F.3d 1416 (5th Cir. 1997)(Table), on remand, 1997 WL 809210 (W.D.Tex. 1997) appeal pending; see also Meyers v. Reagen, 776 F.2d 241 (8th Cir. 1985); Myers v. State of Mississippi, *supra*.

being sought represents the only form of treatment within a covered service that will be of any benefit to a Medicaid recipient. See Hunter, *supra*, 944 F.Supp. at 922. Exclusion of ACDs is justified under the DeSario panel's standard solely because the circumstances giving rise to ACD needs are not common in the Medicaid population as a whole.

C. Home Health Care Assistance to the Elderly

In 1994, persons age 65 and older received approximately 73 percent of all home health care services in the United States. Although only 9 percent of those receiving home health care services require eating assistance¹¹ -- a number which, under the panel's test, might exempt it from being a required type of service within the home health category of services, the ability of persons age 65 and older to continue to live independently is in substantial part tied to their ability to maintain adequate nutrition. Absent that ability, their health will deteriorate to the point where nursing facility care will be required.

A basic goal of the Medicaid program is to provide medical services that assist recipients to attain or retain their capability for independence.¹² However, that purpose is not a factor the DeSario panel requires to be considered. Thus, eating assistance could be excluded from the Medicaid home health benefit thereby forcing otherwise independent older Medicaid recipients to be placed in nursing homes.

D. Ex-Sufflicator

Jamys Moriarity is a Connecticut Medicaid recipient with severe Muscular Dystrophy, chronic bronchitis and a range of chronic pulmonary impairments, all of which render her unable

¹¹ Statistical Abstract, *supra*, Table 202 at p. 135.

¹² 42 U.S.C. ' 1396(2); Meyers v. Reagen, *supra*, 776 F.2d at 243.

to cough. Coughing is essential to clear fluids from the lungs. Ms. Moriarity lacks that ability, yet it is especially important for her because chronic bronchitis causes fluid to fill her lungs. This has resulted in respiratory infections which were treated through intensive care hospitalization, with respiratory support through a ventilator. Although these infections have been resolved to date, Ms. Moriarity's life has been at risk.

Ms. Moriarity requires an assistive device to help suction those fluids. Because she is unable to cough, her doctor sought Connecticut Medicaid funding for an "ex-sufflicator," a device that suctions the fluids in her lungs. Following a trial use of the device, the doctor reported it had prevented her from being hospitalized due to respiratory infection. There were no adverse side effects from use of the device and its cost is less than that of even *one day* of intensive care hospitalization.¹³

Nevertheless, because an ex-sufflicator is not on the Connecticut Medicaid fee schedule, it was not provided. She only received authorization for it because, after the injunction granted in this case, her doctor convinced Connecticut Medicaid that the device was the only item of durable medical equipment that will effectively treat her condition, and that its provision will prevent illness and suffering (as well as avoid unnecessary costs to Connecticut Medicaid). Under the standard established by the DeSario panel, however, this device is excludable because it is not generally needed by the Medicaid population as a whole. Indeed, it may not be needed by any other Connecticut Medicaid recipient.

¹³ Affidavit of Brian Michael, M.D., October 25, 1996, filed in In re: J. Moriarity, Case No. 656-8141 (Conn. Dept. of Social Services).

CONCLUSION

Needless, preventable death, rape, severe burns, care reduced to veterinary proportions, institutionalization and hospitalization are not results that reflect reasonable or rational interpretations of federal Medicaid program rules. Nor are these consequences consistent with the goals of the Act. As the author of the DeSario panel decision noted in another case, "Appalling . . . consequences can arise when Medicaid programs choose not to cover specific populations or optional categories of services in their state plans. Skandalis v. Rowe, 14 F.3d 173, 181 (2d Cir. 1994). However, based on DeSario, these extreme results are authorized regardless of whether the populations and services are covered. If the DeSario panel decision is left unchanged, for many thousands of people with disabilities and those who are elderly, eligibility for Medicaid may become all but meaningless.

Amici therefore urge this Court to rehear this appeal and to hold that Medicaid scope of coverage choices will not "be sufficient to reasonably achieve their purpose," 42 C.F.R. ' 440.230(b), if they eliminate the only form of treatment within a covered category of service that will be of benefit to a Medicaid recipient. When a recipient has established that a treatment fits the definitional criteria of one or more covered services, that it is medically necessary and not experimental, and that it is the least costly equally effective form of treatment available, the Medicaid programs should be required to provide it. Any standard that excludes consideration of these factors cannot be considered reasonable or rational.

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